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Health Literacy:
Patients' texts, context and mediation

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Dedication

To my girls, Laura and Grace

Abstract

Health literacy encompasses people's knowledge, motivation and competences to access, understand, appraise and apply health information to make judgments and take decisions in every-day life concerning health care, disease prevention and health promotion (Kickbusch et al., 2013). Research in health literacy has grown in prominence as a separate entity over the last twenty years, partly in response to the growth of chronic disease requiring greater patient self-management. Research has found significant relationships between reading comprehension levels and different health outcomes and health behaviours, with reading comprehension being used as a way to measure health literacy despite its accepted definition being much broader. However, there has been little research which takes a social practices perspective on health literacy.

In this thesis, health literacy is viewed from a social practices perspective. Literacy events in this research have been predicated on the existence of written texts as part of a patient's journey using health related texts, resources and services. The thesis explores how people go about accessing, understanding, appraising and using health-related services and information, and the social and cultural practices inherent in those activities. It asks how much written patient text is used with patients in hospital; who is using it; what the discourse features of those texts are; and how patients respond to the texts. This mode of exploration is called *textual ethnography* (Swales, 1998).

The research takes an ethnographic perspective not only on text, but also on participants and their journey. It shadows eleven patients through a cardiology service of a hospital in New Zealand. It identifies literacy events and practices occurring in that space and examines the patient texts themselves using a discourse analysis (Bax 2011; Faircough, 2003; Clerehan, Hirsh, & Buchbinder, 2009; Franken & Hunter, 2011) and geosemiotic (Scollon & Scollon, 2003) approach.

The key themes to emerge from the research centre around the complexity of access to patient information, both physically and linguistically, and around the dynamics of patient agency. The ability to encode and decode written text played

a minor part in patient access to information. The analysis showed that the amount and types of text material present for patients in hospital were limited. Access to key texts required a deliberate decision by a health professional to dispense the text items. Mediation of text in the research by *literacy sponsors* supported Brandt and Clinton's (2002) observation that "access to literacy has always required assistance, permission, sanction, or coercion by more powerful others or, at least, contact with existing 'grooves' of communication" (p. 349). Patient agency therefore came to the fore, and practices that patients did actually use to make information personal to them such as talking with room mates, or requesting paper and pencil were dynamic and socially mediated.

Implications lie in the way health literacy is conceptualised, moving the focus from individual abilities as portrayed in current health literacy definitions, and pointing to the wider role of the health organisation and health care practitioners as literacy sponsors. Practice implications arising from this reconceptualisation relate to patient information strategies within health care organisations and pedagogical implications for health professionals and adult literacy educators. The notions of text mediation and full contextualisation of learning also became apparent with evidence pointing to the effectiveness of text mediation by a more knowing other. The hospital itself was found to be a potentially rich and meaningful setting for adult learning about health where full contextualisation of adult learning is possible. These patient learning opportunities need to be further exploited by health organisations and professionals.

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Chapter One: Introduction

Hospitals are “textually mediated social environments” (Papen, 2010, p. 145), or at least one would expect them to be, but are they really? How much text is actually used in a hospital, by whom and with whom? What are the discourse features of those texts? How do patients respond to these texts? The scope of this research is not to map all texts used in hospitals, but to focus on written texts given to patients that primarily concern their condition or treatment and which are mediated by a health professional. Patient consent forms and any material not pertaining to cardiovascular conditions directly are not included in this analysis, although the presence of any other documents is noted where they co-occur with texts under investigation.

By examining the written text and distinguishing its place in the complex healthcare context, we can begin to make meaningful observations of the social practices, the patterns of text use in this context. This in turn can give us insight into the broader scope of a patient’s health literacy, especially a person’s accessing and understanding of health information. How is talk structured around the texts and what of the texts themselves? What are their features and how do patients respond to them and particular aspects of them? These are some of the questions this research addresses.

There is much to be said about the meaning of *health literacy* and this will be explored in detail later. However, for the purpose of introducing the concept, I will begin with the definition used in the American Patient Protection and Affordable Care Act of 2010: “The degree to which individuals have the capacity to obtain, communicate, process and understand basic health information and services needed to make appropriate health decisions (Title V).”

This is not dissimilar to the World Health Organisation (WHO), which has used the European Health Literacy Consortium definition of health literacy:

Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in

every-day life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course (Kickbusch, Pelikan, Apfel, & Tsouros, 2013, p. 4).

Both definitions allude to literacy practices in that they acknowledge social context. Papen and Walters's (2008) definition for health literacy elaborates:

Health literacy is the ability to understand, access, and use health-related tools and services in a given location. . . . Health literacy has to do with the social and cultural practices that individuals and groups may engage in, in the process of understanding, accessing and using health-related tools and services (p. 10).

Papen and Walters make explicit the picture of literacy in the health context as being situated in social practices and mediation. I also subsume numeracy under this definition, as accessing, understanding and using numbers is also part of the process of using health services.

The issues associated with literacy and health literacy both in New Zealand and abroad provide the broader context and motivation for this research. While recent statistics on health literacy in New Zealand do not exist, figures released in 2010 by the Ministry of Health (2010), based on the 2006 Adult Literacy and Life Skills survey (ALL), present some insight into New Zealand's current functional health literacy situation from a racial perspective namely,

- 54% of non-Māori females and 54% of non-Māori males have poor health literacy;
- 73% of Māori females and 80% of Māori men have poor health literacy.

The 2006 ALL measures literacy into five levels of proficiency ranging from a score of 0 to 500 with individuals scoring within levels 1 and 2 (a score of 0 to 275) deemed to have very poor and poor literacy levels respectively. A score of over 275 (levels 3–5) is deemed to represent adequate to effective literacy skills. Further afield, a 2006 study by the Australian Bureau of Statistics using the Australian data from the 2006 ALL Survey found that “on the health scale, approximately 9 million Australians (60% of the adult population) attained scores

at Level 1 or 2,” (Australian Bureau of Statistics, para. Literacy in 2006). The OECD and Statistics Canada maintain Level 3 as a cut-off point, stating it is “the minimum level for coping with the increasing demands of the emerging knowledge and information economy” (OECD and Statistics Canada, 2000, p. xiii). The framing of literacy in terms of economic outcomes will be discussed later in this thesis. However, these statistics do not tell the full story. There is more to health literacy than the way it is measured by the ALL survey text and this will be examined in more depth in Chapter Three.

As a society, we are facing challenges with the increasing complexities of healthcare and the greater literacy needed to navigate health services. In New Zealand, 30% of deaths in 2010 data were caused by cardiovascular disease (heart, stroke and blood vessel disease) (Heart Foundation of New Zealand, 2014). Deaths from all forms of cancer account for close to a third of all deaths in New Zealand (Ministry of Health, 2013a). Many of these conditions are chronic where the role of the individual patient in their own health management is particularly crucial. Chronic disease is any disease which persists over time or is recurrent. Forthofer (2003) observes that, “[the majority] of the most significant health problems today (e.g., lung cancer, cardiovascular disease, diabetes, osteoporosis) have multiple complex causes—often indirect causes with effects mediated by individual behaviour” (p. 528).

With more onus on the individual to self-manage, the importance of an individual being able to access, understand and use the health information and services to enhance their health status and quality of life is significant. This ability to access, understand and use health information and services is the crux of health literacy and is where adult literacy and health intersect.

A telling comment from Kickbursch, a leading European health literacy advocate, acknowledges the perceived gap between the demands of managing chronic illness and the perceived ability of patients. She comments, “the (health care) system is not equipped to empower patients to self-manage ongoing medical conditions. We might need to look at a new kind of professional that can broker information” (“Parliament to Press”, 2010, para. Positions). This type of acknowledgement is also echoed in another of Forthofer’s (2003) observations,

that “increasingly, health science researchers are aware that no individual is an island—that individual health is influenced by the surrounding context” (p. 528). It is for this reason that this thesis explores a context (cardiovascular health) in which self-management is prevalent and expected, and like all conditions where self-management is an aim, the success or lack thereof is the result of a complex set of factors.

1.1 A personal aim of the thesis

Health and literacy first came into focus for me while I was volunteering for an Indian non-government organisation, Asha (www.asha-india.org), working in some of Delhi’s slum areas. The focus was primarily on communicating health information to the lead care-givers—the women, to improve maternal health, child health, wider family health and to ultimately impact on the slum area and build community. Many of the women receiving information and acting upon that information would be classified as *illiterate* or unable to read (decode) text, but despite this, Asha has been able to make notable gains in infant mortality and other quality of life and health measures amongst slum dwellers. Being involved in the work of Asha left me with many questions, and some concerned the role of literacy in community development and health improvement, especially concerning the role of text encoding and decoding in improving a community’s health literacy. I also witnessed the importance of personalised mediation of health information. The model that Asha uses depends on training community women to teach their neighbours using visual aids and practical support. Personalised mediation of health information by these community women in the face of widespread literacy challenges is commonplace. Research questions in this thesis then are an iteration of those earlier questions from India.

The thesis has also been important for positioning me amongst the broader questions of ontology and epistemology, and developing “principled alignments between and among epistemological positions, relevant theoretical frameworks, approaches to research, and strategies for collecting, analysing, and interpreting data” (Kamberelis & Dimitriadis, 2005, p. 13). However, there is a tension between the disciplined approach of research and the dynamic complex nature of the world under study. I am a researcher who is constructing concepts and

theories out of “stories that are constructed by research participants who are trying to make sense out of their experiences and/or lives” (Corbin & Strauss, 2008, p. 10).

1.2 Research focus

In this research, I use ethnographic and discourse analysis methods to improve understanding of health literacy and its meaning for patients in health-care contexts. Papan (2008) considers that there is a need to conduct more qualitative research on patients’ strategies to access, comprehend and use written information they receive. Clerehan (2014) acknowledges that “carefully planned research into the interactions between spoken and written communications—how healthcare practitioners develop or select, present, and deliver patient information—is the task awaiting applied linguistics researchers” (p. 223). My research was not exempt from the difficulty that Clerehan (2014) highlights of “researchers gaining access to healthcare settings . . . for research into written communication which aims to explore social and organizational contexts” (p. 213). Further details of these challenges are in Chapter Five.

Garner, Ning, and Francis’s (2011) review of research evaluating patient information leaflets confirmed the need to have a working model for evaluating the effectiveness of text. Their approach had three pillars: readability of the text, comprehensibility of the text by the reader, and communicative effectiveness of the text. Garner, Ning and Francis’s principles have been reflected in earlier approaches to patient text evaluation (Clerehan, Hirsh, & Buchbinder, 2009; Doak, Doak, and Root, 1996) and to text evaluation in general (Bax, 2011; Fairclough, 2003). The matrix in Appendix 2 draws together these different approaches and is the matrix used in this research. In a related call for further research, Protheroe, Wallace, Rowlands and DeVoe (2009), in their synopsis of a brainstorming session on setting an international research agenda for health literacy, consider that there is a need to explore how individuals access health “information as a function of their health literacy skills” (p. 2). Capturing such patient response data requires an ethnographically styled research methodology and a carefully targeted research scope.

Papen and Walters's (2008) earlier description of health literacy encapsulates the goal of my research: to analyse and document the nature of health-related texts and to capture the social and cultural practices that individuals and groups engage in, in the process of understanding, accessing and using health-related texts, resources and services. Dray and Papen (2004), after Swales (1998), have labelled this mode of exploration as *textual ethnography* where the ethnography "concerns itself primarily with the mediating role of (written) texts in social events such as healthcare encounters" (Dray & Papen, 2004, p. 316). Swales (1998) labelled this mode of exploration *textography*.

How the mediation of text occurs is central in my research, as is the position I have taken on health literacy, a view that reconciles social practices and autonomous perspectives. An ethnographic approach to methodology provides the framework for my exploration of literacy in a health care setting, namely, written cardiovascular text within the clinical setting. This involves the exploration of the literacy and numeracy demands of the texts and the practices that surround them, the mediation of the texts by health care providers, as well as an exploration of the response to those texts by patients.

1.3 The structure of the thesis

The following two chapters provide background to concepts needed to explore the research questions for the study. A discussion of literacy, apart from its use in health literacy begins the next chapter. A thorough grounding in literacy is a focus in this thesis because it provides an insight into the heritage and major movements of literacy theory. This is important because it creates a theoretical foundation for the conceptualisation of literacy in health, or health literacy, especially when much of the conceptualisation thus far arises from within the field of health or does not represent the historical theoretical movements within literacy studies. Chapter Three follows with an exploration of health literacy through the lens of the literacy foundations laid in Chapter Two. The evolution of health literacy as well as relevant research and conceptualisations are also examined to background the research questions. Chapter Four then elaborates on the conceptual framework underpinning the research, which in the words of Bloomberg and Volpe (2012, p. 89), functions to provide "a bridge between

paradigms that explain the research issue and the actual practice of investigating that issue.” Chapter Five outlines the methods used to generate data and manage it. Chapters Six and Seven then present findings, with the final chapter, Chapter Eight, discussing themes around those findings and concluding with implications and recommendations for further research.

Chapter Two: Literacy and Texts in Context

In order to explore texts as they are used in a context and relate this to the broader concept of literacy, and then health literacy, there is a need to traverse a broad range of literature. Backgrounding literacy especially, in this chapter provides a conceptual basis for then examining literacy in a health context in the following chapter. The scholarship found in the literacy domain needs to inform discussion and understandings of health literacy. This chapter begins with a background to both literacy and numeracy followed by an examination of the major movements and contentions in the literacy field. The scope is then broadened to examine aspects of text, and the concepts of artefacts, context, mediation and sponsorship which feature in my research questions.

2.1 Literacy

The word *literate* comes from the Latin *litteratus/litteratus* meaning literally *one who knows the letters* which eventually came to mean *educated*, or *learned*. It dates from the early fifteenth century (Harper, 2012) coinciding with the wider availability of the printed word, on account of Gutenberg and the spread of the printing press. The concept of knowing the letters is relatively recent, as prior to the development of letters, there were other forms and systems of *knowing*. The early Polynesian navigators, for example, who found their way to islands in the Pacific had their own set of literacy events and practices, none of which involved reading written texts or representing experiences using text as we know it. The literacy of stars, winds, clouds, waves and wildlife was highly prized. These achievements no doubt occurred because of a passing of knowledge and expertise from one generation to another – a different concept of literacy – not conveyed in written form but in other ways, often in song, but a literacy nonetheless. This concept of literacy as distinct from the definition of literacy foreshadows the discussion to come.

The rise of the term *literacy* in the eighteenth century was a term to describe the fashion of the day: reading the printed word. This was a fashion which was valued by those in positions of power and one which came to have great significance for the future in Western civilisation. This was in sharp contrast to

earlier periods. Freebody and Freiberg (2011) reveal that Socrates could not read and write, and in fact Socrates believed that “this invention (writing) will produce forgetfulness in the minds of those who learn to use it because they will not practice their memory” (Socrates in dialogue with Phaedrus, Sections 275e-276b, reported by Plato, 360BC/1925). The meaning and scope of literacy has continued to evolve and in the late nineteenth century came to specifically include the cognitive skills of reading and writing (EFA Global Monitoring Report Team, 2005), as well as being *educated*. Olsen and Torrence (2001) observe that “the evolution of the literacy tradition in the West and passed on through schooling is a particular orientation to language, . . . an orientation to such linguistic entities as phonemes, words, and sentences and their counterparts, word meaning and sentence meaning” (p. 7).

We live in an era where literacy as it is now defined needs no justification; its benefits and fundamental importance are seldom questioned in the West. The position of the written word is evidenced, for example, by the laws, treaties, and constitutions which undergird nations, many of which sit in museums as artefacts. Debate and controversy may still surround the meanings and interpretations of those written texts, but the reality of their presence in written form bears evidence to the central role of the written word. Literacy, consequently, still remains capable of provoking public debate with on-going regularity possibly because it is often where individual and public worlds collide. Consequently, as Freebody (2005), for example, points out, “literacy is something of a superstar, with . . . the capacity to energize and disturb a community” (p. 444), especially if there is a downward spiral in perceived literacy *standards*.

2.2 Numeracy

The term *numeracy* was first included under the term *literacy* in the 1959 Crowther report submitted to the Ministry of Education in the United Kingdom (EFA Global Monitoring Report Team, 2005, p. 149). This pattern has continued with numeracy still often subsumed under literacy. Johnston (2002, p. 10) comments, “We have learnt that to be ‘incorporated in literacy’ was both good – it brought us funds – and bad – it made us invisible.” That invisibility continues in

many ways in this research, primarily because it is not a major component of patient stories or patient demand.

Numeracy in this research uses Coben's (2000) definition:

To be numerate means to be competent, confident, and comfortable with one's judgments on *whether* to use mathematics in a particular situation and if so, *what* mathematics to use, how to do it, *what* degree of accuracy is appropriate, and *what* the answer means in relation to the context (p. 35, emphasis in the original).

The ALL referred to earlier uses the following more narrow definition for numeracy, "the knowledge and skills required to effectively manage and respond to the mathematical demands of diverse situations" (National Centre for Educational Statistics, 2013).

Coben's definition allows a social practice orientation to numeracy where the numeracy demands of the context can highlight the characteristics of the numeracy required. In numeracy studies there has also been a shift from a concentration on standardised *skills* to numeracy *practices* and a recognition that the social context is a key driver in numeracy. There has also been the shift in viewing people as agents, as having their own numeracy practices rather than a focus on their numeric deficit (Johnston, 2002, p. 20). Further discussion on numeracy will be situated within the distinct field of health numeracy and this will be examined in more depth in the following chapter.

2.3 Literacy: Autonomous and social practice

Literacy standards are usually referenced to a view of literacy as cognitive (Goody, 1986) or autonomous (Street, 1984), as the individual skill of decoding and encoding language (reading and writing), the mental capabilities, perceptions, memory, reasoning, comprehension, and language acquisition, essential for society. These skills are considered autonomous because they are seen to be used in a de-contextualised way and are able to have effects on other cognitive and social practices (Street, 2009a, p. 23). This view draws a clear distinction between speaking and writing, placing the cognitive decoding/encoding language

skills as essential skills in literacy. An individual then sits on a continuum with those who have these skills being *literate* and those who do not as being *illiterate*.

The early debates around this view were clustered under theories called the *great divide* or *literacy thesis* (Scribner & Cole, 1981, p. 235; Reder & Devilia, 2005, p. 171; Olsen & Torrence 2001, p. 3). The literacy thesis sought to construct the differences between literate and illiterate communities in terms of cognition and language. Many dichotomies were used to illustrate these differences: simple vs. advanced, or primitive vs. developed, or primitive vs. civilized, or concrete from abstract, or traditional from modern thought. Scribner and Cole did not ascribe to this theory, but rather attempted to question this notion through their five years of ethnographic study among the Vai of Liberia. Scribner and Cole (1981) found that cognition could not be linked to the literacy that was learned in the context of schooling. Their conclusion came from testing people literate in Vai script and in Arabic to see if there was transfer of specific skills between different literacies. Scribner and Cole found these different language literacies to be “highly differentiated” (p. 132). They maintain that “men literate in Vai script qualify as having a written language but they do not (behaviourally or verbally in the experimental tasks) *look like* their peers with schooling” (p. 132–133). In other words, those whose literacy was learned in a school context had quite different literacy compared to those who had not learned script in another context. Rather than constructing literacy on a polarising scale, Scribner and Cole’s ethnographic research reinforced the importance of different types of literacies reflecting the cultural roots of a literacy’s characteristics and practices, regardless of where the literacy was learned. They state “literacy is not simply knowing how to read and write a particular script but applying this knowledge for specific purposes in specific contexts of use” (p. 236).

Scribner and Cole’s work began to create a case for a more complex and in-depth treatment of literacy, which highlighted and made visible literacy practices already existing in so-called illiterate communities. It allowed a step away from the polarisation prevalent in the literacy thesis and offered a view of literacy that could explore and make explicit the cultural and ideological assumptions underpinning views of literacy.

Heath's (1983) research was also instrumental in moving the scholarship forward. Her extensive ethnography included question use with children in three different communities in the USA. Heath found that children of one group were not spoken to or asked questions in the same way children of another group were. Not only this, those former children were raised to be suspicious or not divulge information to anyone from outside or anyone they did not know. They were taught not to reply and responded how they had been taught was appropriate. Therefore, in the classroom situation, those children were not used to school displays of questions and did not reply or respond according to the teachers' expectations. Heath was able to show that questions had different meaning depending on the context; the literacy practices were context driven. This focus on the importance of context in shaping literacy practices began a moderation of the differences between literacy and orality which had been prevalent in the polemic representations in the literacy divide.

The reaction to the view of literacy as independent, and being able to be separated from its social context, led to an expansion and development of literacy theory called *new literacy studies* (NLS) (Barton & Hamilton, 2000; Street, 1984; Gee, 1990). NLS saw literacy as more than what is taught in school. It used ethnographic research methods to examine literacy as social practices and to therefore explore the different literacies existing in different domains or contexts of life. This theoretical turn acknowledged the existence of literacy in cultural contexts that could be interpreted as having little access to formal literacy training. Street (2010) summarises this view:

Policy makers and educators from 'literate' societies see others' practices as lacking 'literacy'; like the fish from their water, they ask 'do they have x . . . literacy' – and when their lenses prevent them from seeing what the local people actually do have, they invoke the 'not'–'illiteracy.' But perhaps local people do have significant uses of reading and/or writing (p. 205).

Street has recently gone further in his criticism of the autonomous model, discounting it almost completely. Rogers and Street (2012) and others consider that the autonomous model "is not an appropriate intellectual tool, either for

understanding the diversity of reading and writing around the world or for designing the practical learning programmes required” (p. 13). However, the autonomous model does provide insights into cognitive aspects of literacy.

A literacy environment as complex as a hospital needs approaches such as those developed within the NLS tradition. A nuanced view of literacy is required which takes into account the subjectivities of the individuals creating their own meaning within a context. It allows an examination of *literacy events* and *literacy practices* contextualised in a hospital. An important distinction is made in the literature between literacy events and literacy practices. The notion of literacy events was originally introduced by Heath to describe “any occasion in which a piece of writing is integral to the nature of the participants’ interactions and their interpretative processes” (Heath & Street 2008, p. 104). Street (2010) views literacy events as being those activities where literacy has a role – writing emails, or reading a bill, for example. Literacy practices, on the other hand, are not just a collection of literacy events or ways that people use written language in their cultural or social setting, but are also somewhat abstract. They are not always observable and can include people’s internal individual attitudes, values or feelings. Literacy practices can be revealed in the conversations around literacy, in the shared social rules or ideologies, and in the physical spaces. They can be viewed from a local perspective as well as a broader or more global context. Barton and Hamilton (2000), drawing a distinction also between external practices (social worlds of the texts) and internal practices (personal beliefs, constructs, discourses, understandings of literacy), maintain that practices are not wholly observable, unlike literacy events; literacy events are “observable episodes which arise from practices and are shaped by them” (p. 8).

The discussion of literacy practices and events raises some interesting questions: Does a literacy event need to be centred on the presence of a written text? Do literacy events still occur in a context where written text is marginalised or is not at all central to social practices? This is examined in more detail in the following chapter.

2.4 Social practice

Discussion and scholarship continued on the social approaches to literacy and emerged conceptually as the *social practices* approach (Lave & Wenger, 1991; Barton & Hamilton, 2000). A social practice approach recognises that people encode and decode text for a reason, usually to achieve a particular purpose. These practices or activities (Papen, 2005) may include such things as participants, actions and sequencing, setting, performance modes, participant eligibility conditions, presentation styles, artefacts–texts and other objects, the rules, the interpretation, and other aspects of the contexts (van Leeuwen, 2008; Pahl & Rowsell, 2010; Rowsell, 2012; Street & Lefstein, 2007). Scollon and Scollon’s (2003) approach to texts found in the spatial context could also be part of the social practices of literacy in a context. For example, the use or otherwise of multi-lingual signs and their positioning in a public space may index a larger discourse or literacy practice. Exploring these elements of social practice is essential for the present study.

There are also aspects of social practices which endure over time. Cordella (2004) helpfully refers to social practice as the result of the reproduction of a structure and in that reproduction, preserving social practices for that time (p. 16). In an interaction between a nurse specialist and a patient for example, there will be features which are present across all conversations and others which are a result of an interplay between the particular interlocutors involved. Cordella (2004) also points to the notion of power and the power differentials that may exist between participants, especially those having more knowledge of the social practices of the situation. These power differentials create dynamism in social practices. Further discussion of discourse and power takes place in Chapter Three.

Lave and Wenger (1991, p. 50) summarise, “A theory of social practice emphasizes the relational interdependency of agent and world, activity, meaning, cognition, learning, and knowing. It emphasizes the inherently socially negotiated character of the thought and action of persons-in-activity.” Lave and Wenger introduce the notion of context here with the interdependency between an agent

and the world. It is to context we now turn to explore further the nature of this interdependency.

2.5 Literacy and context

2.5.1 Local and global contexts

In literacy, acknowledging context in social practice is to acknowledge that literacy cannot be confined to “a uniform set of skills applicable to different situations” (Barton & Papen, 2010, p. 19), but that is not to diminish that there is a set of activities needed to decode and encode written text in the current view of literacy. Rather, literacy as social practice has to be, by definition, situated. The shape, scope and characteristics of the situation are crucial to defining context, both local and global and it is for this reason that context needs to be examined in more detail as it requires a clear position before coming to data analysis. What is the nature and scope of these contexts? An answer to this question is needed for any critical appraisal of the literacy practices and events.

Smith suggests that we live in a ‘textually mediated social world’ where an “individual’s engagement with a text is locally observable and, at the same time, it is connecting the local into the translocality of the ruling relations” (2006, p. 66). This distinction in the scope of context is important because it acknowledges that broader or unseen circumstances or events impact on local contexts and therefore need to be investigated in the literacy context. Brandt and Clinton (2002) especially argue for the inclusion of the context outside of the immediate local context, the global, in explaining the nature and uses of literacy. They conceptualise this local/global approach to context as *localising moves* and *globalising connects* (p. 351) where the localising moves are the actions people undertake to mould literacy practices to their immediate settings and social groups, for example, reading preferences, or shared habits (p. 351). The globalising connect, on the other hand, describes the connections that local literacy practices have with the wider or global context. These globalising-connect literacy practices could be the social, political or hegemonic relationships or links, sometimes unseen or unacknowledged that have connections to the local.

Street (2003) responded to Brandt and Clinton's localising moves and global connect discourse by clarifying how literacy events and literacy practices can be applied to consider both the local and global. He clarified further in 2007 by stating with Lefstein:

Formulation of context allows for distant influences on local practices to be clearly identified not as disinterested 'autonomous' forces, but as ideological players in their own right. . . . There is no divide between local and global contexts: People's everyday intimate experiences of literacy are in conversation with remote forces at play in the larger socio-cultural context (Street & Lefstein, 2007, p. 175).

What is important to glean from this is the movement within NLS to tackle the scope and meaning of context in literacy: that context is both seen and unseen, close and distant and cannot be approached in a reductionist style.

Reder and Davila's (2005) response to the contributions by Brandt and Clinton, and Street and Lefstein was to return to the influence of the written text as a shaper of "local literacy events" and a mediator of "distant social relationships" (p. 181). They maintain it is this connection which "expands the mediated context" (p. 181). They advocate further research into specific communicative practices in order to describe more fully the impact of written texts on literacy events. There is little doubt that written text can be a shaper of literacy events in a particular context, but there are other influences that affect literacy events as well, as Brandt and Clinton's contribution highlights.

Pettigrew (1999), for example, exploring how particular contexts affect the flow of information in chiropody community clinics, divided context into four categories: environmental factors, clinic activities, factors associated with nurses, and those associated with patients. Pettigrew considered that these different aspects of context together created a "grand context" (p. 809). She deduced from this grand context that the clinics she was studying could be described as *information grounds*. An information ground was defined as an "environment temporarily created by the behaviour of people who have come together to perform a given task, but from which emerges a social atmosphere that fosters the

spontaneous and serendipitous sharing of information” (Pettigrew, p. 811). This spontaneous sharing of information is context driven. Though demonstrating the importance of local context and providing a useful approach to interpreting the participants’ behaviours, Pettigrew’s approach to context does not take into account the globalizing connect, coming to the conclusion that information sharing is very much local, and perhaps does not take into account the influence that the external has in a local context. A critical stance is therefore required when considering context.

For a slightly different perspective on context, but one that extends Pettigrew’s information grounds, Smith (2006) constructs context for ethnographic study through the lens of the *social*—“what we are calling the social is only to be discovered among actual people and their on-going activity” (p. 2). Smith also alludes to the same local-global perspective that Brandt and Clinton elaborated on but constructs it as a social context with dimensions “that transcend the local” (p. 3). Scollon and Scollon (2003) add to this understanding of social by including the relationships between people and the inanimate objects in the physical space.

2.6 Variations within literacy domains

A social practices view of literacy holds that there are many literacies, driven by the differing practices surrounding reading and/or writing and/or orality in different contexts. Some of these literacies are “coherent configurations” (Barton & Hamilton, 2000, p. 10) and can be labelled, for example, computer literacy or health literacy. Other literacies are found in the specialised knowledge required to read particular kinds of texts for example, architectural plans, legal contracts, or financial statements. Hunter for example, (as cited in Rogers & Street, 2012), gives the account of variations in situated literacies when she describes the specific short-hand a new hotel employee had to learn in order to communicate effectively with the workers she supervised. The hotel workers had developed their own local vernacular to communicate about assigned jobs, giving weight to Barton and Hamilton’s (2000) observations that “people use written language in an integrated way as part of a range of semiotic systems” (p. 9).

Ethnographic studies of literacy provide many examples of these different literacies, for example, Besnier's (1993, 1995) work amongst the Nukulaelae, and ur's work on significance of objects. , Rockhill's (1993) work with Spanish speaking settlers in Los Angeles, Belfiore, Defoe, Folinsbee, Hunter, and Jackson's (2004) Canadian workplaces literacy research, and Kell's (2010) African community research. Kell's (2010) research for example, focussed on one particular respected and active community leader who was a fluent speaker of three languages and had knowledge of three more, yet considered herself 'illiterate' (p. 270). Kell tracked the woman's attempts to learn to read and write at adult literacy classes and the onset of her marginalisation amongst her peer community as the community became more print-text dependent. Kell comments, "The arrival of night school infantilised Winnie, foregrounding her deficit and back-grounding her strengths as an effective and powerful community leader" (p. 270). This is also an illustration of the power of definition. Literacy defined in a particular way by a more powerful group has ramifications for the detractors, who may begin to, or find themselves re-classified as a *not*. Acknowledging the existence of power in literacy definitions necessitates a brief overview of ways that power can be analysed, a field in literacy called critical literacy.

2.6.1 Critical literacy

The notion of critical literacy grew out of the work of critical social theorists who examined social injustice and inequalities with a view to creating change. Freire and Macedo's (1987) view of reading the word and the world encapsulates that notion of critical literacy. Coffey (2008) defines critical literacy as "the ability to read texts in an active, reflective manner in order to better understand power, inequality, and injustice in human relationships" (para: 2). Text here is defined as the "vehicle through which individuals communicate with one another using codes and conventions of society" (Robinson & Robinson, 2003, p. 3). Thus a text includes anything that needs to be decoded, for example, websites, pictures, artefacts, conversations, test results, songs. Further discussion of text is in section 2.7.

Egbo's (2003) elaboration of critical literacy makes reading and writing a pre-requisite. Despite this, Egbo's idea of critical literacy goes a step further than

Coffey by stating that it “hinges on the rationale that, through reading and writing and the concomitant expansion of language and knowledge base, people can begin to deconstruct and reconstruct their identities, and personal and collective histories, thus replacing hegemony with critical action” (p. 248).

A detailed examination of the teaching of critical literacy is outside the scope of this thesis, but examining critical literacy from an educational perspective is important because it gives valuable insights into how critical literacy is conceptualised or defined. This is in preparation for how it may be viewed within health literacy approaches in the following chapter. In an educational setting, critical literacy is fostered through activities that acknowledge the interrelationships between power, language, and social practice. A literature review (Behrman, 2006) into how critical literacy is taught in school classrooms showed it to be a theory that informs teacher practice rather than being a central driver. Behrman found the most common school classroom practices used in teaching critical literacy were reading supplementary text, reading multiple texts, reading from a resistant perspective, producing counter-texts (a student-created text that is non-mainstream in its perspective on a topic), conducting student-choice research projects and taking social action (p. 492). Behrman’s findings support Freebody and Freiberg’s (2011) view and my own that critical literacy should not be “a cause” (p. 449). Rather, it is a set of resources that students have in order to evaluate and compare the different ways of interpreting texts and literacy practices.

Janks (2013) has developed a model of critical literacy which provides a useful tool for conceptualising critical literacy in a health context. The *interdependent model* links “literacy to a politics of self-empowerment and an ethics of care” (2013, p. 227). Her model examines events and practices from four key perspectives:

1. power or domination which sees language and discourse as a way of preserving and replicating domination;
2. access to dominant forms of literacy, for example, language or knowledge;
3. diversity in discourses generates the momentum required for modification and change. Different discourses link differing contexts and communities.

Contact with these differences creates opportunities for reflection and new ways of being;

4. design/redesign across multiple literacies and modalities emphasises opportunities for transformation and reconstruction using different technologies and media (Janks, 2010).

The current use of a wide range of multi-media, especially technologies is challenging and changing discourses. Janks's interdependence model allows each of these variables to be examined as it relates to each of the others, so that for example, one can have power with or without access, or design without diversity. This interdependence helps to formulate a critical perspective on literacy events and literacy practices found in the data. Further discussion of power and domination as it relates to my research is found in the following chapter and re-examined in Chapter Eight in light of the data found in the hospital literacy context.

2.6.2 *Distributed literacies*

Distributed literacies refer to a view of literacy which recognises the role of the individual as the central literacy agent, but acknowledges the group, community, or social relationships surrounding text as being just as rich in providing insights into each literacy (Barton & Hamilton, 2000; Purcell-Gates, Jacobson, & Degener, 2004; Curtis, 2008, p.244). Literacy then can be distributed or collective as well as individual. Examining distributed literacy in a context involves looking at how a community or group actually practically manage their relationship to printed text. Is there a distribution of labour which is part of how the group or community navigate their relationship with text? In a workplace, literacy tasks may be managed by a group or the institution, rather than any individual. Distributed literacy does not discount the role the individual plays as the central literacy agent, but it acknowledges the wider context that literacy practices are part of (Curtis, 2008, p. 236). Distributed literacy is another lens to view the hospital context from and thus it is important to make this variation explicit in the literature as participants may display these types of literacy practices. Up to this point, I have used the term *text* widely. The term now needs clarification.

2.7 Text

In a previous section, I have defined the notion of text as a mode of communication between individuals that requires the use of codes and social mores, for example, pictures, artefacts, test results, songs, conversations or patient information leaflets. A text itself is made up of patterns and symbols which require decoding. Regardless of the actual physical manifestation of those patterns and symbols, a text has three separate components: “the production of the text, the text itself and the reception of the text” (Fairclough, 2003, p. 10). These components echo the previous discussion on context and the forthcoming discussion on mediation, all of which confirm Fairclough’s observation that the interplay between the three components is how meaning is made. However, the context and mediation of texts are separate from the text itself. Fairclough’s work on text built on the earlier work of Halliday (1994) and Halliday and Hasan (1976, 1989) who are credited with the development of the Systematic Functional Linguistics (SFL) linguistic theory, a theory which views language as a social system of meaning making. Fairclough’s third perspective, text reception, includes the construction of the text in the instructional context or the mediated context, whereas Golden (1988) maintains text is created by the reader as he or she is reading since the text is influenced by “the textual cues and the reader's background knowledge and experience” (p. 21). A critical realist approach would designate the created texts as a perspective on reality, rather than a constructed new reality. Both of these views add to the complexity of text and its use in this thesis where it is limited to artefacts of written language, pictures, or diagrams, and *realia* (real-life objects used to teach learners about real life conditions or states). Certain artefacts within contexts could be seen to be texts that need to be decoded. The human body for instance in a healthcare context is constantly *decoded* as part of diagnosis and treatment. For a health professional, the human body is the subject of years of intense study, learning how to decode the body’s anatomy, physiology and biochemistry for example. Further exploration of this is beyond the scope of this thesis; suffice to say that diverse literacies have diverse texts. Much like the early Polynesian endeavours touched on in the introduction, written text is not always the main mode of communication or knowledge transfer in a literacy.

However, in this current age, written text in public life is often the medium of communication. Texts are created for a myriad of reasons and serve a multitude of roles, not least of which is to inform, coerce or entertain. Slembrouck (2010) raises a pertinent question which reflects the text-context interrelationship of my research: “If our aim is to understand the role of leaflets in contemporary social processes, how much of that role can in fact be gleaned from just the text itself?” (p. 255). Smith (2006) had already advocated for ethnography as a way to study the role of texts in communication, supporting the research methods adopted in my research. It also moves us onto discussing Fairclough’s third aspect of text, its reception. Literacy sponsorship and mediation are two practices which can be part of text reception.

2.8 Literacy sponsorship

The practice of explication of text in all of its forms (literary or art criticism, for example) is as old as biblical exegesis. However, Brandt’s (2001) use and definition of literacy sponsorship recognises and introduces the notion of power or influence into the discussion. Brandt (2001) defines sponsors “as any agents, local or distant, concrete or abstract, who enable, support, teach, and model, as well as recruit, regulate, suppress, or withhold, literacy – and gain advantage by it in some way” (p. 19). From a historical perspective, “access to literacy has always required assistance, permission, sanction, or coercion by more powerful others or, at least, contact with existing ‘grooves’ of communication” (Brandt & Clinton, 2002, p. 349). The recognition of the ideologies and power relationships inherent in literacy is crucial when using this concept to examine the nature of literacy in context. Sponsors bring “ideological freight” (Brandt, 2001 p, 20), which must be accepted to gain access to what they are offering. Brandt continues, “sponsors of any kind, as we know, lend their resources or credibility to the sponsored, for their own advantage, whether by direct repayment or, indirectly, by credit of association” (2003, p.247). This position on sponsorship as always serving to further the sponsor’s advantage is not the position adopted in this research. I prefer to create space for benevolence also being a factor in sponsorship. Though sponsorship may result in advantage to the sponsor, this may not have been the underlying motivation for it to occur. How sponsorship

actually occurs in practice varies widely. However, mediation can be one of the ways that literacy sponsorship takes place.

2.9 Discourse, power and agency

An NLS approach to health literacy involves a critical examination of discourse and power. The state and use of power in the hospital setting need to be acknowledged when examining social practice and health literacy. The hospital is a highly structured and patterned place with social, cultural, hegemonic and political contexts for literacy events. Skutnabb-Kangas notes the forces at play in contexts as the “power relations in which the meanings and images are produced, where legitimate knowledge and social relations are negotiated and validated or invalidated, where hegemonic meanings are challenged and where individual groups are disempowered or empowered” (Skutnabb-Kangas, 1999, p. xii). Power is dynamic; however, it requires agents as it does not reside in space. How agents (including not only the knowledge empowered, but also the disempowered) apply ethics in the knowledge/power construct makes a difference. I concur with Janks and Vasquez (2011) who present Foucault’s (1980) notion of power as circulating, rather than as just dominating or subordinating. They maintain, as do I, that both types of power exist in the world today and thus are eligible for critique.

Cordella (2004) interprets power “as an activity that separates those *knowledgeable* [original italics] from those *not knowledgeable* within the social system” (p. 13). For those knowledgeable of the system, there is little that is surprising, in contrast to those clients who just visit. Related to this knowledgeable notion, is the relationship of power to resource allocation. Cordella again observes that “communication in institutions appears to be a fertile ground for the reproduction of power because participants of different status come face to face in a system where resources are not equally distributed” (p. 16). Participants in such institutions respond in dynamic ways to what power enables and what it constrains. Davis (as cited in Cordella, 2004) considers that “it becomes essential to uncover the subtle mix of what actors do (and refrain from doing), what they achieve (and fail to achieve) and what they might have done

(but didn't)" (p. 17). It is in examining those responses that the concept of *agency* connects to power.

This exercise of power and its relationship to *agency* is fundamental. This research uses Ahearn's (2001) definition of agency as being "the socio-culturally mediated capacity to act" (p. 112). A treating physician is also part of a complex, dynamic context, where patient fatalities, errors of judgement, or medical misadventure carry their own consequence. A patient's agency in this context can, as Ahearn (2001) points out, shift over time, and present in many different guises. In fact, Ahearn encourages a focus on agency which delineates "different kinds of agency, or different ways in which agency is socio-culturally mediated in particular times and places" (p. 122). This approach, as well as the previous discussion on power moves us towards a view of power that is dynamic, circulating and/or dominating and hierarchical.

Papen's (2010) account from interviews with patients who for various reasons preferred to stay passive, but still displayed agency, provides an example of agency of a particular place and time. One participant liked to trust in a doctor's words and advice because of the years of medical training to learn such advice. Another rejected written information given to her in order to self-protect as too much knowledge about the illness became frightening. The concept of agency was not wasted on her because she disagreed with the *partnership* model in healthcare and wanted to trust that the doctor or health professional knew best. Papen surmised that a lack of interest in written material could reflect the implicit trust a patient may have in their doctor. This is a literacy practice, but it is dependent on the dynamics of power in the context.

Skutnabb-Kangas (1999) elucidates the power dynamic further, stating that "unless literacy leads to a capacity to analyse those power relations, it will once again reproduce disempowerment" (p. xii). Health literacy is no different – the dialogues between knowledge giver and receiver may not be empowering for the patient. This is not to say knowledge authority is problematic; rather, it is problematic in the way the power differential can position receivers or patients into an undesirable passive response. Language in use is not neutral, especially

where more powerful interlocutors can restrain, limit or encourage the participation of the other less powerful interlocutors.

2.10 Mediation

Capturing the mediation of text occurring in a context is depicting aspects of social practice. Barton and Hamilton (2000) place the mediation of written text as central to literacy events from which social practices can be inferred. Fairclough (2003) takes a similar view seeing mediation as “the ‘movement of meaning’ from one social practice to another, from one event to another, from one text to another” (p. 30). It is therefore worthwhile to examine mediation to determine how the mediation of texts in a context is part of any literacy event or practice, and how my research might expand the use of mediation by exploring its presence in a hospital setting.

Several disciplines outside education also use the concept of mediation. Silverstone (1999), who engaged with the concept of mediation through a media and communications studies lens, sees mediation as involving the “movement of meaning from one text to another, from one discourse to another, from one event to another” (p. 13). He maintains that in mediation, we need to “understand its politics: its vulnerability to the exercise of power; its dependence on the work of institutions as well as individuals; and its own power to persuade and to claim attention and response” (p.18).

Effective mediation in which outcomes are achieved is a process that relies on trust (Silverstone, 1999) between the mediators and the readers. This need for trust is evident in healthcare where information in the text needs to be accurate (that requires consensus of medical opinion) and where many texts are written to be mediated by health professionals to the public user. What makes Silverstone’s view on mediation so useful is the fact that it is not just viewed as a pedagogical process in which a mediator acts to make knowledge accessible to the audience. He considers that mediation has both epistemological and ethical dimensions: epistemological in that mediation creates a definition of what is understood, and ethical in that the mediator is using power in the mediation process, by choosing

what and how mediation will occur. This is important to remember when coming to my research data.

From an educationalist's perspective, mediating the writer's texts to the reader is based on the assumption that with written text, discussion about the content of the text assists understanding, and that new knowledge has to be fostered during this mediation time making the teacher's role a pivotal one (Golden, 1988). With younger learners, Sipe (as cited in Ghiso & McGuire, 2007) contends that teacher mediation helps children navigate the different sign systems present in picture books. Golden (1988) analysed the teacher-student interaction with text during reading and the discussion of the text after the reading. She found that the teacher's mediation included monitoring of student word identification, links to life experiences, teacher and student interpretations of text, and inter-textual references—techniques which can be reformulated as scaffolding the students towards the text. In education, scaffolding is when a student is given progressive levels of support to help them attain a higher level of independent knowledge or skill. The help is temporary and changes as the student gets progressively more competent. Golden considers that the teacher “functions as a mediator of the text by emphasizing certain aspects of it” (p. 21). Golden, as an educator, also draws our attention to issues of power and ethics in the mediation of texts. Mediation is often done with a prescribed set of assumptions about the text and prescribed goals for interacting with the text, and these assumptions are not always identified and/or articulated, but they need to be.

Gibbon's work in mediation is very useful for my research as she examined the concept of mediation while investigating how teacher-student discourse in a science class contributed to the language development of language learners. Her mediation study was therefore between two different discourses—the discourse of the language learner with limited English language ability and the specialist vocabulary required to successfully complete a content-based course of science. Gibbons (2003) differentiated mediation of this kind “occurring in situations characterised by difference, difficulty, or social distance” (p. 248). Gibbons (2003) considers that this characterises the teacher-student relationship “because in the great majority of school classrooms there is considerable linguistic and conceptual distance between teacher and students, especially when they do not

share the same language, assumptions, and life experiences” (p. 249). This same characterisation could be made of the relationship between a patient and their health professional, where there often is the same considerable distance between the two interlocutors, especially concerning knowledge of the human body. There is usually considerable linguistic and conceptual variation between the patient’s reading of their body and a medical specialist’s.

The patient-health professional relationship has many things in common with Gibbons’s conceptualisation of mediation for language learners in a science class. There are two distinct discourses in this context: the patient’s current knowledge and ways of thinking and the knowledge and specialist language of the hospital and the speciality that the patient is being apprenticed into. Gibbons found that mode shifts found in teacher-talk illustrated “the way the discourse operates as a linguistic bridge between students’ current language abilities and the demands of the school curriculum” (p. 259). The teacher mediated between the demands of the science curriculum and the language abilities of the students. Gibbons’s comment is notable that “comprehensibility here is not synonymous with simplification; rather students are given access to key technical terms in a context where meanings are made transparent” (p. 259). It is interesting as well that her findings also confirm that an increase in negotiation of meaning increases second language learning (p. 262). These insights can provide a way to view the mediation discourse captured in the hospital context and whether or how it operates as a linguistic bridge and therefore, meaning making.

Pettigrew (1999, p. 803) helpfully conceptualises how a form of mediation may actually happen in providing an example of literacy sponsorship. She cites Granovetter’s theory of the strength of weak ties. This social network theory proposes that a person’s relationship networks will have ties that are weak (acquaintance) and ties that are strong, (close friend). Granovetter considered that weak ties are the conduit for new information within an individual’s relationship networks because closer friends move in a closer circle and therefore possess the same information. However, Granovetter proposes that strong ties are the information validators and suppliers of affective fulfilment. Pettigrew hypothesized in the hospital context that a nurse is a patient’s weak tie and

provider of new information but that a patient would not act on the information until first conferring with a strong tie, a close friend or family. From an educational perspective, in a hospital, the literacy sponsor and the weak tie may be one and the same in terms of a provider of new information. This form of mediation may be visible in my research data.

Typically the use of written text in social practices has the role of mediating distant or remote epistemologies, social interactions, and power relations, “resulting in the expansion of context for specific literacy practices” (Reder & Davila, 2005, p. 180). Reder and Davila (2005) call this a mediated context. This seems useful in that any text written by a person or group of people outside of the local context can be seen as a more distant, or global artefact, constructed by others with agendas not always transparent to readers.

Mediation is a dynamic process involving new connections, new knowledge and physical artefacts. In a health care setting, patient information texts are the likely artefacts that a patient will encounter in hospital and leave with. Research done specifically on the mediation of patient texts in hospital is scarce. Dray and Papan’s (2004) work, discussed in more depth further on, attempts to understand the role of patient information leaflets in a healthcare setting, the “subsequent actions they invite and how they mediate communication between patient and doctor” (p. 318). However, their study was limited to one patient and was auto-ethnographic. In terms of their examination of mediation of the artefact, they approached it from a critical perspective. They were interested in whose interests were represented in the text, where the text was positioned in the context with the patient and analysis of the text itself. Nevertheless, their work informs the direction taken in my research and is presented more fully in the following chapter.

2.11 Artefacts and geosemiotics

Most agree that mediation involves an artefact or a tool (concrete or conceptual), in a relation between a subject—a person who might be a learner, and a desired outcome which may be new learning. A text may be an artefact. Vygotsky, (1997) theorising the mediating power of artefacts or tools on human activity

systems, views mediation as creating “connections in the brain from outside” (p.55). Lantolf and Thorne’s (2006) analysis of Vygotsky’s perspective places some weight on the presence of these artefacts stating that, “primary artefacts such as communicative semiosis and physical tools enable the construction of social and physical realities” (p. 63).

Pahl and Rowsell’s (2010) work takes an artefactual literacy approach which is helpful as it positions non-text artefacts such as a child’s stuffed toy or a grandfather clock as having significance for literacy, by examining the role that such objects have in talk. “Objects can be described as semiotic when they are bound up with an act of meaning making” (p. 39). Examining “how the physical/material characteristics of language in the world give meaning to communications” (Scollon & Scollon, 2003, p. x) across different localities, extends the notion further. For example, the positioning of text, which may appear on an artefact such as a sign or a monument, and the meaning surrounding that discourse in that location may be influenced by the local or global contexts. Exploration into discourses in place can investigate the institutional processes or systems of context. Scollon and Scollon (2003) contend that “one of the major means by which socio-political control of the spaces in which we live is produced and maintained is through the control of discourses in those spaces” (p. x). Scollon and Scollon (2003) call this type of analysis geosemiotics – which brings together the fields of linguistics, cultural geography, communication and sociology.

Geosemiotics is a derivative of semiotics which is the study of the making of meaning through signs and symbols. Geosemiotics studies the location of language in the physical world and the surrounding systems. Locating the written texts and other artefacts in space provides insight into how the social actors are woven into the objects, time and space in the physical context, the local moves. It provides insight into the role of texts in institutional processes and *interaction order*, which embodies the ground rules or conventions of particular interactions (Jacobs, 2007, p. 2365). It examines *indexicality*—the meaning of signs based on their material location and points us towards recognising the globalizing connects embedded in the local context. The fields of geosemiotics and artefactual literacy

provide a helpful background to interpreting relationships to literacy events and practices found in the study site. The fields also provide a way to examine the language used in texts as something more symbolic. Putting the linguistic analysis aside, we can view the physical nature of the paper pamphlet from a different perspective. Rooke, Rooke, Koskela, and Tzortzopoulos's (2009) work on the role of artefacts in bearing information and knowledge found that "knowledge can be embedded or encoded into the physical properties of artefacts and that this can be successfully transferred from artefact to user" (p. 1). The context for their study was building design and construction management. What is helpful about Rooke et al.'s (2009) work is the acknowledgement of physical environments and objects as bearers of information in social practices. They cite door handles as information bearers, "the designer must provide signals that naturally communicate to the user where to push or pull" (p. 7). This line of enquiry has implications for the meaning and role of the physical nature of patient information, the paper pamphlet and the pamphlet holders in the collected data.

Noy (2008), in a study of the semiotics of a visitor book at an Israeli commemoration site, maintains, there is "no such thing as *unmediated writing* [emphasis his]" (p. 177) because unlike speech, writing needs some form of person-device (usually paper) interaction. Noy (2008) demonstrates how the presence of that device "not only convey[s] meaning(s) but also projects meaning(s) onto its surroundings" (p. 179). Noy examined the accessibility of the visitor's book, its physical setting, inferring from this a message of restriction, organizers wanted the entries into the book short and the setting of the book on a pedestal ensured writers would not be in a comfortable physical position when making their entry. This style of semiotics is another way to view the context of text artefacts since its focus does not lie solely in finding meaning in the text.

Work by Shohamy and Waksman (2009) in linguistic landscapes extends text types beyond written artefacts and looks at texts situated and displayed in dynamic public spaces. The changing and diverse linguistic landscapes of public spaces have implications for the multiple modes of meaning construction in those places. Blommaert (2014) advocates for an ethnographic approach to capturing this "superdiversity" (p. 433) because it captures the complexities of the space,

which reflect vast changes in social, language and migration patterns in the public context.

2.12 Literacy consequences

The significance or consequences of literacy are well documented and also well debated. A 2004 UNESCO (United Nations Educational Scientific and Cultural Organization) report on the benefits of literacy and/or education cites evidence across human domains such as self-esteem and empowerment, political benefits of increased political participation, cultural change, preservation of cultural diversity, health status, and economic growth. Stromquist (1997) reinforces the implications of literacy for self-esteem.

But beyond a sense of comfort given by increased coding and decoding skills, literacy has been found to produce feelings of confidence when the former ‘illiterates’ now see themselves as regular and ‘normal’ adults, as individuals with a certain autonomy of judgement, mobility, and increased freedom to move and act (p. 138).

Skutnabb-Kangas (1999) takes this further, stating that “unless literacy leads to a capacity to analyse those power relations, it will once again reproduce disempowerment” (p. xii), implying that critical literacy skills are essential. The impact of literacy on economic growth reported on in the Education for All Global Monitoring Report 2005 cites research by Coulombe et al. (2004) which found that

the average literacy score in a given population is a better indicator of growth than the percentage of the population with very high literacy scores. . . . A country that focuses on promoting strong literacy skills widely throughout its population will be more successful in fostering growth and well-being than one in which the gap between high-skill and low-skill groups is large (p. 144).

The Longitudinal Study of Adult Learning (LSAL) reported on by Reder (2010) found strong relationships between literacy proficiency and earnings amongst high school youths no longer attending school. Reder also reports on literacy

proficiency affecting earnings growth in a positive direction although he states that “there is no evidence of a reciprocal effect between literacy and earnings in the LSAL population (i.e., that changes in earnings lead to changes in literacy proficiency)” (p. 19). A New Zealand Treasury Working Paper (Johnston, 2004) had earlier made similar concluding remarks to those found by Reder.

2.13 Texts and ethnography

This thesis has already discussed early examples of ethnographic research into the role of texts in contexts, the earlier work by Scribner and Cole (1981) and Street (1984) for example. Swales’s ethnographic account of the writers and writings of a small university building provides another contribution. Swales (1998) explored social practices surrounding text in a *textography* of a three-storied university building in order to illustrate ethnographic principles applied to the place of text. His textography was an exploration into “the way text is *situated* [his emphasis] in the local, institutional context” (Swales, p. 1). It included a particular focus on how the text was mediated and features of the text itself. Swales uses the term textography to mean “something more than disembodied textual or discourse analysis, but something less than a full ethnographic account” (p. 1). He positions texts in the life and time of the author in the writing environment, which from Scollon and Scollon’s (2003, p. 95) perspective, is one of the three types of interactive participants of texts, i.e., the interactions between the maker of the image/text and the people or things represented in the image/text. Swales’s approach explored this interaction, between the writer and what was represented in the text, by situating himself in the context, taking an ethnographic approach. Swales’s work is important for my research because his focus was on the text; it was central to his ethnographic research. Scollon and Scollon’s other two types of interactions are between the representations/participants in the picture/text, and the interactions between those representations or participants and the viewer/reader/user.

Dray and Papen (2004) built on Swales’s work, but in a healthcare environment. They undertook an auto-ethnography that was concerned “primarily with the mediating role of (written) texts in social events such as healthcare encounters” (p. 6). They deviated from conventional literacy ethnographies by also including

linguistic analysis to understand the texts used in the healthcare event. Fairclough (2003) recommends this broader approach to textual analysis when he suggests that “textual analysis is best framed within ethnography” (p.15) in order to investigate the meaning-making of the texts. This development of text ethnographies or textographies provides a starting point for my research.

Dray and Papen (2004) took these situated and social practice concepts and combined them with the field of critical discourse studies. They were looking at the power relationships between the participants and how the textual analysis of, in this case, a coeliac disease leaflet, furthered their understanding of those power relationships and the provision of information. Dray and Papen conducted this research with the aim of challenging the “deficit discourse” (p. 326) of health literacy prevalent in England at the time, a discourse which originates from an autonomous view of literacy. Their concern was that if patients were going to be empowered by being given more written information, did the literacy events and practices confirm that position? They contended that this move to patient empowerment challenged the existing hegemony between doctors and patients, hence their critical approach. Dray and Papen invited others to use their research methodology to continue to explore the tensions around written text use in the healthcare setting, and my research has taken up that challenge. The context is different in New Zealand to that in England. However, the dearth of research on text use in the healthcare setting is the same.

2.14 Situated patient texts and roles

Research that examines written texts used in the hospital context in order to understand the role the text plays is limited. Papen (2010), using Smith’s (1999) *relations of ruling*, examined this idea in a healthcare setting where oral communication between clinicians and patients often includes written text. Papen contends that specific roles and structures of authority exist in healthcare, and these are reflected in the written material given to patients. She used semi-structured interviews with adult students to explore their experiences with the health texts. She found the texts played a role with patients as a backup or confirmation of what had already been talked about with the patient. However, this was not always a positive thing. She also recounts a situation where a patient

had doubted the knowledge authority of a health professional because they had reached for written text to help rather than explaining it directly to the patient. The use of the written text by the health professional cast doubt on the patient's perception of the doctor's knowledge authority. This was in contrast to other participants who had found the reading material empowering. She contends that the way in which patients respond to written patient information reflects their engagement with the authoritarian voice contained in the written patient texts. Papan's research findings present a range of patient responses to written patient information leaflets: seeing them as an item which can challenge the authority and status of the health professional giving the texts; seeing the giving of text as merely part of the medical ritual prevalent in English surgeries; provoking fright/flight at what might happen as the illness progresses; and provoking a lack of interest because of implicit trust in the doctor.

Papan's work relates to Dixon-Woods's (2001) call for research into how patients respond to and understand the written patient leaflets used in different healthcare contexts. Dixon-Woods's work cuts across aspects of text, text role and into broader issues within health literacy. By identifying prevalent discourses existing in patient information leaflets, Dixon-Woods reveals the assumptions or approaches to patients by the authors. She uses two discourses, *patient education* and *patient empowerment*, (p. 1419) which have parallels with the functional/cognitive and social practice approaches to literacy. Patient education has useful biomedical outcomes where patients move from deficit to credit in terms of their knowledge, when they understand and enact the instructions. This measurable, deficit approach has echoes in the functional literacy literature. The patient empowerment discourse on the other hand is about giving patients choice, and having information available that enhances that choice and empowers them in their decision-making as a patient. Obviously it is not polar opposites, but elements of a text can push the text towards education or empowerment.

Dixon-Woods found that patient education discourse was more prevalent than the patient empowerment discourse. Patient education discourse discounted the "principle of patient autonomy, often adopting the view that information, while necessary for compliance, should not be freely available to patient" (p. 1420).

She found that the reason for using these patient education types of leaflets or pamphlets were the advantages to healthcare providers, for example, saving time in the consultation and the promotion of compliance. Their use was also motivated by a “discursive construction of patients as irrational, passive, forgetful and incompetent” (p. 1419). Dixon-Woods found these constructions were unchallenged in the patient education discourse. Another reason she found for using patient information leaflets was the possibility of creating patient change: change in cognition, attitude or behaviour.

Dixon-Woods also cites evidence for Pahl and Rowsell (2010), Noy (2008) and Rooke, Rooke, Koskela, and Tzortzopoulos’s (2009) contention that the printed patient information itself carried knowledge apart from what was written therein. In this context, the printed material is an artefact. Dixon-Woods found the printed patient information (holding something in your hand) had a part in improving patient satisfaction and reducing patient fear, in some studies reducing patient fear more successfully than verbal communications. Lantolf and Thorne (2006) also highlight the power of *visible language*. Further exploration into the effects of actual paper, visible language, or having something to hold in hand (physical artefact) and its relationship to patient satisfaction would be useful.

The patient empowerment discourse Dixon-Woods identified used printed patient material in contrasting ways. The goal was to provide information to empower patients to be active in their care, not passive, to bolster patient choice, or in Ahearn’s (2001) words to empower patient *agency*, which Ahearn defines as the “socio-culturally mediated capacity to act” (p. 306). The phrase, *socio-culturally mediated*, is key in building the capacity of patients to be active in their care. It implies involvement of others outside of the individual patient, and is something Papen and Walters allude to in their definition of health literacy. “Health literacy has to do with the social and cultural practices that individuals and groups may engage in, in the process of understanding, accessing and using health-related tools and services” (2008, p. 10). This is discussed further in the following chapter.

Studies within the patient empowerment discourse, according to Dixon-Woods, seek to discover if patient leaflets include the type of information shown to be

most relevant for patients, and how leaflets “promote shared decision-making” (p. 1422). She has found within the patient empowerment discourse a focus on the *imagined reader* and cites Coulthard’s (1994) analysis that showed “badly written leaflets fail to maintain a *consistent* [emphasis mine] imagined reader throughout the text” (p. 1422).

Seeing the patient, the reader of patient texts, as active and engaged in meaning making takes us back to Fairclough’s definition of text (text recipient) and reveals the scope and breadth that analysis of literacy can involve. There is still need for further research into patient text use in healthcare contexts as Dray and Papen (2004) encourage, and as Dixon-Woods displayed. Artefacts like patient information leaflets and wall-board pamphlet holders are a significant part of patient text in these healthcare contexts.

2.15 Patient text approaches

Dixon-Woods’s (2001) call for a “rigorous theoretical framework within which to think about [printed] patient information” (p. 1428) has according to Clerehan’s (2014) review, generated research from a broad array of methodological approaches, but with little linguistic analysis. This is an observation also expressed by Dray and Papen (2004) who did use linguistic analysis (critical discourse analysis) to analyse a patient information leaflet. Their analysis of a patient information text provides an approach to looking at patient text used in a health context but does not formalise the approach into any model. Rather, their example examines texts in a multi-layered way, from the grammar and voice, to text density and design, to examination of any power differential between writer and readers, and includes a perspective on the voice of the data collected ethnographically. Clerehan, Hirsh, and Buchbinder (2009) put forward an itemised analytic linguistic framework, based on systemic functional linguistics, to evaluate patient information leaflets. The framework identifies and analyses generic structure, rhetorical elements, meta-discourse, headings, technicality of lexis, lexical density, writer-reader relationship and factual content (p. 118). Both of these approaches have merit as they bring together ways of looking at the text as well as the factors external to the text itself. Appendix 2 has an overview of the approach I have developed to analyse the texts collected in this study. The

overview draws together the work of Clerehan, Hirsh and Buchbinder (2009), as well as that of Dray and Papen (2004), and Franken and Hunter (2011). In developing the matrix, I have sought to use aspects of critical discourse analysis and functional linguistics.

2.16 Conclusion

This chapter has given an overview of literacy scholarship and introduced major movements around how literacy is conceptualised. The inclusion of geosemiotics, artefacts, mediation and sponsorship broadened the notion of identifying literacy practices in a context. Freebody and Freiberg's (1999) comment on literacy still holds true in the context of this discussion. "History taught us that literacy refers to a malleable set of cultural practices shaped and re-shaped by different – often competing and contending – social institutions, social classes, and cultural interests" (para: Drawing on History). How this literacy is conceptualised in the health context will be explored next.

Chapter Three: Literacy and Health

The discussion of literacy in the previous chapter is important groundwork before reviewing literacy as it has evolved in the health care context. The review in this chapter reveals not unfamiliar tensions. Research in health literacy has mirrored somewhat the social practice/ autonomous split in literacy as well as the patient education/patient empowerment discourse contrasts referred to in the previous chapter. Literacy in health has been measured primarily by reading comprehension tests. An examination of this scholarship along is covered in this chapter because it has made an important contribution to the field.

The journey to defining health literacy has been iterative and has taken different turns. Papen's (2008) review of literature found that there are four major fields of research examining health literacy: medical research and health education, literacy studies, linguistics and discourse analysis, and medical anthropology and sociology, with each making a unique contribution. Other health researchers and policy makers have grappled with the meaning and measurement of health literacy as well as how to begin to conceptualise health literacy (see Adkins & Corus 2009; Friedman, Corwin, Dominick, & Rose 2009; Jordan, Buchbinder, & Osborne 2010; Osborne, Batterham Elsworth, Hawkins & Buchbinder, 2013; Nutbeam 2008 & 2009b; Paasche-Orlow & Wolf 2007a; Parker 2009; Rootman & Ronson 2005; Sørensen 2010; von Wagner, Steptoe, Wolf, & Wardle 2008; Zarcadoolas, Pleasant, & Greer 2005 & 2006; and Rudd, McCray, & Nutbeam 2012). An overview of these approaches is also covered in this chapter.

The definitions of health literacy are examined in this chapter which leads to investigating ways that health literacy is measured. Ultimately this chapter seeks to position health literacy from a social practices approach, much like my presentation of literacy in the previous chapter.

Street's (2010) observation concerning the defining of literacy has relevance to these different orientations to health literacy, not just because of its implications for policy, but also because of how the notion of literacy is represented in light of the discussions in the previous chapter:

The power to define and name what counts as literacy and illiteracy also leads to the power to determine policy, to fund and develop literacy programmes in international contexts, to prescribe ways of teaching, development of educational materials, text books, assessment . . . So, from this perspective what counts as ‘literacy’ depends crucially on who has the power to define ‘it’ (p. 206).

3.1 Defining health literacy

As Nutbeam, a leading voice in health promotion and an early commentator on health literacy, pointed out in 2008, there is room to incorporate voices from many fields into the health literacy literature. Despite this viewpoint, research has continued to progress the notion of the measurement of a patient’s literacy in order to identify statistically significant associations between the literacy measures and patient outcomes. The literacy field however has advanced the notion of a social practices approach to health literacy (see Papen, 2005; Street 2009a). Some convergence between these approaches has emerged in strategic documents positioning health literacy as a whole-of-health-system issue rather than an individual deficit issue (Rudd, McCray, & Nutbeam 2012; Brach, 2013; Rudd, 2015). However there has not yet been inclusion of leading literacy researchers’ work in discussions of definitions of health literacy in the public arena.

Two views of health literacy, with one approach labelling health literacy as a risk factor and another labelling health literacy as an asset, are reminiscent of the autonomous/social practices tension seen in literacy studies. Nutbeam (2008) attributed the asset approach to being more grounded, in “educational research into literacy and concepts of adult learning and health promotion” (p. 2074) by being more focussed on factors that give people more control over their own health, with the clinical risk factor approach as justifying screening of patients for their individual literacy skills. Nutbeam’s premise is that both approaches are important.

However, empowerment needs to be incorporated into the definition of health literacy and this has not been easy to achieve. In trying to incorporate

empowerment, Nutbeam (2008) categorized health literacy in levels which “progressively reflect greater autonomy and personal empowerment in decision-making” (p.2075). In coming to this *levels* approach, Nutbeam categorized health literacy into three layers using the notions of:

1. functional health literacy – literacy skills that allow the user to “function effectively in everyday situations” (p. 2075);
2. interactive health literacy – advanced cognitive and literacy skills that allow the user to engage and participant in everyday health activities and to “apply new information to changing circumstances” (p. 2075);
3. critical health literacy – advanced cognitive skills that can critically assess information and “use information to exert greater control over life events and situations” (p. 2075).

Nutbeam drew from Freebody and Luke’s (1990) four resources model of reading which posits that the following four roles are necessary for a reader “in a postmodern, text-based culture” (para, 2): code-breakers (coding competence), text-participants (semantic competence), text-users (pragmatic competence) and text-critic (critical competence) hierarchy. Freebody and Freiberg (1999) responded to Nutbeam’s analysis and adaptation of their model with a call to further emphasize the social practice, stating that it was social practice, which needed to be the unit of analysis (p. 63). Furthermore, any further analysis of the local and global context should be explored through the lens of the participants in the social events or practices. Freebody and Freiberg were calling for an event centred approach to health literacy research where the event is the key driver. They consider that whether or not it is a *literacy event* is dependent on whether or not the *literate* aspect of the context is valued by the participants. Their point is that the best that research defining health literacy as encoding and decoding skills can offer is insight into making written materials easier to understand and more accessible or looking at other modes of information dissemination not involving written text. Such an encoding/decoding approach to health literacy therefore avoids the social context that these literacy levels operate in, which precludes the examination of literacy practices.

Nutbeam (2008) did not engage directly with Freebody and Freiberg's response, but did acknowledge that the asset approach is a concept that requires more systematic research:

The concept is less well tested through systematic research. In the absence of better-developed measures and quality research and evaluation, the 'asset' model remains a powerful idea, but not one that is yet established as practical for widespread implementation. Systematic research is needed to develop the empirical basis for the concept, lest the advocacy for this model exceeds the evidence for its adoption (p. 2077).

The work done by Street (2001, 2009b, 2010), Street and Lefstein (2007) and Rodgers and Street (2012) provides support for such a concept in that they have documented literacy practices in contexts and communities outside of the health domain. There is therefore scope to pursue research of the social practices existing in the health context from a patient perspective.

3.1.1 Further definitions

Sørensen et al. (2012), who are members of the European Health Literacy Consortium, define health literacy as applied to the three health domains of healthcare, disease prevention, and health promotion:

Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply, health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (p. 3).

In coming to this definition, Sørensen's European research team reviewed publications dealing with health literacy definitions and conceptual frameworks of health literacy. Their goal was to capture all aspects of the concept to serve as a robust basis for developing measurement tools. A review of the journals cited and keywords used by Sørensen et al. centres them within medical literature, leaving

out the distinct fields of linguistics and literacy. Their work may have been in response to earlier calls, aside from Nutbeam, for refinement of the health literacy definition and conceptual models. This type of work occurred at the 2009 36th Annual Meeting of the North American Primary Care Research Group (Protheroe et al., 2009). Attendees at this conference considered that current definitions were “limited in both scope and complexity” (Refining Health, para. 3). They also called to “further refine health literacy assessment tools for use in diverse populations” (para. 6) citing the REALM as one such tool, indicating a more cognitive and clinical risk approach to health literacy.

This approach is a confirmation of Fleischman’s (2001) analysis of the medical/linguistics methodological and theoretical research divide. Fleischman (2001, p. 472) summarised biomedical research into doctor-patient communication for example, as having quantification or taxonomy production as the goal. This was in contrast to the discourse analytical literature which tended to be more interpretive of the data. Another salient point Fleischman found in the medical literature was that “this literature (discourse) is rarely cited by medical researchers, from which one might infer that they do not read it” (p. 472).

Nutbeam’s earlier overview of health literacy (1999) would dispute Fleischman’s generalisations, but conversely Fleischman’s generalisations are given salience by the conceptual framework development of Sørensen et al. (2012) mentioned previously and the data they used to come to their conclusions. Also in 2012, Nutbeam and others acknowledged the importance of context in a health literacy definition and the need to consider agency and the participation of the patient (Rudd, McCray, & Nutbeam 2012).

In order to develop effective responses to the concept of health literacy and what it means at the bedside or consulting room, it needs to continue to be further refined and conceptualised. Sykes, Willis, Rowlands and Popple’s (2013) work is helpful in this regard. They took Nutbeam’s concept of critical health literacy and undertook a concept analysis to identify the key components and characteristics of the term. Using the search term *critical health literacy*, they targeted both theoretical and colloquial uses in both text and through interviews in the UK. They found that the concept is in fact a distinct, unique concept with attributes,

antecedents and consequences, but there are “distinct differences in the way that academics and professionals interpret the term” (Discussion, para 2). The key features of critical health literacy that Sykes et al. found are “advanced personal skills, health knowledge, information skills, effective interaction between service providers and users, informed decision making and empowerment including political action” (Abstract, para. 4). The authors warn that with research in health literacy dominated by functional approaches, “this dominant discourse assuming critical health literacy to simply be a set of higher order cognitive skills may be a natural progression” (Discussion, para. 4). Placing critical theory more centrally within critical health literacy is important in order to avoid the negation of the political and social action which is part of critical literacy. Sykes et al.’s warning with regard to this aspect of critical theory could be lost unless there is more research which positions political and social action at the fore of critical health literacy, or health literacy generally. Examining patient agency is one way that can be explored to conceptualise action associated with health literacy. This notion will be revisited in Chapter Eight.

A recent review by Rudd (2015) of the health literacy definition journey confirms the need for a new definition of health literacy, one which includes the “interactions among individuals, materials and messages designed and delivered by health professionals, and the norms, policies, and practices within institutions” (p. 8). As we are about to see, the definition of health literacy is important because it shapes the resulting research.

3.2 Measurements of health literacy

The measurement of health literacy has predominantly been individual and grounded in normative, cognitive tests and would fit in Nutbeam’s clinical risk mitigation category. Allen (2009, p. 93), who, speaking at a 2009 Institute of Medicine workshop on measures of health literacy, encapsulated the intended direction of the measurement movement: “If there are no data, there is no problem. If there is no problem, there is no action.” There has, however, also been a move to understand how a person becomes health literate in an attempt to develop more sensitive measurement instruments which take into account other

established factors like the patient-provider relationship or self-care. This will be discussed further after an overview of tests currently available.

3.2.1 Measurement tools

By 2013 there were over 50 tools available to measure an individual's health literacy (Haun, Valerio, McCormack, Sorensen, Paasche-Orlow 2014). Currently, the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA), and the Newest Vital Sign (NVS) test (Weiss et al., 2005) are the predominant tests used when assessing aspects of functional health literacy - reading comprehension and numeracy abilities. The REALM (longer) and REALM-7 (shorter version) are word recognition tests where the patient reads a list of words and their understanding of the words is assessed on their correct pronunciation of them (Ryan et al., 2008). The TOFHLA tests a patient's ability to read health-related material and perform numeracy tasks. It has a longer version (over 20 minutes to administer) and shorter version (about 8 minutes) (Parker, Baker, Williams, & Nurss, 1995). The NVS is a screening tool, able to be administered in about three minutes and tests a patient's reading (document literacy) and numeracy abilities. Patients are asked six questions about a nutrition label they are given. Weiss is reported as saying that the tool, when used by health practitioners can motivate clinicians to "clean up their act" and learn to communicate in more effective ways, more of the time (Osborne, 2010). This may well be the case, but as we have canvassed in the previous chapter, literacy is not just about the ability to interact with text; it encompasses understanding and critiquing as well as an awareness of the social practices surrounding the literacy events.

The Adult Literacy and Life Skills (ALL) survey undertaken in twelve OECD countries in 2006 and the USA 2003 National Assessment of Adult Literacy (NAAL) (Kutner, Greenberg, Jin, & Paulsen, 2006) both included health literacy measurement components. The NAAL included health content in the prose, document and quantitative literacy domains. The ALL measured across prose and document literacy, numeracy, and problem solving domains (Satherley, Lawes, & Sok, 2008) and used health content from health promotion, health protection, disease prevention, health care maintenance and systems navigation knowledge

areas (Ministry of Health, 2010; Barber et al., 2009), in recognition of the health knowledge domain. Outcomes from this measure are on a scale from level 1 to 5 with the highest level being the most proficient. A more recent survey sponsored by the OECD is the Programme for the International Assessment of Adult Competencies (PIAAC) survey which is currently taking place in New Zealand under the name of International Survey of Adult Skills (ISAS). Results for New Zealand are expected sometime in 2016.

Those that have used these different tools to measure literacy have had to contend with the variability in what they test and what the results actually mean. What does a score actually mean for an individual's literacy status, apart from showing a deficit? Results from studies into the use of the tools suggest that the tools are “moderately correlated, appear to measure different but related constructs and use different cut off points to indicate poor health literacy” (Barber et al., 2009, p. 252). This is a finding confirmed by Griffin, Partin, Noorbaloochi, Grill, Saha, Snyder, ... van Ryan (2010) who looked at the variation in performance of the TOFHLA and the REALM and found that the measurement of literacy varied according to the tool used.

3.2.2 Health literacy management scale

Jordan, Buchbinder, and Osborne (2010) and Jordan, Osborne and Buchbinder (2011) endeavoured to develop a tool to capture other aspects such as the access and use of health care services, the patient-provider relationship and self-care – all variables that Paasche-Orlow and Wolf (2007a) had also identified. Their tool development grew from their review findings that “health literacy is not consistently measured, making it difficult to interpret and compare health literacy at individual and population levels” (p. 366) (see also Griffin et al., 2010). Jordan et al.'s (2010) research and conceptualization of health literacy as individual (patient health literacy abilities) and external (patient–health professional interaction, and broader factors) led to the development of the Health Literacy Management Scale (HeLMS) survey. To develop the psychometric HeLMS survey, Jordan et al. (2010) explored the journey of a patient through the health system. There were 48 individuals interviewed, and using a grounded theory approach along with thematic analysis, Jordan et al. (2010) identified the eight

constructs below. They also identified factors critical in an individual's ability to retain, process and apply the knowledge and skills: how health professionals delivered the information—too much information and use of technical vocabulary were a hindrance; whereas the use of pictures was a help. They considered that verbal communication, literacy skills, and knowing where to access health information partially map onto Nutbeam's model and that those and other individual capabilities are situated in a broader social context.

This survey tool was used in my research in interviews with patients because of its coverage of major components in health literacy. However, the survey captures neither the ways patients use different strategies as part of their health journey nor the literacy practices and events operating in their local health context: something that ethnographic-styled field work can capture. The HeLMS survey frames eight distinct constructs as abilities, which suggests an autonomous approach to literacy measurement—does the patient have x or y ability? The survey, however, does incorporate the individual's local and global contexts albeit from a limited skills and knowledge perspective. These eight abilities are

Individual abilities:

1. understanding health information;
2. accessing general practitioner (GP) (doctor) healthcare services;
3. communicating with health professionals;
4. being proactive;
5. using health information;

Broader factors:

6. patient attitudes towards health;
7. social support;
8. socioeconomic considerations.

The survey tool does not assess an individual's micro-literacy skills—the decoding and encoding of language, but acknowledges it as one of the variables, by using the term *literacy* and acknowledging broader factors that affect abilities.

Research using this HeLMS survey tool was undertaken by Edwards, Wood, Davies and Edwards (2012) who helpfully, rather than trying to measure a patient's health literacy, explored how a patient became health literate through a longitudinal study of 18 individuals using serial interviews. They used Jordan's work as a basis for the framework they developed to analyse their data. From this they were able to map the stages of their participants into a health literacy pathway (p. 11) (with the help of Nutbeam's (1999) model of health literacy). Edwards et al.'s pathway model has five stages of health literacy processes which they maintain contribute to health literacy outcomes. These five stages are

1. building health knowledge;
2. developing health literacy skills and practices;
3. displaying health literacy actions;
4. producing potential informed treatment options; and
5. making informed decisions with outcomes of an increased knowledge and understanding how to manage and cope with condition, and active involvement in consultations (p. 12).

Their five stages begin to expand Nutbeam's earlier call for a categorization of health literacy into different levels that "progressively reflect greater autonomy and personal empowerment in decision-making" (p.2075) and is part of a move away from just measuring word recognition or reading comprehension ability. Edwards et al.'s stages, along with Nutbeam's levels approaches, position health literacy as occurring as a process and an outcome, where one skill builds on another. It is a question whether health literacy is that systematic and whether patients display health literacy actions without the expected knowledge or understanding, and whether positioning these literacy events in a context will reveal broader processes at play in health literacy.

Building on the HeLMS survey tool, Osbourne, Batterham, Elsworth, Hawkins & Buchbinder (2013) continued on to develop the Health Literacy Questionnaire (HLQ) which was validated in 2013 with further validation in 2014 in New Zealand, Australia, Hong Kong and the United Kingdom among university students. It is currently being translated into 14 languages (University of Auckland, 2015).

Whether it is necessary to measure a patient's reading or numeracy comprehension and map their progress on a health literacy scale is questionable. The movement to define in order to measure health literacy approaches literacy from an individual, functional, skills-based perspective and is of limited benefit. A notion Paasche-Orlow and Wolf (2007b) have advocated is that they believe it is unmerited to measure patients' literacy: "Until research has shown a literacy screening program that can benefit patients without evidence of harm, physicians and other health professionals should pursue responses to the problem of limited health literacy that do not depend on screening" (p. 102). They go on to suggest a *universal precautions approach* to patient care "to confirm all patients' understanding of critical self-care activities and to support problem solving" (p. 102).

In a further study using Nutbeam's model of health literacy layers, Friedman, Corwin, Dominick and Rose (2009) investigated African American men's understandings and perceptions of prostate cancer and advocated the future use of the model as a way to assess the health literacy (functional, interactive, and critical) of any target group after finding how limited the normative tests were for measuring all of these aspects of health literacy. They also acknowledged the differences in what is valued as literacy across cultural groups, especially where an oral culture is strong. Their recommendation for the use of qualitative research to investigate the interactive and critical aspects of health literacy is also noteworthy, but the pursuit of measurement of patient's health literacy continues to reflect a clinical risk approach rather than pursuing a universal precautions approach. Measuring a patient's reading comprehension also contributes little to the added complication of the nature of knowledge, its coded or un-coded status, its dissemination, and the hegemonies of the contexts involved.

My research transects Edwards et al.'s five stages of health literacy development, as the approach taken in my research is context and event driven with a literacy event/literacy practices perspective rather than a patient skills hierarchy that Edwards et al.'s stages would suggest. The presence of the written patient information text is the centrepiece to a literacy event which is used with the patient in a dynamic social context. As Freebody and Freiberg (1999) consider,

the meaning of the event is constructed in large part by the social practices associated with the context it occurs in. Using social practices also allows a broader examination of the hegemonic dimensions of critical health literacy which Sykes et al. (2013) advocate.

Currently, there is little in the field looking at the social practices surrounding patient text use in healthcare, as well as linguistic and discourse analysis of the text itself. Dray and Papen (2004) and Papen and Walters (2008) investigated which written texts were used in a health care context, and how patients interacted with them. This research was discussed in the previous chapter. Rogers and Street (2012) ask a pertinent question, “How can we decide which literacies to teach and how to teach them unless we have descriptions of such practices?” (p. 66). The reason for reviewing conceptualisations of health literacy is to position the approach taken in this research in a historical context. I anticipate that my research will help to build a body of knowledge surrounding textual ethnographies in a healthcare setting thereby developing a more sophisticated understanding of literacy in the healthcare context.

3.2.3 Health literacy and outcomes

The research findings that follow highlight some of the research outcomes which show relationships between health outcomes and different reading or spoken language measurements. The evidence confirms a relationship between the different reading measures and poorer health outcomes (albeit using a range of literacy measures), adding weight to the various calls for an agreed approach to health literacy and more consistent measures if a clinical risk approach is to be pursued in health literacy research.

- A study of 217 patients with type 2 diabetes found patients with a low score on the Spoken Knowledge in Low Literacy patients with Diabetes (SKILLD) test had higher glycated haemoglobin (An indicator of the average plasma (blood) glucose concentration) (Rotham et al., 2005).
- A study of 408 over 30 year-old, type 2 diabetic patients found patients with inadequate reading ability had worse glycaemic control (Schillinger et al., 2002).

- Sudore et al. (2006) found an association between limited health literacy (using the REALM), low socioeconomic status, co-morbidities and poor access to health care (median age 75.6).
- Baker, Wolf, Feinglass, Thompson, Gazmararian and Huang (2007) found that “inadequate health literacy, as measured by reading fluency, independently predicted all-cause mortality and cardiovascular death among community-dwelling elderly persons” (p. 1503).
- Martin et al. (2010) looked at the four literacy skills, reading, numeracy, oral and aural language, and their relationship to the calculated 10-year risk of coronary heart disease (CHD). They found that on their own, stronger literacy skills of reading, numeracy and aural literacy each were associated with a lower risk of CHD in women.
- Howard, Gazmararian and Parker’s (2005) research into the relationship between health literacy and emergency department costs found that of the 3260 elderly subjects tested using the Short Test of Functional Health Literacy in Adults, those with inadequate levels of health literacy had significantly higher emergency room costs compared to those with sufficient health literacy.

Additional identified outcomes of low health literacy are also

- increased hospitalizations (Sobel, Paasche-Orlow, Waite, Rittner, & Wolf, 2009; VanGeest, Welch, & Weiner, 2010; Berkman, Sheridan, Donahue, Halpern, and Crotty 2011);
- inefficient utilization of medical resources (Howard et al., 2005).
- underuse of preventative services, e.g., immunizations (Nielsen-Bohlman, Panzer, & Kindig, 2004; Berkman et al., 2011);
- limited patient involvement in medical decision-making (Nielsen-Bohlman et al., 2004);
- inadequate self-management (especially with chronic diseases) resulting in higher risk of poor adherence (Nielsen-Bohlman et al., 2004);
- late presentation and diagnosis (Nielsen-Bohlman et al., 2004)
- less ability to properly manage and understand their medications (Berkman, et al., 2011).

Berkman et al. (2011) consider that there is a greater need to understand the relationship between low numeracy and health outcomes as well as more evidence to understand the “relative importance of the print literacy and numeracy aspects of health literacy” (p. 103). Understanding the importance of print literacy is woven into my research, but from a literacy practices perspective. I expect that there will be evidence gained from the data to comment on the importance, or not, of print literacy.

These studies suggest there are ripple effects across the health system from lower level patient reading and numeracy abilities. Aside from poorer outcomes for patients, the economic costs for the health system are also thought to be significant. Eicher, Wieser, and Brügger (2009), in a systematic review of the costs of limited health literacy on the health care system, concluded that the costs may be substantial. However, “results of cost studies are heterogeneous, relate to selected groups and studies show methodological shortcomings” (p. 322). An interesting feature of these studies is the reflection of the power of context, or the situated nature of literacy. The different illnesses, for example diabetes, have quite distinct literacy demands for a patient.

3.3 The New Zealand context

The 2006 Adult Literacy and Life Skills Survey (ALL) judged that 43 percent of the New Zealand adult population aged between 16 and 65 do not have the literacy and numeracy skills needed to participate fully in a modern, high-skilled economy. They are classified as Levels 1 and 2 of the ALL taxonomy. The ALL divides literacy into five categories with individuals scoring at levels 1 and 2 deemed to have insufficient skills to cope with the health literacy demands they may face. Within the general New Zealand population, Pasifika and Māori adults have lower literacy and numeracy skills than the general population for all reported age groups with over half of the Māori adults in 2006 having skills at Levels 1 or 2. Around 318,000 New Zealanders in 2006 were measured as having Level 1 skills in both literacy and numeracy. Thirty eight percent of these 318,000 people are migrants (Tertiary Education Commission, 2010).

Health literacy research in New Zealand is in its infancy. The New Zealand Ministry of Health in 2010 published its first report on the subject entitled *Kōrero marama health literacy and Māori* (Ministry of Health, 2010) defining health literacy using Kickbusch, Walt and Maag's (2005) definition as "a person's ability to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions" (Ministry of Health, 2010, p. 1). This report used data extrapolated from the 2006 Adult Literacy and Life Skills Survey (ALL). Further research has been funded by the New Zealand Health Research Council into health literacy and communication of immunisation information to decision makers (Murray, Watson, Tilley, Sligo, & Handley, 2010). There have also been other separate projects examining Māori health literacy and palliative care and a review of the health education resources available for gout medication with a focus on Māori patient users of written gout information. This review found that the written information on gout was seldom read because of patient beliefs about the nature of gout—that it is self-inflicted, and that the resources are too long, too dense, and are hard to navigate (Ministry of Health, 2012b, p. vi).

The New Zealand Health Quality & Safety Commission has commissioned work in health literacy and medication safety and has a host of resources on their website for practitioners. This may have been in response to earlier findings by the Pharmacy Guild of New Zealand (Knight, 2006) which provided examples where literacy was seen to directly affect health outcomes by:

- incorrect use of medicines;
- failure to comply with medical directions;
- errors in administration of infant formula;
- unhealthy lifestyles invalidating drug therapy;
- misunderstanding of the goals and expectations of therapy;
- safety risks in the workplace, the community and at home, e.g., in the handling of chemicals and machinery.

The Ministry of Health Statement of Intent 2013 to 2016 (Ministry of Health, 2013b, p. 21) states an intention to build health literacy by publishing and updating guidelines to support healthy lifestyles. The report acknowledges that

health literacy is more than just health messages, “it is also about ensuring that they [the patient] can interact with the health system, and supporting people to make good decisions about their health and lifestyle behaviours” (p. 21). In May 2015, the Ministry of Health launched a series of documents to enable New Zealand health organisations to review their own health literacy practices and develop a health literacy action plan. The Ministry also provided a framework to outline the multi-layered, multi-system approach needed to build health literacy in New Zealand .

3.4 Social practices and Health Literacy

Taking a social practices approach to analysing literacy in the clinical context is to build on the response that Freebody and Freiberg (1999) gave earlier to Nutbeam’s first model of health literacy, where they declared that it allowed literacy to be reconfigured, to include “programs of individual and communal efficacy organised around change” (p. 59). This, according to them, relates literacy to know-how, “whereby individuals and communities can ‘read’, ‘reread’, ‘write’, and ‘rewrite’ the parameters of individual and social action aimed at the enhancement of their health and circumstances” (p. 59). In other words, the presence of empowerment and political action in individuals and society comes as a consequence of critical health literacy, Nutbeam’s third layer.

Examining the approach Nutbeam and others have taken to modelling and conceptualising health literacy, especially critical health literacy, and aligning it with a social practices approach to literacy, outlined in the previous chapter, has merit, especially in light of Sykes et al.’s (2013) call for more engagement with those in the community development field to examine critical health literacy more closely. Street, a leading proponent of New Literacy Studies, grounded much of his approach to literacy from work in community development (Rodgers & Street, 2012). It makes sense then to examine how these two approaches might speak to each other in light of health and literacy.

Rather than looking at encoding and decoding as a technical skill, which Nutbeam’s model does, a social practices approach would view the uses and meanings of literacy in the health context—the literacy events and literacy

practices. It would look at the broader literacy environment. This is the approach that was taken in the 2006 Global Monitoring Report which Rogers and Street (2012) report as having an emphasis mobilising the “environment to increase the effectiveness of literacy learning programmes at both school and adult levels” (p. 145). Street interprets this move as a move away from the individualistic approach to student learning and a recognition that “it is this social context that largely affects the success and retention of literacy learning” (p. 146). However, this social approach does not preclude encoding and decoding skills: rather it is re-focussing on such teaching being driven by context.

Rodgers and Street (2012) maintain a literacy environment should be viewed through the following lenses:

1. What written texts exist and how are they used dynamically?
2. What are the practices which underlie and give meaning to such usages?
3. What are the as-yet-unfulfilled activities and aspirations for literacy in the community? (p. 158)

Analysis by Rodgers and Street, both of whom are grounded in a second and third world community development background, cuts across some of the discourse coming from the first world, especially in the health context. Specifically, they cite research to support the misconception that texts need to be *easy reading*; they hold that research and experience “shows that adults can and do learn very quickly to read and write words which they use every day and which make sense to them, irrespective of their apparent complexity” (p. 161). They maintain that a learner’s experience of what is being taught will dictate how quickly or not a learner will learn. This proposition relates to adult learning theory or andragogy (see Knowles, 1980) where adults know why they are learning and learning is related to real problems or concerns in their lives (Tusting & Barton, 2006). Rogers and Street outline misconceptions related to adults learning literacy - that literacy is an individual activity and, that the act of provision of literature will lead to demand (p. 160). Rogers and Street consider that there is in fact no evidence for this belief that “supply will lead to the increase of demand, although it appears that demand will die without the provision of material to fuel it (p. 160). Their conclusion is directly applicable to the health context and worth considering. They warn

against assumptions being made about literacy: “Many of the approaches of such agencies focus on people’s capacity to cope with the *literacy environment*, as though the readers and writers are not themselves part of the environment or making it what it is” (p. 162). They point out that each environment is a new literacy environment, whether work or home or community. Their conclusions will be considered again in light of data collected in this study.

3.5 Written patient texts

As Freebody and Freiberg (1999) commented, research on written materials for patients should take a literacy event-centred approach to avoid defining health literacy as encoding and decoding. The best that research defining it as such can offer is insight into making written materials easier to understand and more accessible. However, given the amount of health literacy research already using reading tests—as outlined in the previous section, it is not surprising that there has also been a significant amount of work done on readability, text accessibility and other aspects of written patient text. It is to this we now turn to gauge how features of patient information texts are considered, a journey that has been dominated by events in the USA.

In the USA, Doak, Doak and Root (1996) published the first edition of their book *Teaching patients with low literacy skills* in 1985. The book became instrumental in pushing forward a plain language agenda for patients. Koh et al. (2012) summarise the health literacy journey in the USA where research has already informed policy, which in turn has informed much of the debate and action in other parts of the world. The key policy publications addressing health literacy are

- The 2010 public health plan, Healthy People 2020 (Department of Health and Human Services, 2000);
- The 2010 publication National Action Plan to Improve Health Literacy released by the Office of Disease Prevention and Health Promotion (U.S. Department of Health and Human Services, 2010). There are two principles underlying the Plan: “all people have the right to health information that helps them make informed decisions; and that health services should be

delivered in ways that are understandable” (Koh et al., 2012, p. 436). There are explicit goals to improve health literacy in the USA, and the Plan calls for an increase in research into health literacy.

- The Affordable Care Act 2010 aligns with the National Action Plan and integrates health literacy into professional training, and simplifies health insurance procedures (Koh et al., p. 436).
- The Plain Writing Act 2010 which requires the federal government to write clearly so that the general public can understand and use the documents (Koh et al., p. 437).

Koh et al. (2012) consider that the final three initiatives completed in 2010 became the critical mass to move health literacy “from the margins to the mainstream of health care practice” (p. 434). The Joint Commission (2010), an agency that accredits health care organizations in the USA and across the world, also in that year included the following requirement in its guidelines:

Use discharge instructions that meet health literacy needs. Materials should be written at a 5th grade or lower reading level. Consider revising written materials to address the health literacy needs of all patients. Use readability tests, divide complex information into bullet points, and modify document font, layout, and design to revise written materials to improve readability (p. 30).

Garner, Ning, and Francis’s (2011) review of the evaluation of patient information leaflet literature (166 published pieces of research) up until the end of 2009 found that there were a variety of ways existing to determine leaflet usefulness and quality. Readability scores were the widespread way that leaflet reading ease was gauged. Garner et al. found other examples of leaflet evaluation (See also Apfel et al., 2010), but found no comprehensive model for evaluation and improvement of patient leaflets. They then set about developing a basic model based on a constructivist approach to communication, which is situated and co-constructed, with a view to having other researchers develop it much further. Their comments again confirm the split between autonomous approaches to literacy and social practice notions of literacy in terms of ease of measure:

The evaluation of PILs (patient information leaflets), for example, is incomparably more difficult when it is accepted that communication is a dynamic process. The one certainty is that the meaning constructed by a reader can never be precisely the same as that intended by the writer. There can be no failsafe linguistic template for writing PILs, or a neat formula for evaluating their effectiveness with patients: investigators have to be content with probabilities and approximations (Garner et al. 2011, p. 286).

Garner et al. adopt a framework based on readability, comprehensibility and communicative effectiveness to evaluate patient texts. An adaptation of this framework, along with the work of Clerehan et al., (2009) and Franken and Hunter (2011), for use in the current study is in Appendix 2. The implication of Garner et al.'s observation is that mediation of patient texts becomes more critical, and it also raises questions about the readability. Rodgers and Street's (2012, p. 161) position suggests that not avoiding technical terms in text may be more acceptable and useful than currently believed, especially if text is mediated by a more knowing other. We now turn to the communication between the health professional, the patient and the text.

3.6 Communication and health professionals

One aspect of the social practice in a health care context is the communication between the patient and health professionals. Exploring this from a healthcare professional's perspective is not the focus of this review. Rather, it is to explore that communication from a patient's perspective and understand something of the relationship between health literacy and communication. Early work on patient-physician communication published by Stewart and Roter in 1989 arguably began the health literacy conversation in the USA. Stewart and Roter's (1989) work called for a patient-centred clinical method which aimed to not only "diagnose the patient's disease but also to understand the meaning of the illness for the patient" (p. 18). They considered it would require "radical change in the very person of the physician" (p.18) as well as radical change in the way physicians were educated. They called for communication to be patient-centred, for patients to be involved in their own care, and for patients to have "a sense of control over their

own treatment” (p. 19). Cordella’s (2004) research using outpatient consultation data from a hospital in Santiago, Chile, also contributed to identifying forms of patient-doctor communication. Cordella’s central finding that the medical consultation is “intrinsically asymmetrical” (p. 3) was a further confirmation of the need for a patient-centred approach. The asymmetry was attributed to the knowledge imbalance between the health professional and the patient with their respective roles being clearly defined (having evolved in the practice of medicine over time). Maynard (1991) considered that medical discourse is asymmetrical in specific and particular ways, like the number of questions asked or interruptions made (p. 456), and that any challenge to this asymmetry results in those with the most power or knowledge winning. This asymmetrical analysis however, makes assumptions about the nature of power which will be discussed in the following chapter.

By 2006, Roter and Hall had described a patient-centred approach that had become embedded across the health system. Health communication goals for the USA were included in the surgeon general’s Health People 2010 objectives (Roter & Hall, 2006). Reforms to clinical education programmes were also embedded and research into health communication flourished. A full review of this area of enquiry is beyond the scope of this thesis, suffice to say that a lot has become known about the characteristics and significance of patient-doctor communication. For example, research exploring the communication skills needed by patients carried out by Frosch, May, Rendle, Tietbohl, and Elwyn (2012) maintains that “the reasons . . . patients may defer decisions to physicians have not been explored in any depth; the focus has largely been on demographic factors” (p. 1030). They explored this through focus group sessions and settled upon four themes in their data analysis. “These are that patients feel compelled to conform to socially sanctioned roles in the clinical consultation; that physicians can be authoritarian; that patients work to fill information gaps; and that patients feel the need to bring social support to the consultation” (p. 1032). They found participants frequently adopted obsequious attitudes to avoid disappointing their doctor by posing too many questions or by disagreeing with them. A quote from one of their forty-five year old participants illustrates this: “You’re worried . . .

you're going to piss the doctor off, . . . [that] it is going to change the relationship. . . . I don't want to rock the boat" (p. 1032).

Papen (2010) concluded that her research supported the proposition that "healthcare contexts are highly textually mediated environments" (p. 162), concluding with "despite a rhetoric that professes the opposite, the literacy practices of information provision and healthcare more generally continue to be grounded in a transmission model that privileges the institution's point of view" (p. 163). My research will evaluate her findings in light of my own.

In response to findings from fieldwork and to the call for a universal precautions approach to health literacy, health literacy education has begun to look at what can change from a systems perspective. For example, Hunter and Franken's (2012) "Health Literacy Education and Resource Framework" which identifies the core aspects of health literacy patients and practitioners need to know in a New Zealand context, such as the relationship between patients and health care providers and the kind of knowledge a patient needs about their care and condition. The Framework identifies challenges to health literacy and strategies for both patient and practitioner to overcome those challenges including guidelines for written patient information leaflets.

Koh et al. (2012) advocate a cycle of care model where the sick patient seeks medical help, and such actions as the health administrator reminds the patient about what to bring to the office visit, the staff at the doctor's office give patients simple forms and offer help with filling them out, the doctor listens to the patient describe symptoms in the assessment, the doctor describes the patient's condition using easy to understand terms, the doctor discusses treatment options with patient and solicits questions, for example (p. 439). This cycle of care depends heavily on the role of a more knowing other mediating and assisting.

3.7 Positioning the patient

Another aspect of literacy practice is the negotiation of positions by those involved in interaction (interlocutors) and how they do this through discourse. The "negotiation of identities . . . takes place every day in multilingual contexts, where different ideologies of language and identity come into conflict with each

other with regard to what languages or varieties of languages should be spoken by particular kinds of people and in what context” (Pavlenko & Blackledge, 2003, p. 1). Identity then, is dynamic, multifaceted and constantly being constructed and/or co-constructed.

Pavlenko and Blackledge make the point that “language choice and attitudes are inseparable from political arrangements, relations of power, language ideologies, and interlocutors’ views of their own and others’ identities” (p. 1). They position this observation in a multilingual context, but it also exists in a monolingual context where language presents the barrier between those in one discourse community, in this case the medical community, and those who are not, the layperson or patient. Pavlenko and Blackledge’s use of Davies and Harré’s (1990) *positioning theory* is helpful where positioning is the way participants are situated in conversation as ones jointly producing “story lines, informed by particular discourses” (p. 20). They outline two types of positioning—interactive positioning where one person positions another and reflective positioning where a person positions him or herself. Pavlenko and Blackledge (2003) apply this theory to all discursive practices where positioning occurs. The identities they propose in their identity framework are 1) imposed identities—those that are not negotiable in the time and place, 2) assumed identities—those that are accepted and not negotiated, and 3) negotiable identities—those that are contested by groups or individuals (p. 21). This is one possible frame through which to view the discourse surrounding a patient at the bedside in communication with health professionals and recognise whether positioning theory can speak to a patient’s health literacy, identity and agency.

Pavlenko and Blackledge (2003) also outline Heller’s theoretical framework linking language practices and power in two important ways: a) “language is seen as part of processes of social action and interactions and . . . influence” (p. 12), and b) language is a “symbolic resource which may be tied to the ability to gain access to, and exercise, power” (p. 12). These tensions between language practices, power and identity construct the possibility of complex multiple identity creations or agentive turns. As previously discussed in critical literacy, the

growth of knowledge and language can be a disruptive force in identity construction, as can the social constraints or moral order of the context.

3.8 Health numeracy

Part of accessing, understanding and using health information is being able to manage any numeric information one may encounter in a health context. Numeracy in health can be found in a myriad of different domains (Zikmund-Fisher, Mayman, Fagerlin, 2008) for example, risk assessment, record keeping, and medication management. Osborn, Cavanaugh, Wallston, White, and Rothman (2009), for example, explored the association between poor glycaemic control amongst African Americans and numeracy ability in a cross-sectional study. The REALM, the maths section of the WRAT-3, and a validated diabetes specific numeracy test, Diabetes Numeracy Test (DNT) were all used to assess the African American and white English-speaking participants. Osborn et al. (2009) concluded that “African American race predicted poor glycaemic control, (but) diabetes-related numeracy reduced the explanatory power of African American race, such that diabetes-related numeracy, not African American race, significantly predicted glycaemic control” (p. 1617).

As outlined in the previous chapter, to be “numerate means to be competent, confident, and comfortable with one’s judgments on *whether* to use mathematics in a particular situation and if so, *what* mathematics to use, *how* to do it, *what* degree of accuracy is appropriate, and *what* the answer means in relation to the context” (Coben, 2000, p. 35, emphasis in the original).

A definition offered by Golbeck, Ahlers-Schmidt, Paschal, and Dismuke (2005) which has had widespread acknowledgement (Ancker & Kaufman, 2007; Nelson, Reyna, Fagerlin, Lipkus, Peters, 2008; Czaja, Zarcadoolas, Vaughn, Lee, Rockoff, & Levy, 2015) since its publication, further conceptualises the aspects of numeracy in health numeracy as “the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, biostatistical, and probabilistic health information needed to make effective health decisions” (p. 375).

Like literacy events, numeracy in health is highly situated. Quantitative, graphical, biostatistical, and probabilistic numeric knowledge domains may describe the “what” and “how” (Coben, 2000, p. 35) of mathematics in the health context but leave areas unexplored in terms of “whether” to use mathematics and “what” (Coben, 2000, p. 35) the answer means in the context. Contextual factors were found to be important in a review of health numeracy by Anker and Kaufman (2007) who found that the ability to use quantitative information was “strongly influenced by two other factors: design of information artefacts, and providers’ communication skills” (p. 719). Perhaps not surprisingly, they advocated that health numeracy conceptualisation move beyond an individual’s numeric skill set to look at an individual’s use of numeracy. Another study by Wright Nunes, Osborn, Ikizler and Cavanaugh (2015) also amongst African American dialysis patients found that a crucial way to meet patients’ numeracy needs was “appropriately matching communications with an individualised presentation of patient-specific quantitative health information, which may need to include less use of technology rather than more” (p. 293). Wright Nunes et al. did not conceptualise their findings in numeracy as social practice, but findings such as these point to retaining a similar stance on health numeracy as I have in health literacy, ie., viewing it through a social practices lens. Coben’s definition of numeracy allows for the social context to be foregrounded, much as Wright Nunes et al’s., (2015) findings suggest. Golbeck et al’s., (2005) delimitation of numeracy domains allows numeracy events to be identified according to the type of numeric demands. For example, Zarcadoolas and Vaughn (2014) report on research assessing patient-accessible electronic medical records where they identified tables and graphs (graphical) as having the “highest barrier elements” (p. 61) for consumers with low educational levels.

Health numeracy is now a distinct field of research and it is beyond the scope of this thesis to further investigate the development of the field. However, as seen in the previous discussion, there is still movement around the definition and approach to health numeracy. My hope is that the research in this thesis can capture numeracy events: how patients are using numeracy in the cardiovascular context.

3.9 Conclusion

This chapter has found convergence points between approaches to health literacy and to literacy, positioning sociolinguistic research in the health domain in a social practices approach to literacy. The review of the definitions and measurement tools within health literacy has revealed the different research approaches active in the field. The review has positioned the use of an ethnographic perspective to research literacy in health, not just isolating literacy to the complexity or otherwise of patient texts. Spoken and written texts as they appear with a patient in the healthcare setting need to be collected and considered to understand more fully what literacy events and practices are occurring in the patient's space, and specifically in this study, in a cardiovascular setting.

Chapter Four: Conceptual Framework

4.1 Introduction

After the overview of the subject area of the research in the previous two chapters, this chapter will introduce the conceptual framework which underpins the investigation into health literacy in a cardiovascular setting. There are a variety of ways qualitative researchers choose to frame their research. Denzin and Lincoln's (2005, p. 183) use of the concept of a paradigm, "first principles, or ultimates" (p. 183) provides an "interpretive framework" (p. 22) for my research. A paradigm, according to them, includes four domains: axiology (ethics and values), ontology, epistemology, and methodology. I am drawn to this paradigm because of the inclusion of the axiology domain and the distinction drawn between ontology and epistemology. Reflections on these four domains are imperative for a qualitative researcher because in attempting to describe the worlds and experiences of others, which can never be fully described or known, researchers themselves need to present their own account of what guides their interpretation of the world around them: What is reality? What is the nature of the researcher/researched dynamic? And, how do we expand knowledge? It is therefore important to explore this paradigm in more detail so that the researcher's position is clear.

4.2 The Paradigm

4.2.1 *Axiology*

Denzin and Lincoln (2005) define axiology as ethics and values. Axiology provides the answer to their question, "How will I be as a moral person in the world?" (p. 183). Guba and Lincoln (2005) give us insight into the complexity and difficulty of including axiology in their paradigm.

Doing so [including axiology] would, in our opinion, begin to help us see the embeddedness of ethics within, not external to, paradigms and would contribute to the consideration of dialogue about the role of spirituality in human enquiry (p. 200).

Any answer to this question from a research perspective introduces the concept of

other since research is positioned in the world amongst people. Being in the world, with others - patients, health professionals, those known and unknown, necessitates the inclusion of ethics and values in a central paradigm because acknowledging that I am not alone in this world forces me to take account of the other. And, positioning ethics alongside ontology and epistemology places the notion of the other as being as important as the self in the constructing of meaningful reality. It is acknowledging that, as Laible (2000) states:

exposure to the other is the bedrock of our selfhood; it is the condition of subjectivity, not an aspect of it. ... He [sic] is responsible to the other because . . . his very subjectivity, is dependent upon his relation to the other (p. 689).

Placing the other as important as self still gives limited direction on axiology. What is a responsible, moral, epistemological and ontological approach to producing knowledge about other human beings (Laible, 2000, p. 688)? The answer to this question requires a consensus on the meaning of moral or responsible which is complex and a matter of philosophical debate. Such a question reintegrates “human life with the moral order” (Christians, 2005, p. 154). I concur with Lincoln who holds that “social science research is enabling community life to prosper—equipping people to come to mutually held conclusions” (p. 151). Such an approach should serve “the community in which it is carried out, rather than the community of knowledge producers and policy makers” (Lincoln, as cited in Christians, 2005, p. 151). This appreciation of one’s connection to the other and cooperative community approach provides broad principles which can help to answer Guba and Lincoln’s opening question of how one will be a moral person in the world.

Ethics applications, that are part of any research involving human subjects, codify the meaning of being responsible, moral, or ethical to a certain degree. They involve the development of a research protocol, participant information sheets and consent forms drafted in accordance with the requirements of the New Zealand Health and Disabilities Ethics Committee’s guidelines (NZHDEC). As a researcher, I have used these guidelines to define responsible and moral data collection and use. However, there are broader ethical considerations which go

beyond ethics applications. The power differential between an ill patient lying in bed and the approaching charge nurse of the ward cannot be underestimated in considering the ethical issues surrounding the style of research. The charge nurse is charged with canvassing the patient whether they would like to be involved in the research and talk to the researcher. Adherence to protocol required by the ethics application process can mitigate this differential, but the difference remains and means that I must continue to check that the patient is still happy to be part of the research.

A study looking at adult literacy and using a written text in the language style and format required for patient consent raises ethical questions for me concerning the literacy load placed on prospective participants to be fully informed when signing their consent. There is a lot of reading required by prospective participants, which is why, where possible, I tried to mediate the patient information and consent forms for the participant, using the headings as signposts to guide them through the documents and giving them some time to reflect before signing their consent. In addition, the NZHDEC decided that clinical staff involved in the patient's care were not required to give their consent which meant that I always informed clinical practitioners that the sessions were being recorded.

4.2.2 *Ontology*

Ontology, (*ontos (Gk) - being*) or the study of the nature of reality, being or existence, is another of the domains in Denzin and Lincoln's (2005) paradigm. "All research is interpretive; it is guided by the researcher's set of beliefs and feelings about the world and how it should be understood and studied" (p. 22). Denzin and Lincoln use the terms paradigm and interpretive framework synonymously and consider the constructivist-interpretive paradigm to be one of the four major paradigms that inform qualitative research. Interpretation is the narrative used in a constructivist paradigm. Denzin and Lincoln consider that having a constructivist paradigm necessitates a relativist ontology (because of the existence of multiple realities) with an interpretive epistemology. However I disagree, being unable to support a position where the only reality which exists is that which we construct. I position myself nearer the scientific realist on the

ontological spectrum which assumes that “there is a real world” (Maxwell, 2012, p. 5) but there are many ways to interpret and understand that reality.

Maxwell (2012) takes a similar view and I shall use his approach because firstly it clarifies my position very succinctly, and secondly, the scope of the thesis is not to have a full philosophical debate on the nuances of the ontology and epistemology undergirding this research. It is sufficient to present a position. Maxwell goes on to quote Frazer and Lacey (1993, p. 182), to clarify my ontological position further: “even if one is a realist at the ontological level, one *could* be an epistemological interpretivist . . . our knowledge of the real world is inevitably interpretive and provisional rather than straightforwardly representational” (p. 5).

4.2.3 Epistemology

Denzin and Lincoln (p. 22) ask of epistemology, “What is the relationship between the inquirer and the known?” Crotty (1998) defines epistemology as a “certain way of understanding *what it means to know*” (p 10). This central question directs the nature of research questions developed by the researcher and the methods used to gain answers to those questions. Under a constructivist paradigm, the epistemology is subjective/transactional and co-created (Guba & Lincoln, 2005, p. 195) and the ontology is a relativist position. There is therefore a tension between my ontological position and that which fits Guba and Lincoln’s (2005) description of a constructivist paradigm—a relativist ontology. We will consider constructivism and then return to consider epistemology and the nexus between ontology and epistemology.

Constructionism takes the view that “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42). Guba and Lincoln (2005) position constructivists as “anti-foundational”, who see that “truth—and any agreement regarding what is valid knowledge—arises from the relationship between members of some stake-holding community” (p. 204). As I have previously explained, I do not take such an exclusive position on valid

knowledge. Consequently, I divide ontology from epistemology and will go onto to examine this division before returning to the discussion of ontology in the final part of the next section.

4.2.3.1 Ontology and epistemology nexus

One of the dangers of positioning oneself is that all of these positions lie on a continuum and yet the words used to describe them cannot adequately reflect the shades of difference. Denzin and Lincoln (2005) observed this: “No longer is it possible to categorize practitioners of various perspectives, interpretive practices, or paradigms in a singular or simplistic way” (p. 1115). I have enlisted the perspectives of Cupchik (2001) and Maxwell (2012) to provide a bridge between my realist ontological leanings and my constructionist epistemology. Cupchik takes the position of *constructivist realism* acknowledging that

social phenomena exist in communities quite independently of professional researchers. These *real* [italics his] phenomena will be observed and named by members of the natural community, and understood by experienced or wiser people of good judgement. Scholars can approach this *real* [italics his] world each in their own way (p. 9).

Cupchik is defining a real reality, which fits with a positivist or post-positivist ontological position, yet acknowledges that each will interpret or construct the world in many different ways. Though Cupchik is referring to social phenomena, and I would also include physical phenomena, his approach of defining something as real and providing a process for interpretation is helpful for resolving a realist/constructivist ontology/epistemology position.

Critical realism, a view which adds a critical stance to constructivist realism, joins a realist ontology with a constructivist epistemology, viewing knowledge as always incomplete or imperfect. Maxwell (2012) succinctly comments on critical realism:

Critical realists thus retain an ontological realism (there is a real world that exists independently of our perceptions, theories, and

constructions) while accepting a form of epistemological constructivism and relativism (our *understanding* of this world is inevitably a construction from our own perspectives and standpoint) (p. 5).

These positions assist in joining together my ontological view and the epistemological and methodological approach I have taken. My research questions seek insight into both the constructed realities of patients as well as the real realities of written patient texts.

Crotty (1998, p. 10) though avoids the discussion altogether because he believes that dividing ontology from epistemology is fraught as the two coalesce because to “talk of the construction of meaning is to talk of the construction of meaningful reality.” Crotty is espousing a relativist ontology, being radically constructionist in that there is no reality for him apart from that which he constructs. Therefore, not distinguishing his ontology from his epistemology is understandable, and is not unusual in the qualitative domain (see Corbin & Strauss, 2008).

Before turning to the methodology of my research paradigm, I will examine how the paradigms discussed above relate to health and health literacy

4.2.4 Paradigms in health literacy

Health literacy research, as discussed in Chapter Three, traverses a range of research paradigms with an accompanying ontology and epistemology. Those ontologies and epistemologies are often in opposition to each other. The approach taken by a constructivist researcher capturing the literacy practices of a hospital patient and those around him/her is quite different to that taken by the functionalist or positivist researcher seeking to predict the relationship of health literacy scores to diabetes patient compliance, for instance. Those who have reviewed the paradigms prevalent in health research see that the “dominant biomedical paradigm is rooted in patriarchal positivism” (Miller & Crabtree, 2005, p. 610). Miller and Crabtree typify that paradigm with reference to the following characteristics: scientific rationality, individual autonomy (compared to family or community), the body as machine, mind-body separation, disease as entities, patient as the object, emphasis on the visual, diagnosis and treatment

from the outside, reductionism and seeking of universals, separation from nature. This observation is evident in the literature review in Chapter Three when one examines the paradigmatic orientations underlying much of the research in health literacy.

Miller and Crabtree categorise the research orientations used by clinical researchers (which health literacy research is subsumed under) through a division into six main categories: 1) experimental, 2) survey, 3) documentary-historical, 4) field (qualitative), 5) philosophical, and 6) action/participatory. They see them as all contributing to “clinical research at ground level” (p. 609) which they maintain needs to “*deepen and contextualize the practical and ethical questions* [italics theirs], concerns, and emerging understandings for healers and their patients and policymakers” (p. 609). Miller and Crabtree consider that the second aim of clinical research is to “*trouble the waters and seek change* (italics theirs)” (p. 609) to create space for qualitative research.

A related factor when bringing together the two fields of literacy and health and deciding on forms of research and analysis, is that of the audience. Fleischman (2001), quoted in the previous chapter, saw little evidence of discourse literature being cited by medical researchers, and from this, infers that “they do not read it” (p. 472). This is a theme picked up by Green (2002), a qualitative researcher, who encourages the researcher to consider the type of research that the discipline values and the intended audience values (p. 12). Miller and Crabtree (2005) provide helpful hints and approaches to bolstering qualitative clinical research, creating a space within what they call “technocratic biomedicine” (p. 610). They consider that to successfully enter into this world as a qualitative researcher requires clinical questions being asked which create shared understandings and greater depth to what is already known.

Parker’s (2009) summary of the position of health literacy typifies the prevailing medical hegemony:

What gets measured gets done. This is very important. To develop interventions that improve health literacy means that health literacy has to be measured. There is a developing science for health literacy,

but it is not yet robust. One might think of health literacy as one thinks of medicine. Medicine may be a science, but it is practiced as an art. That is what needs to happen with health literacy. There must be a science of health literacy, but it must be artfully practiced. One must align skills and abilities with the demands and complexity of the system. When that is accomplished, one has health literacy (p. 92).

Parker's view of health literacy is somewhat narrow given the complex and constructed nature of artful practice. With a growing focus within health on patient literacy, research is essential to illuminate what literacy practices exist in the healthcare domain from a patient's perspective and this requires a move away from the functionalist approach Parker advocates.

Dray and Papen (2004) offer a qualitative approach to researching the "concept of health literacy that seeks to overcome the limitations of the widely-used functional models by conceptualising health literacy as an element of a situated and social practice" (p. 312), so a constructivist epistemology. Crucially, Dray and Papen aim to reflect power relations between the participants in the situated practice. They cite Candlin (2000) and Henwood et al. (2003) in proposing that their approach could be used to address debate created through the emergence of the *informed patient discourse* that infuses recent health policies. They take a social approach to their research methodology which combines an ethnographic perspective (Bloome & Greene, 1997) with textual analysis developed in the field of critical discourse studies. Their approach, which mirrors the approach I have taken in my research, helps to create space for ethnographic approaches in the health literacy literature.

4.2.5 Methodology

The fourth domain of Denzin and Lincoln's paradigm is the methodology resulting from the researcher's positions in the other three domains as well as the research topic at hand. My research, exploring how text is constructed and mediated in social interaction within the context of cardiovascular services, emulates the methodology used by Dray and Papen (2004) and Swales (1998), and uses ethnographic approaches to try to capture and interpret the complexity of

the nature of the health literacy required when facing cardiovascular disease, where knowledge (from a patient's perspective) is highly contextualized and subjective. A theoretical approach important to forms of ethnography is grounded theory and this will be explored first before moving to look at ethnography more closely.

4.2.5.1 Grounded theory

Grounded theory relies on the *construction* of knowledge through the lens of a researcher. Charmaz (2005) considers grounded theory “consists of simultaneous data collection and analysis, with each informing and focusing the other” (p. 508). Its ontology therefore has to be towards the relativist side of the ontological spectrum. Holton (2007) sees that the goal of grounded theory is “to offer the reader a conceptual explanation of a latent pattern of behaviour that holds significance within the social setting under study” (p.268). Holton stresses the need for the complete absence of any preconceived ideas when using grounded theory, maintaining that the data must speak for itself. We must not, she stresses have “yet another preconceived theoretical framework . . . forced upon the data” (p. 270). Having a complete absence of any preconceived ideas was not my condition when I came to data generation, coding and analysis so I used a less formal approach to grounded theory. In formal grounded theory methods, there is some debate over the positioning and timing of the literature review because of the importance placed on a researcher coming to the research with no preconceived ideas. I took a pragmatic position on this question, agreeing with Lempert (2007) who advocates an approach to grounded theory that includes a literature review prior to data collection and analysis in order to protect oneself against “ignorance of the present conversation” (p.254). I therefore went into the field with a literature review in progress and many ideas about patient agency, discourse, and approaches to literacy and health literacy.

Nevertheless, grounded theory provided a methodological background to caution against preconception during the thematic analysis of the collected data. Because of the lack of definitive guidelines concerning how much background reading or background knowledge is acceptable for grounded theory, and when is grounded theory not grounded enough, I turned to Braun and Clarke's (2006) thematic data

analysis for a methodological iteration of grounded theory. This approach is detailed in the following chapter.

4.2.5.2 Interpretive/ethnographic perspectives

In order to position the methodology I used, it is important to consider ethnography in more depth. Ethnography is similar to discourse analysis in that its meaning and application have been modified through time and adopted by a broad cross section of disciplines. Kell (2010) comments that ethnography across a range of academic disciplines shares the epistemological orientation: “the idea that the ethnographer seeks to engage with the subjects’ experiences first-hand and that ethnographic data is *produced* dialogically in the field as well as dialectically in an engagement with existing theoretical frameworks and wider research” (p. 217). Using an ethnographic perspective to illuminate literacy practices can highlight practices that are different from those defined by experts in the setting. The setting, the participants, the texts, the actions and sequences, rules, interpretations and contexts are some of the ways an ethnographic perspective can consider literacy practices (Street & Lefstein, 2007).

Drawing on an older typology, Bloome and Green (1997) consider there are three main categories of ethnography (p. 183): doing ethnography—which is a fully conceptualized study of a cultural or social group that is long-term and expansive; adopting an ethnographic perspective which is narrowly focussed and studies a distinct feature of a social group; and using ethnographic tools which involves using the methods and techniques of ethnography but which may not be exploring social or cultural theories or questions of the group under study. I used Bloome and Green’s ethnographic perspective in my study of situated cardiovascular text. By positioning myself in the context, I have attempted to capture the social group surrounding the *life* of that text within the context, and to recognise and capture both “what is believed and expressed and what is actually done and is often inexpressible” (Heath & Street, 2008, p. 16). The application of the ethnographic approach I used is detailed in the following chapter. However, the notion of shadowing is worth also briefly examining in the literature.

Shadowing: One-on-one ethnography

A further variation of ethnographic approaches is shadowing and it is examined here in more depth as it was used during the fieldwork. Gill's (2011) review of shadowing considers that "the research site emerges out of the co-construction of the relationship between researcher and participant" (p. 115). There are three manifestations of the use of shadowing according to Gill: a) as a form of experiential learning; b) as a means to count, quantify and report on daily tasks of employees or managers, and c) as a means to understand the experience of work, in context, across different work situations. My use of this style of data collection was a combination of b), with counting of text use occurring, and c). My misgivings over obtrusiveness, researcher presence, and the difficulty in "gaining a holistic understanding of an entire lived culture" (p. 117) are legitimate. However, in the present study, these misgivings were mitigated by shadowing eleven participants, thus getting a range of participants experiencing the hospital service, and researcher sensitivity and rapport building with participants in the study. Reflexivity was paramount in also helping to mitigate these misgivings, and had to involve "a critical awareness of how the researcher views herself and what this means for the research" (Gill, 2011, p. 118). I used audio and written journal entries to record these reflections. Shadowing patients was just one avenue for gaining data on patient texts in the lived culture of the hospital. Observation, conversation and semi-structured interviews also formed part of building understanding of patient text and literacy practices in the hospital environment.

Situated literacies and textography

This approach of shadowing texts and people in an ethnographic style and combining it with text analysis was practiced by Swales (1998) who coined the term textography. Dray and Papen (2004) later used a similar mode of exploration to capture the way texts are positioned in events such as those found in a health care setting. Investigating these social and cultural practices that individuals and groups may engage in requires researcher presence which an ethnographic approach facilitates.

4.2.5.3 Discourse

Discourse has been the subject of much scholarly endeavour over the previous fifty years across a range of disciplines. This broad reach has succeeded in growing the field of discourse analysis into many streams of enquiry, for example, sociolinguistics, semiotics, pragmatics, conversational analysis, and critical discourse analysis (Labov, 2001; Grice, 1989, Kress, & van Leeuwen, T. 1996; Gumperz & Hymes, 1972; Searle, 1992; Wodak, 2001, Flowerdew, 2014), Fairclough's (2003) iteration of discourse analysis has most informed the approach taken in this research. His approach is based on the view that "language is an irreducible part of social life, dialectically interconnected with other elements of social life, so that social analysis and research always have to take into account language" (p. 2). He advocates discourse analysis as one strategy amongst many, (for example, ethnography), and sees discourse analysis as "oscillating between a focus on specific texts and a focus on . . . the relatively durable structuring and networking of social practices" (p. 3). Figure 1 outlines how this dynamic of specific texts and social practices is configured in my research. A fuller description of how I will analyse the specific texts is in Appendix 2. The notion of *constituents* (Hunter & Franken, 2012) used in Figure 1 is examining the broad functions of the text, or in Fairclough's words, the ways of acting.

Fairclough considers that discourse features in three central ways in social practice: genres (ways of acting), discourse (ways of representing) and styles (ways of being) (p. 26). As well as using tools such as genre mixing, and interdiscursivity to examine text, Fairclough also includes mediation (discussed in Chapter Two) as a tool of discourse analysis to use when looking at the external relations of texts to social events and social practices. Fairclough offers ways of analysing how texts are related to social practices. In particular he looks at genre chains as being particularly important in mediation when "different genres . . . regularly linked together, [involve] systematic transformations from genre to genre" (p. 31). This can then be a way of "linking together social events in different social practices" (p. 31). Fairclough's approach to discourse allows a workable frame for the interconnected nature of text, social context and social practice and his approach is woven into the matrix in Appendix 2.

4.2.5.4 Critical approaches to discourse analysis

A critical approach to discourse analysis characterises the researcher rather than the method (van Dijk, 2009. p. 63). A researcher with a critical lens to discourse sees language as *social practice* (Wodak, 2001). It asks of these practices such questions as: Whose interests are represented by the text and where is the text positioned in this context? Critical discourse analysis (CDA) however, is more overt. It begins with a problem in mind and seeks to deconstruct the responsibility and power distribution around the problem, with the goal to take action as a result. This research does not so much begin with a problem in mind, but rather a question about patient texts and their use in a hospital context. It is during the course of the research that the central problem of access evolves. In this way, the research is grounded. However, Fairclough's (2003) approach for the process of critical analysis of discourse is useful for asking questions of text in this research and provides a suitable framework to analyse text. He approaches discourse from three-levels:

- micro-dimension: This is a description of the text itself looking at such features as use of active/passive voice, use of nominalisation, choices of mood, choice of modality or polarity, thematic structure of the text, information focus, or cohesion devices.
- meso-dimension: This examines the human production, and receiving of the text, the guidance to reader. How does the text position the reader?
- macro-dimension: This is the social/historical/political conditions influential in the how of production and reception. Does the text for example reproduce dominant hegemonies or prevailing conditions?

Fairclough (2003) recommends that the researcher identify obstacles to the problem by analysing the network surrounding the problem, and the discourse itself (structural and textual/interactional analysis). He then suggests the research consider whether those who derive gain or benefit from the problem would want the problem to be solved and then to identify ways to respond, with a final directive to reflect critically on one's analysis. This critical approach to discourse frames the approach to analysing the collected discourse data in this research. It recognises that in any social context there exist dynamics of power, which may or

may not result in power abuse or resistance. The collected data correspondingly may reveal such tensions. In this research therefore, critical discourse analysis is not used as the dominant theoretical lens through which to plan the research methodology and method, to review literature and to analyse and interpret data. However, a short examination of a critical approach to the analysis of the discourse that arises from the research context can bring to the surface issues of power. Such an examination follows to further prepare the ground for data analysis.

4.3 Critical approaches to discourse and power

The examination of power relationships is central in a critical approach to discourse. My position, as I touched on in Chapter Three, is that power presents as something that circulates but the way or process of circulation can include domination and subordination, but not necessarily always in that form. These uneven notions of power are eligible for critique. In a similar vein, Martin and Rose (2007) argue that a critical analysis needs to be balanced by analysis that seeks the “interventions (that) have good news to learn from as well as bad news to overthrow” (p. 315). Their point, which I concur with, is that critical analysis also needs “a complementary focus on community, taking into account how people get together and make room for themselves in the world in ways that redistribute power without necessarily struggling against it” (p. 315). How an individual navigates power in a context, especially when faced with domination or subordination requires a critical lens. An individual’s agentic voice may be revealing in analysing how power is wielded in a context, not just for those in ‘empowered’ positions but also those who are not. This type of approach is a more nuanced view of power, providing an alternative way to view asymmetric power relations and how they are sometimes contested.

Figure 1 is a methodological map of the research, showing where the methodologies and methods coalesce. It represents the three data gathering focal points: the health care context, the written text and the patient. It also places Fairclough’s micro, meso, and macro approach to health literacy as social practice into the hospital context. Each of these requires individual focus, although, the centrality of the text remains and is represented as such in Figure 1. However, it

is as much about how those texts are *peopled* in the context, as about the texts themselves. To capture this peopling, or the mediation of text, I needed to collect data at the point at which the three variables, the health care context, the written text and the patient could assemble and this invariably happened at the patient's bedside.

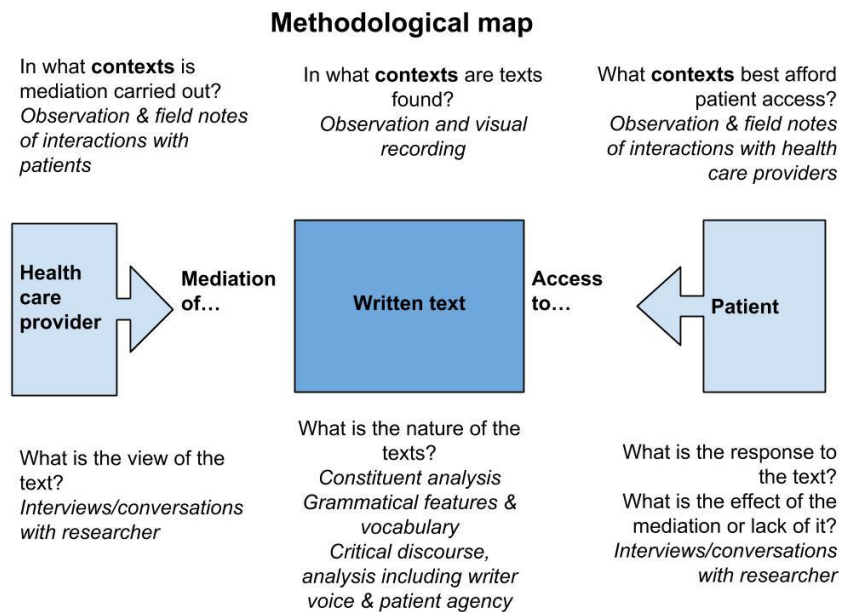


Figure 1: A pictorial summary of the research approach

4.4 Conclusion

This chapter has taken the reader through the four domains: axiology (ethics and values), ontology, epistemology, and methodology. It has borrowed from Denzin and Lincoln's paradigm to organise this interpretive research but deviated from it by taking a critical realist approach to ontology and epistemology. The chapter has also reviewed the methodological approaches that informed the research methods. The following chapter, Chapter Five, provides more detail of Figure 1 by describing the context in more depth, outlining the research questions, and describing the data collection, management, and analysis.

Chapter Five: Methods

5.1 Introduction

“The particular value of qualitative research lies in its ability to explore issues in depth and from the perspectives of different participants, with concepts, meanings and explanations developed inductively from the data” (Lewis & Ritchie, 2003, p 267). How that exploration of issues and inductive data analysis was carried out is the subject of this chapter. Figure 1, providing the overview of the research, places texts as the central organisational feature primarily to capture the way the texts are peopled in the context. To document this *peopling*, I positioned myself alongside the central user of patient texts, the patient, and captured the social context through logged observation and description, audio recordings, researcher reflections and photography as he or she encountered the texts and the hospital context. A newly admitted patient into hospital is welcomed into a highly complex literacy environment: the admission, the bed, the (often gaping) pyjamas, the uniformed personnel, the new illness, the uncertainty, the treatment, the storytelling to each health professional. There is much to understand. However capturing and interpreting that data is just as complex, especially given the ethnographic perspective approach taken. As I have previously discussed through the work of Fleischman (2001) and Miller and Crabtree (2005), in a research area dominated by empirical research, taking such a research approach behoves a careful treatment of methodology and issues associated with generalisability, credibility, and dependability.

After outlining the specific research questions, the chapter will (a) describe the research site; (b) provide an overview of the research design; (c) explain how the sampling of cardiovascular patients occurred; and (d) provide an account of how the data was organised and coded in order to report and interpret the findings. An account is included of the ethical considerations that were predominant in the study and how those ethical issues were addressed. A discussion of the scope and generalisability, credibility and dependability conclude the chapter.

5.2 The research questions

The research questions were as follows:

1. What is the nature of written texts?
 - a. What are the features of the written texts presented to patients in cardiovascular health care services?
 - b. What literacy and numeracy demands do the written texts place on patients and how are those demands related to the patients' health literacy?
2. What are the opportunities to engage with texts?
 - a. How are the texts embedded in the social contexts and practices of cardiovascular health services?
 - b. How are they mediated?
3. What are the patient reactions to text?
 - a. What is the nature of the patients' responses to texts?
 - b. How do patients value the texts?

5.3 Site description

5.3.1 *New Zealand context*

There are 20 district health boards (DHBs) in New Zealand and these were established by the New Zealand Public Health and Disability Act 2000 (Ministry of Health, 2012a). The boards are based on historical provincial geographical boundaries within New Zealand. DHBs have responsibility for “improving, promoting and protecting the health of people and communities” (Ministry of Health, 2012a) as well as a raft of other strategic health goals for the country. DHBs own and fund public hospitals. All district health boards are accountable to the Minister of Health via two bodies that oversee their work, the Ministry of Health (MOH) and the National Health Board (NHB). Membership on the NHB is by Ministerial appointment. Government goals for the health and disability system in New Zealand are to achieve better, sooner, more convenient services for patients through a range of cost-effective mechanisms. One of the broad measures of DHB performance is the six national Health Targets. Currently the 2014/15 health targets are shorter stays in emergency departments, improved access to elective surgery, shorter waits for cancer treatment and radiotherapy, increased immunizations, better help for smokers to quit, and more heart and

diabetes checks. These targets are reviewed annually. Cardiovascular health has remained a national priority.

5.3.2 Local contexts

For the research, patients were recruited and followed into various places within the health care system as well as within their own homes. The following section gives an overview of the locations where most of patient contact took place.

5.3.2.1 The hospital

The hospital is a 390-bed hospital serving a population catchment area of over 200,000. It has grown significantly since its beginnings early last century. Some distinguishing features of the population the hospital serves include a high number of people living in rural areas, a less than New Zealand average life expectancy, higher than New Zealand average smoking rates, and the highest proportion of Māori.

The hospital is classified as a secondary hospital with some tertiary services also being delivered and is called the provider arm of the district health board. There are other arms, for example, planning and funding. Each division has an executive head who is accountable to the district health board's chief executive officer. One of the many identified priorities for this DHB is the prevalence of cardiovascular disease.

Ten of the eleven participants in the research came through the emergency department (ED) with the eleventh patient recruited at an outpatient clinic. The ED has 40,000 users a year. It is situated in a prominent position at the front of the hospital. It has its own drive-through drop-off loop and longer-term parking is nearby and free. Just beyond the ED is the assessment unit (AU) where admitted ED patients are taken to be further assessed and either moved by porters onto the appropriate hospital ward or discharged. The AU is staffed by permanent nursing personnel on rostered and rotating shifts. Specialist medical staff visit according to patient speciality need. There are also two clinical managers.

5.3.2.2 Assessment unit

Ten of the participants were recruited into the study in the assessment unit after coming through the ED. The assessment unit has 28 beds and is set in the shape of a rectangle. It has two wards within it, which are called pods. It has an entrance at the long end of the rectangle which is accessed through a security-controlled door from the hospital's main reception area. At the other end of the rectangle is the clinical charge nurse's office from which everyone can be seen coming or going from the entrances.

Each pod has a clinical station or office which has windows looking out onto nearby beds lining the walls in front. The clinical room has a white board with each patient's name and responsible clinicians beside it. There are phones, computers, equipment such as a crash trolley, and other administrative folders and drawers. There are no separate desks, just a ledge that lines the edges of the room and wheeled office chairs that are in high demand because of the volume of passing clinical staff. Registered nurses staff the pods. Many of the hospital specialists and their accompanying registrars and house officers visit during the day to assess and plan for the admitted patients falling under their care. Patient notes are all kept in this office area. The maximum length of stay in the AU is supposed to be just 24 hours, but this can be longer if beds in the appropriate areas of the hospital are full due to high demand. Cardiac patients are transferred from the AU to a cardiac ward or to the specialised cardiac unit near the intensive care unit.

Within the AU, beds are close together, separated by a curtain. Each bed has a control system which allows patients to elevate or recline their bed, a bed table on wheels that fits over the bed and can be used as a meal table, and a bedside cabinet. There is a choice of lighting as well. There are no windows to the outside in the whole unit so the AU inhabitants have no natural light clues to the time of day aside from a clock, the format of the meals and the daily routines of staff changes and other regular occurrences. On arrival, a patient will find a welcome pamphlet waiting for them on their bed. This pamphlet gives a basic overview of the AU, the team approach to a patient's care, the meals and visitors, and infection control.



Figure 2: AU bed area

There are two exit and entry points, but only one of these is available to the public. The public door to the AU is locked and access is gained from the front desk of the hospital or the desk of the unit's administrator. The AU is often very full and therefore can be very noisy. The thin curtains separating patients from the public world do not screen out noise or other human activity. The noise can be intimate human noise—coughing, wheezing, snoring, flatulence, groaning, or voices loud and soft—doctor or nurse-patient interactions, tea ladies offering hot drinks, the newspaper lady selling her wares, echo-cardiograph nurses wheeling their trolleys, an administrator pushing a supply trolley, sobbing of someone losing their loved one, or the conversations of visitors in person or on the phone. There appears to be very little privacy in the AU, (see Figure 2) except if a patient is in a private room. No patient involved in the research was housed in a private room.



Figure 3: The AU entrance and hallway

This picture looks forward from the entrance. The first pod is to the right in the picture while the second pod is further down the corridor to the right. Private rooms with closing doors open onto the left side of the corridor. Otherwise, beds line the walls and partitions as seen in Figure 2. To the right of where this picture is taken there is a lounge area with chairs which doubles as the entry way, and to the left, a pamphlet holder full of pamphlets on the wall.

5.3.2.3 Coronary unit and wards

Patients were also often transferred directly from the ED to the specialised cardiac unit (SCU) if initial assessment in the ED indicated a cardiac condition and there was a free bed. That did not preclude cardiac patients being in the AU, and if the SCU was full, the AU would still be used or patients would go to another cardiology ward. The SCU was also a place I attempted to recruit patients or visited them once they had been transferred from the AU. No patient was successfully recruited from the SCU. The specialised cardiac unit (SCU) is in a more modern wing of the hospital and consists of two large, airy rooms, each with four beds and with more space around them than in AU. Natural light is abundant through large windows on each side of the unit and quiet is more prevalent. A

corridor transects the middle of the two large rooms. Two very small offices open off the corridor, one to the right and the other to the left. There is a computer and two office chairs in each office which enable those sitting to look out directly through the window into each SCU four-bed room from the office. Otherwise, there is very little room within the office itself. In the corridor leading to SCU there are no chairs or places to wait; rather, there is a well-resourced family/visitor lounge out of the secured unit near the entrance door where patients can meet with friends and family. The doors to the SCU, the intensive care unit and the coronary care unit are locked at all times and access is either by a swipe card or a request to the administration person in the reception area. Given the smaller number of beds, the larger space between beds and the fewer people circulating in this area, it is quieter than the AU.

There are just eight beds in the SCU and more beds further down the corridor in critical care and intensive care. However, those areas and beds cannot be seen from the SCU and the layout of the area invite itinerant wanderers. My research did take me into the intensive cardiac care unit which is a large room with beds laid out in a row side by side on one wall. There is a reasonable space between them and a curtain. The clinical office down one end is compact and has open window views out onto the beds.

The cardiology wards have several four-bed rooms, two-bed rooms and some single rooms. They are also very busy and often noisy places, with healthcare professionals and assistants visiting for various reasons at various times, family and friends visiting with the negotiation to use other chairs when numbers exceeded a couple, the proximal bathroom and its noises. The curtain is one of the few things a patient can control to determine his or her level of visual privacy. Private or sensitive conversations are shared with roommates by default. Consultations with medical and nursing staff are done at normal conversational volume making it difficult for anyone in a bed nearby not to overhear.

5.3.2.4 Cardiac classes

Cardiac education classes run on a six-weekly cycle for cardiology patients. After a patient is discharged from hospital, some are invited back to attend the six-week (one morning a week) cardiac education class where they can examine the range

of issues surrounding what it means to live with a cardiac condition. This is voluntary for patients, but not all patients are invited to attend because of capacity issues. I did not succeed in learning what the criteria were for invitation to the cardiac classes. The classes cover a range of topics (e.g., anatomy and physiology, diet) and all have an exercise component. The meeting place for these classes is in an outpatient area of the hospital in a spacious room. There is room for attendees to stand and do some movement exercises.



Figure 4: The cardiac education room

The cardiac nurse specialists have a variety of realia in their repertoire to assist with their classes. This enlarged version of the heart in Figure 5 was one such piece. The heart model could come apart to reveal its inner structure. The use of the realia (real-life objects used to teach learners about real life conditions or states) appeared to be confined to the cardiac classes.



Figure 5: The human heart model

5.4 Overview of research

Given the study was largely concerned with the social practices around text, the need for what Bloomberg and Volpe describe as *perceptual data* and *contextual data* were paramount (Bloomberg & Volpe, 2012). Contextual information included the culture and environment of the setting, which in this instance was a hospital. Perceptual data related to the participants' stories, how they described their experiences and decision making, changes in behaviour or thought, participants' perceptions of their own experiences. This was augmented by demographic information about the participants: their age, gender and aspects of their personal stories.

5.4.1 Ethical approval

As a researcher, being involved in the lives of others raises ethical considerations because of the access, the associated power, the confidentiality of data, and the blurring of lines between participant observer and the observer (Fehring, 2002). Ethical approval for this study was sought from the hospital concerned, the University of Waikato, and the New Zealand Health and Disability Ethics Committee. Northern Y Human Ethics Committee granted ethics approval (#NTY/11/EXP/030), as did the University of Waikato Ethics Committee and a Māori ethics review group from the Clinical Ethics Committee of the hospital where my research took place. The ethics application process addressed participant recruitment, informed consent processes and guidelines around data security. Ethical approval required consent from the patient only. Health professionals recorded were informed of the recording taking place.

Much of the true ethics of research is glossed over in the ethics process. As Bloomaert (2008) observes, "existing ethical codes do not solve the moral dilemmas of social research" (p. xvi). One area of concern is patient consent. An in-patient is in a vulnerable position in hospital and therefore whether the hegemony of power operating in a hospital setting gives a patient the capacity to decline involvement in research without feeling fearful or anxious is an important question. The work of Frosch et al. (2012) referred to in Chapter Three would support this as being a very real issue for patients. However, in this research, there were patients who declined to be involved. In addition, the directive that

consent was only required from the patient, gave rise to vulnerabilities for the staff involved in this research. Non-patients recorded at the bedside were merely informed of who I was, what I was doing and the presence of the recording device.

There were several steps undertaken to progress this research. Orientation to the research site and the development of contacts and relationships was needed prior to beginning participant selection. Having a family member who worked in the hospital assisted with making these initial contacts. Patient participants were recruited over a period of five months with their journeys through hospital recorded. This included interactions patients had at the bedside with doctors, nurses and other health professionals as part of the journey. There were also several semi-structured and unstructured interviews with the eleven patient participants also taking place over that time, as patients were followed as they journeyed through the health system with their illness. Patients were recruited from both in-patient and outpatient settings within the hospital over the five month period. Unstructured interviews and conversations were also conducted with clinical and non-clinical staff within the context. I collected texts and artefacts over the duration of the fieldwork. Data organisation and analysis took place primarily using NVivo data management software which enabled data coding and thematic analysis across data sets.

5.4.2 Data collection

5.4.2.1 Shadowing

Shadowing, as discussed in Chapter Four, meant being alongside patients as they encountered their health journey and allowed collection of a variety of data. The conversations and consultations with medical and nursing staff were recorded, as were observations of the surroundings, rituals and events that took place while the patient was in the hospital space. Shadowing generated thick descriptions (Lincoln & Guba, 1985), or contextual and perceptual data making up different *data sets* (Braun & Clarke 2006, p. 79). However, how much I could accompany each patient was variable. Appendix 1 presents a data summary of each patient. The amount of time in audio recordings is one indicator of the amount of time I spent shadowing, but is only one indicator as I did not record all of the time spent

with various patients, especially when we were talking about things that were more personal to the participant and which did not relate to the research. Appendix 1 provides a summary of the data trail and also provides a list of texts collected from each participant.

5.4.2.2 *Unstructured and semi-structured interviews*

A constructivist epistemology and ethnographic methodology for data collection places unstructured and semi-structured interviews very much at the centre of data collection. Miller (as cited in Zhang & Wildemuth, 2009b) states “there is no such thing as a worthless conversation, provided you know what to listen for. And questions are the breath of life for a conversation” (p. 222). So it was for the many conversations I had in the hospital while collecting data. Unstructured and semi-structured conversations were the principal method used in garnering a patient’s perception of their own health literacy. Conversations sometimes included numeracy knowledge and strategies the patients used where it was appropriate to the context of the text interpretation at hand. Conversations were also used to “establish familiarity with the setting(s) and the events occurring within it—as well as the research participants” (Charmaz, 2005, p. 521). This, coupled with a grounded, thematic approach provided opportunity for different voices within the research to emerge, as participants had the opportunities to tell their stories. Using the HeLMS survey provided structure to patient conversations but they varied in the level of structure depending on the rapport which had built between the participant and me. Interviews carried out with patients early on in their hospital or health journey followed the survey more closely, but would usually deviate into issues or stories prompted by the survey.

The semi-structured interviews or guided conversations I had with patients once they had received and read any written material in hospital were guided by questions and topics outlined in Appendix 3, and acted as an *aide memoire* or an agenda (Zhang & Wildemuth, 2009b, p. 223). The questions were formulated from the approach to text analysis I took outlined in Appendix 2. The agenda did not necessarily dictate the order of the conversation but provided topic and/or issues that might be covered and allowed some consistency across participant interviews.

5.4.2.3 *The HeLMS survey*

The HeLMS survey (see Appendix 6) was the tool I used to have a structured conversation with participants. Questions from the HeLMS survey were used to understand the broader factors surrounding a patient's interaction with the health care system. As previously discussed in Chapter Three, the Health Literacy Management Survey (HeLMS) tool attempts to measure the many variables involved in an individual trying to access, understand and use health information to grow their health literacy. HeLMS has now been superseded by the Health Literacy Questionnaire (HLQ) (Osborne, Batterham Elsworth, Hawkins & Buchbinder, 2013) with validation research ongoing. With patients who I spent more time with and/or who were more open, this tool worked well. For others, it was more fitting to let them work through the questions or we worked on it together. I had received permission to use the HeLMS survey from the Curriculum Licensing Services of the University of Melbourne in November 2010.

5.4.2.4 *Case study*

Some of the data collected from each participant will be presented in case study format. Stake (2005) uses the term *instrumental case study*, where a particular case (or *multiple cases*) is studied to give insight to an issue or generalization. The case, in this instance, does not play the primary role; it supports knowledge development (Stake, 2005, p. 445). My research takes this approach as the case studies presented are snapshots of moments in time (transcribed conversations, observations, field notes) where patients interacted with written texts and the health care providers who mediated those texts. The data presented in case studies will be instrumental, in that they will provide insight into the larger picture of how written texts are situated in cardiovascular services, or a cardiovascular textography.

5.4.2.5 *Orientation to the field*

Data collection began with visits to the hospital to gain initial permissions and meet key personnel who would facilitate my presence at the patient's bedside. I was assisted in these approaches by representatives from the clinical school attached to the DHB. These initial meetings also began to place my research into

the broader hospital context through the establishment of relationships with key stakeholders especially in the nursing area. I met with the nurse specialists involved in cardiac care and negotiated ten minutes of their lunchtime to talk about my research. I emailed an invitation and information letter to the cardiology specialists I expected I would come into contact with, informing them of the nature of my research and inviting them to allow me to present a short overview in person. There was no response to those emails so no meeting with any medical personnel took place prior to a brief introduction at the patient's bedside where it seemed they remembered who I was. In the AU, the area where I spent the most time, I introduced myself over morning tea and outlined my research, with a supporting document, to the nursing professionals in the area. This occurred in the AU only. Early researcher reflections in my diary convey something of the struggle to get into the *space*. I was fortunate that the nurse leader of one of the areas I gathered data in was particularly supportive of my research, which facilitated data collection.

As a researcher, I kept a diary to log my visits and record my perspectives on my data collection process and my experiences as I myself became more health literate. I used this diary to critically reflect on *etic* issues, my frame of reference, and my cultural bias. This was not to undertake an auto-ethnography, but to generate information which could be useful for my observation of patient/text/health care provider interactions (Tedlock, 2005).

5.4.2.6 Participant selection

Patient participants agreed to have me *shadow* them as much or as little as they were comfortable with in their interactions associated with their cardiovascular care. I audio-recorded and transcribed interactions between patients and healthcare providers although in some situations I just took notes. This happened when the nature of conversation was too personal or the patient requested I turn off the recording device.

The initial goal was to collect sustained data from at least six participants. My ethics approval provided for the consent of up to 12 patient participants to account for possible participant withdrawal as well as the potential need to serialise participant selection (Green, 2002). Serialisation did happen as I began to select

participants according to the cardiac specialist they were under in order to include as many specialists as possible and thus increase the context represented in the sample data. Since the timings of doctors' rounds and nurse specialists' visits were unpredictable, one, or a maximum of two patients at any given time was best so that I was always available to be present at each patient consultation. There were some days when two people agreed to be involved in the research at nearly the same time. Because I had two participants simultaneously, I missed a crucial meeting between a nurse specialist and the patient for one of the participants.

Any patient was eligible for inclusion in the study if they were placed under a cardiologist for initial assessment once admitted to hospital or if they attended an outpatient visit for follow-up with a cardiac specialist nurse. Nine of the eleven patients in the study, however, were hospital in-patients. At the beginning of each day I would check with the associate clinical manager for potential participants. The manager would indicate whether anyone had been admitted and was awaiting a visit by the cardiologist. The patients in the study were those admitted to or using hospital services from August to December 2011. Selection of participants was according to their willingness, availability, and ability to inform, but with enough variation to glean as much information as possible. Variables influencing selection were gender and age where I tried to get a wide range as possible. I attempted to include patients who were new to cardiac conditions although this was not always possible. I also sought typical cases, not atypical or patients with multiple conditions. It was difficult to find participants younger than 60 years of age and often it was younger patients who would decline to be involved in the research. As data collection progressed, I aimed to have patients from as many cardiologists as I could so I could pick up any variations in approach. In this regard, the selection of participants was *purposeful* (Green, 2002) and aimed to "include as much information as possible [and] . . . to generate the information upon which the emergent design and grounded theory" could begin (Lincoln & Guba, 1985, p. 201).

5.4.2.7 The data collection sequence

Once patients had been approached by the clinic manager or the registered nurse to gauge their interest in the project and meeting with me, I would give them the

information letter and consent form. How I mediated these pieces of paper was very dependent on the patient's receptivity to me and to the project. With all patients I would go through the written material before leaving it with them to think about and sign if they were interested. I would then return an hour or so later in the day to answer any questions and follow-up on their permission. There were a number of patients, who after reading the information about the study and consulting with their family, chose not to participate. The study demanded that an intensely private major event in a patient's life was going to be watched and recorded by a complete stranger, me, the researcher. Rapport and trust were therefore paramount.

When consenting to be involved in the research, patients agreed to take the Health Literacy Management Survey (HeLMS) (see Appendix 6). Once a patient agreed to be involved in the research, we would generally have time after completing the consent forms to chat. Often the conversations would be considerably long. We would talk about topical issues as well as those pertaining to their own health journey. These were unstructured conversations and ones that I mostly recorded. If I was fortunate, the specialist—the cardiologist and his entourage—would visit the patient while I was there, to do an assessment and plan for his or her management. Otherwise I would wait, often alongside the patient, unless they did not want me to. The specialist-patient conversations were audio-recorded and noted and copies taken of any written material given to the patient at that point. The patient would then often be moved around the hospital for different diagnostic tests or be transferred out of the AU at this point. I would then liaise with the cardiac nurse specialists (CNS) to begin tracking the patient's progress and request that I be present at any meetings the CNS would have with the patient. These could occur that day or the following one where a cardiac nurse specialist would go through a structured interview/assessment of the patient and discuss issues related to their cardiac condition, its treatment and management. Again, if any written material was given to the patient during these sessions, I would take a copy.

All of these visits were recorded as I built the picture of the patient's illness and their interaction with the local context. During the meeting with a CNS, there would often be mediation of a written health text for the patient to read. I then

proceeded to visit the patient the day after these nurse consultations in order to talk about the patient's understanding, their thoughts and their interactions with any written text, using the questions in Appendix 3 to guide the conversation. I would also follow up with the patient in subsequent meeting/s. During these follow-up sessions, I asked specific questions about the patient's use of the written texts they had received and conversation would be structured around the following topics:

- interpretation and personal importance/usefulness;
- assessment of ease and difficulty to understand/follow;
- strategies for dealing with difficulties/lack of comprehension;
- help from others: friends, family, health sector;
- accessing additional information: strategies, difficulties;
- recommendations for the text.

These conversations would then often lead to the completion of the HeLMS survey which were structured conversations. At times I found that our previous conversations had already covered the answers to the HeLMS questions. However, the HeLMS questions structured the conversations and further exploration, especially into the way the patients managed their relationship with their primary doctor or general practitioner. Completing the HeLMS survey was therefore done in various ways. Some took the paper and filled it out. Others were happier for me to ask questions and they answered orally and with others, the survey became less meaningful because we had already traversed many survey topics more deeply in conversation making the Likert scale used in HeLMS not applicable. For some patients, holding a pen was difficult due to an intravenous line in their hand, so I held the pen and marked the page according to their directions. The structured conversations mostly took place between August and December 2011, with occasional follow-up occurring in February, June and August 2012.

Follow-up unstructured interviews were also conducted at the cardiac education classes which some participants attended as part of their recovery. I would meet with them there and converse with them about their journey and often listen to and record their check-up conversations with a cardiac nurse. Other patients who did

not attend or were not invited to these classes were followed-up over the phone or at their house (see Appendix 1).

5.4.2.8 Health professionals

Aside from conversations with the patients, I recorded conversations with the nurse specialists assigned to each patient and also with other nurses and hospital employees interested in my research. I also interviewed people I came to recognise as key to controlling the availability of written text in the hospital contexts. While a patient was in hospital, I would collect debriefing reflections from the cardiac nurse specialists after they had seen a patient. During the times I waited in the two units and wards where patients had been transferred, I would usually initiate conversation with other nurses and visitors. I sought conversations with the administrators whose job was to manage the content and availability of written material in the pamphlet holders in their various areas of the hospital, including the specialised cardiac unit and the assessment unit. I also sought out appointments with the director of Māori health in the DHB. These conversations did indeed help to establish familiarity with the setting.

5.4.2.9 Texts and artefacts

The selection of texts to analyse in this research was limited to the texts I witnessed being mediated or introduced to participants—texts that were actually peopled and texts that were key to the user. Invariably these were texts that were directly related to either the illness or the pending surgical or other procedure. A list of those texts can be found in Appendix 1. Text analysis was done manually, not through NVivo.

Part of the work of building the picture of text use was to attempt to discover the place or situatedness of the texts in the environments that they were found and used in. I used Street and Lefstein's (2007, p. 194) approach, discussed in Chapter Two, as a guideline which included not only the texts, spoken and written, and artefacts, but also the sequencing of events and practices, the rules, the participants. So recorded observations and photographs were used in addition to conversations to document practices surrounding text (see Appendix 1b for details). This collection of data involved my witnessing the giving of text to

patients by clinical staff and noting how and where written patient text was organised, stored, displayed, talked about, and managed on the site. I also undertook interviews with the administration staff involved in managing written text. Where text was not available or obvious, I would attempt to find out why through further conversations, often with administration staff.

5.5 Data analysis

Patton (2002) defines qualitative content analysis as “any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings” (p. 453). The volume and diversity of data collected in ethnographic-styled research can be vast. What results is a number of data sets making up the total data corpus. I adopted Braun and Clarke’s (2006, p. 79) use of the terms *data corpus* and *data set* with data corpus referring to all data collected in my project and data set to the data from the corpus that are analysed in a particular way. The three major areas of attention or data sets are text, patient and context, with each having a method of analysis.

5.5.1 Thematic analysis

An iteration of strands of grounded theory methodology that I used in data analysis is thematic analysis although Braun and Clarke (2006), who formalise this approach to data analysis, do not share that view of its historical lineage coming from grounded theory. They argue that thematic analysis is “a method in its own right” (p. 78) and that grounded theory analysis aims to “generate a plausible and useful theory of the phenomena that is grounded in the data” (p. 80). They locate thematic analysis within the field of psychology and define it as “a method for identifying, analysing and reporting patterns (themes) within data” (p. 79). However, they then go on to name thematic analysis as the method researchers can use if they do not want to “produce a fully worked-up grounded-theory analysis” (p. 81), commenting that they are finding the use of grounded theory in a “*lite*” (p. 81) fashion. The distinction then would be whether an outcome from the thematic analysis is theory development and that is a step that the data itself needs to direct, through analysis of emerging themes.

Regardless of where thematic analysis is situated in relation to grounded theory, it is an essential element of data management and one that underlies software programmes like NVivo, where users can code and recode data, and combine coding as data analysis progresses and as the researcher sees themes or patterns appearing. Ryan and Bernard (2003) describe a theme as an abstract construct “that link[s] not only to expressions found in texts but also expressions found in images, sounds, and objects” (p. 87). They consider that a theme will answer the question, What is this expression an example of?

Braun and Clarke (2006) guide the user of thematic analysis to begin by noticing and looking for patterns in the data. Analysis then “involves a constant moving back and forward between the entire data set, the coded extracts of data that you are analysing, and the analysis of the data that you are producing” (p. 86). In this approach, writing should begin immediately in the data analysis as on-going writing is essential.

I used Braun and Clarke’s (2006) advice to researchers to deeply engage with the data, to make notes, to do the transcribing and to re-read. Ryan and Bernard would call this “discovering themes and subthemes” (p. 85) and “winnowing themes to a manageable few” (p. 85). Initial coding of the data used over 40 nodes inside NVivo. Some examples of the nodes used in coding included such things as condition management, discourse modes, imperative verbs, fear, information provider, numeracy demands, patient agency, patient question , patient relationship to GP, patient-text engagement, patient symptom management, and voice of authority.

After the initial coding, I then combined nodes into significant groupings, or “hierarchies of themes” (Ryan & Bernard, 2003, p. 85). This was done within NVivo. Duplicates were identified along with related nodes which were then combined into secondary and later tertiary level themes. For example, the theme of access explored in the later chapters of this thesis, had a sub-theme node of *fear*, which had other related, but more specific nodes under it. The theme of *patient agency* developed in a similar manner.

5.5.2 *Micro-view: Text and discourse analysis*

The previous chapter has outlined several approaches I took in the analysis of text, discourse and the surrounding social practices. My use of discourse analysis spanned both the written text collected in the field and some of the verbal interactions between the patient and the health professionals. The matrix in Appendix 2 provides a summary of the approach to text analysis. The matrix presents a selection of tools which allowed text to be analysed from a number of different angles. It asks, for example, whether the text is part of a chain of texts, and how available the text is. As well, it looks at the constituents of the text, the assumptions inherent in the text, and questions to ask of the text to ascertain the nature of the relationship between the writer and the reader.

Bax's (2011) approach to discourse was helpful when organising my analytical approach to the written and spoken texts. Bax begins with three central questions: What does the particular text do or achieve? How does it achieve this, and why does it seek to achieve this? The first is a static description of the text, the structures/function of the text. What is text? What is the genre? What layout, visual resources, intertextual links, lexical, and grammatical resources? Micro perspectives on the written text are gained through linguistic and discourse analysis and include such analytical tools as discourse mode structures, lexical frequency, modality, and rhetorical structure analysis. Frequency word counts and word categorisation were done using www.lex tutor.ca (Cobb, n.d.). This website allows the simple analysis of texts for highest frequency words.

The second is the structure of the text which reflects the author's intentions and purpose. This is also about the assumed understandings between the writer and the reader. Widdowson's comment (as cited in Bax, 2011, p. 22) on context: "Context is not an external set of circumstances but a selection of them internally represented in the mind". In written text, this inferencing about the shared knowledge can be gleaned by looking at the rhetorical and genre mode and hybrids, its linguistic features and structure.

Rhetorical genre analysis allowed me to look at the connection between the rhetorical type and the syntax the writer used in the written texts, this being

especially so with patient information or direction texts. The written text benefitted from constituent analysis which is used to identify the types of information that exist in written texts. Hunter and Franken (2012) in early analysis of cardio-vascular texts found a predominance of two types of information in these written texts: understanding the condition and understanding care. This is a helpful approach to interpreting written health care information. The matrix in Appendix 2 asks questions of texts and allows a descriptive narrative to be generated which highlights text features. This analysis follows in Chapter Six.

Aside from the texts in patient written information, there are also transcript texts from spoken discourse. These transcripts displayed in the thesis represent in an approximate way what took place. They represent a proportion of what was heard through the use of a simple orthographic format (Jenks, 2011) which represents words only. Most suprasegmentals, for example, are not included. I have also used rows to represent speakers and their dialogue. Pauses, unintelligibility, speaker emphasis, physical proximity and actions of the speaker have been represented by written text in a non-italic font separated from the transcript by square brackets. The ellipsis symbol (. . .) has been used for omission of dialogue.

As the patients were the primary actors in my research, and they agreed to share their intensely personal stories, it was important that their perspective was voiced as much as possible. For this reason transcripts of those stories are in italics.

5.5.2.1 Critical discourse

Each of the different data sets (text, context, and patient interactions) had and have required different approaches. The written patient information text used by patients were analysed by using critical approaches to discourse analysis methods and linguistic analysis (e.g., word order, coherence, turn-taking, modality, vocabulary). Questions to ask of the data were: What, if any, are the power differentials between the discourse participants? What is being foregrounded? What is the health care provider emphasising in text mediation and how is that being achieved? Coding in NVivo reflects these questions.

5.5.3 *Visual data*

5.5.3.1 *Picture/image use*

The simplified semiotic systems I used to analyse the use of pictures in the patient texts are taken from Scollon & Scollon, (2003) who rely heavily on Kress and van Leeuwen's earlier work. Viewing images/visuals through their lens resulted in analysis of the represented participants, the modality, and the interactive participants.

5.5.3.2 *Modality*

Modality, according to Kress and Van Leeuwen (1996) "refers to the truth value or credibility of (linguistically realized) statements about the world" (p. 155). When applied to the visual, this can manifest itself as "the appearance of things, on how much correspondence there is between what we can 'normally' see of an object, in a concrete and specific setting, and what we can see of it in a visual representation" (p. 158). Kress and van Leeuwen use the examples of colour depth, photo or picture depth, and detail as items of consideration when viewing the modality of pictures, with those pictures closest to natural or real as having the most modality. They concede that modality in pictures, like in language, is "realized by a complex interplay of visual clues" (p. 163) not the least of which is the cultural context the images are displayed in. Scollon and Scollon (2003, p. 91) for example, have found that reds in China and Hong Kong tend to have higher modality but in Korea, the higher modality colour is darker greens and brown. They comment that this is an area that requires further research to make any more comprehensive comparisons. However, it highlights the importance of context and its relationship to meaning.

5.5.3.3 *Represented participants*

Represented participants, or people in a picture, is based on the Kress and van Leeuwen premise that there are two participants in an image, those represented—the people, places or things (including text), and the interactive participants—"those that communicate with each other *through* images" (p. 114). Scollon and Scollon (p. 95) isolate three types of interactive participants which I use in analysing both text and visual images. The first is the interactions between the

maker of the image and the people or things represented in the image. The second is the interactions between the participants in the picture, and the third is the interactions between those representations or participants and the viewer/reader/user. It is in this third interaction that Kress and van Leeuwen, and Scollon and Scollon apply Halliday's *demand* and *offer* perspective. The orientation of the participants represented in the image to the viewer according to Kress and van Leeuwen (p. 120) directs whether there is a demanding of the viewer or an offering to the viewer. A direct stare to the viewer from the image demands interaction from the viewer. An indirect stare, no eye contact or body positioning on the other hand can denote an offering. This demand/offer can also be applied to text in discourse analysis when examining the sentence subject and objects and how they position the writer, the subject material and the reader. For the analysis of visual images, I used Scollon and Scollon's interpretation of Kress and van Leeuwen's approach.

5.5.4 Literacy practices

If, as Tusting and Barton (2005) contend, literacy practices "are situated in social relations, which are patterned by social institutions and power relations" (p. 250), then providing a wider view of the social institutions and power relations needs to be part of the data analysis. Data analysis therefore aims to present an account of how participants use literacy in their lives, to make sense of their lives and to get where they want to go. Tusting and Barton (2005) advocate extending local literacy observations more broadly, making visible things that are not easily visible. The hospital is a highly structured place with broader social, cultural and political contexts to literacy events. Bartlett and Holland's (2002) theorizing of the space of literacy practice as having three concepts: figured worlds, artefacts and identities, fit the analysis of this data set. Briefly, the figured world is an interpretation which is "socially produced and culturally constructed," (p. 12) and which is "invoked, animated, contested, and enacted through artefacts, activities, and identities in practice" (p. 12). The artefact is object/s "inscribed by the collective attribution of meaning" (p. 12) and can be physical or conceptual. In a hospital setting, patient notes or patient education texts and realia (e.g., physical models like the heart in Figure 5) may be an example. Identities, Bartlett and Holland explain, are developed in practice through the uniting of cultural and

social artefacts. They break identity into personal and positional, with positional being where “particular people are figured collectively in practice as fitting certain social identities and thereby positioned in power relations,” (p. 14). A personal identity is self-constructed. This theorizing is similar to Pavlenko and Blackledge’s (2003) identity varieties discussed in Chapter Three. Both approaches are taken in the data analysis, especially noticing the artefacts, and positional and personal identity formations.

5.5.5 Researcher reflections

NVivo allows the researcher to make and manage researcher reflection notes, and this is the practice I used during both data collection and data analysis. During data collection I used a voice recorder as well as a journal to make notes and keep records of visit times and places. During data analysis I reflected to capture my thoughts around coding in order to continue to keep trying to raise analysis beyond thematic, to the conceptual level. Holton’s (2007) direction that the skilled grounded theorist must be able to derive abstract concepts “by leaving the detail of the data behind” (p. 273) has been helpful in looking for themes and abstract concepts in the detailed data. Lempert (2007) also advises the use of memos or reflections in data analysis following the grounded theory format.

5.6 Scope

The parameters of the study are laid out below firstly pertaining to the patient and secondly to the position of the researcher in the research.

5.6.1 The patients

The situation patients find themselves in lying in a hospital bed demands the utmost respect for them and their space. For this reason I did not gather comprehensive data on numeracy or reading decoding skills apart from those practices I witnessed. I did not seek ethical approval to administer any reading or numeracy assessments because I considered it to be too invasive, and it would have undermined the social practices approach I was taking. Often a patient had a book or newspaper beside them when I arrived, so to set about with an assessment would have been a distraction. Numeracy did arise, in the discussion of blood test

results and in the understanding of nutritional labels. At these points, I was able to explore the participant's approach to numeracy and glean data from our conversation. Being in this space in the role of a researcher did not, I felt, give me the influence to formally assess a patient's literacy or numeracy. I was not offering them anything in return. I was not involved in their care or decision-making so the results were only of benefit to me, not to them. Like any new patient, I was an outsider in the hospital environment and a stranger to the patient I was sitting alongside; my presence was precarious and completely relied on the goodwill of the patient. For some patients, this goodwill evaporated during their hospital journey and therefore I finished with the patient prematurely but with others, the journey continued with repeat hospital admissions.

Additionally, because of the unstructured nature of doctor/specialist visits, I tried to arrange one patient to be involved in the research at any one time. I had to be available for both the medical and nursing consultations with the patients and these could occur at short notice and at any time during the day. I therefore did not want to risk having two patients at the same time.

Services at the hospital were split at admission. In-coming patients declared their ethnicity and on the basis of this were offered different services if they were Māori. This split was evidenced in the provision of cardiovascular services where Māori patients had the option of going to a Māori *kaupapa* ward and being managed by Māori staff or opting into the mainstream hospital provision for every other ethnicity. This difference in provision was most evident when engaging with clinical nurse specialists as there was a Māori and a non-Māori service, with funding and employment positions taken from the latter to set up the former. As I was mainly encountering patients in the AU, this sorting procedure had not taken place so I did encounter some Māori participants who had identified themselves as Māori and some who had not identified themselves as Māori, but were, and therefore remained out of the Māori service provision domain.

In addition, because I was only following patients who saw the cardiologists and the cardiac nurse specialists and therefore had a chance of receiving written text from these health professionals, I have no way of knowing whether the sample of

patients captured more patients who did actually receive written texts. I am not sure how many patients do not receive any written text before discharge.

5.6.2 Positioning the participant and the researcher

My experiences as a researcher in this hospital context are mirrored in Adler and Adler's (1987) observations. They outline potential membership roles researchers can have in the field. They range from complete observation to complete participation. And within those categories they recognize the overt and covert roles (p. 13). Adler and Adler consider the style that research takes depends on the setting, the field worker (abilities, characteristics, personal philosophies etc.), changes that occur in the setting while the researcher is there, and finally, changes that occur in the researcher him/herself while in the setting. Participation levels may increase or decrease, or not. Their observation was true in my case that "fieldworkers generally form a series of relationships with setting members in which select natives become respondents and key informants, helping researchers gain further insight . . . into the setting" (p. 13). The members in my context were the health professionals who supported me in the context by volunteering information and timing visits to patients at times I was available in the hospital. However, building confidence and relationship with my main participants, the patients, was often more difficult.

5.6.3 Researcher subjectivity and relationships

In the type of research undertaken, my movement within the hospital space and the establishment of relationships was complex and dynamic. Hospitals are highly structured places. The hospital, like any workplace has its share of gatekeepers both literally and figuratively. The hospital issued me with a temporary identification label which was different to a normal hospital employee. Uniforms are the currency of identification, reinforced by a ribbon necklace carrying a clipped on identification card. Dark blue for registered nurses, light blue tops for student nurses, mufti with or without white overcoats, or scrubs for doctors, food distribution workers in a different navy blue combination, patients in hospital pyjamas, orderlies in white, cleaners in blue, volunteers in black and white, clinical nurse specialists in navy blue bottoms with stripped light blue tops, physiotherapists—they all have their own clothing signature. Additionally, the

only identification available from the University of Waikato was my own student ID card. So as a researcher in this environment, I felt caught between two worlds. I wore mufti, the uniform of medical staff (or social workers) with a pin/clip-on nametag. This lack of affirmation affected the way I saw myself, initially. I was fortunate however, that I was in the hospital under the umbrella of a clinical school so I had a means of internal support to be introduced to the right leaders within the different wards. I arrived at the hospital mostly in the mornings which is outside of public visiting hours so access doors were locked. Hospital employees move easily in and out of areas using their swipe ID cards, but my ID card did not function in this way. Consequently, I had to make myself known on a continual basis to the administrator in charge of unlocking the doors.

My experience of being a researcher in this environment gave evidence to Fleischman's divide discussed previously in Chapter Three. There was minimal interest in my research by medical staff I encountered, but nursing staff showed more interest. When discussing potential research projects with a nurse specialist, she commented to me that unless her research had numbers in it, the doctors would not give her much support. I was continually asked whether I had a background in healthcare myself, which I do not. Creating my space was therefore at times challenging. Waiting in the specialised coronary unit's nursing/doctor area for medical or nursing staff to visit my participants was uncomfortable. My clothing suggested I was a member of the medical team; my identification card drew that into question, and I was surrounded by people discussing the complexities of other critical cases lined up outside the small office in the corridor-like ward. Additionally, chairs and space in these shared places are at a premium and so often I would have to stand or loiter in corridors. These in-between times gave me a chance to take a broader look at the environment. I would note the characteristics and use of the space I was in, photograph the proximity and content of any written material and, if I were fortunate, get into a discussion with a free nurse clinician about my research. However, as a researcher I had an awkward presence with clinical staff. I was with a consenting patient so clinicians tolerated me but I was never asked about my research or queried further beyond my initial email which introduced me and explained the research. Moreover, because the hospital operates on a rotating shift schedule,

nursing staff change day to day. I was fortunate because the unit managers were supportive of my research and facilitated my access to patients.

These contextual features outlined above as well as the constraints of the environment itself did affect the ease with which I developed rapport and trust with each participant. At this point I want to raise an (ethical) caution about the use of rapport and relationship in this context. As Maxwell (2012) states, rapport “may be an exploitative or oppressive imposition on the participant” (p. 101). It may be a manipulative strategy “to promote discourse” (p. 101). I believe that the study protocol mitigated this risk. My reflections were that patients generally accepted that I was part of the hospital (despite my ID card) though there were times when a participant would realise that I did not bring medical knowledge to the bedside and therefore could offer them few insights into their condition or care in exchange for the contribution they were making to my research. There was one such time when a participant enquired into my own health and what was going on in my life since he had shared so intimately with me. Slembrouck (2010) discusses this in terms of the ethnographic approach which comes with a commitment to “an explicit display of the participant perspective: the participant as a resource of knowledge and . . . not ‘talking’ data without returning something of immediate usefulness to the community” (p. 257). Talking to a patient at the bedside in the role of a researcher is a collaboration. There is construction of new knowledge and perceptions. Asking questions and enquiring was mutual between the participants and the researcher. The degree of mutuality was variable though depending on the particular patient. For some, my presence may have offered companionship. So, it was with a conflicted self-awareness I entered into the complex hospital system.

5.6.4 *The HeLMS survey*

Using the HeLMS survey as a data collection tool had strengths in that the development of the tool was based on solid evidence and statistical relevance, but obviously my sample group was not large enough to perform any meaningful quantitative analysis and nor was aggregated group data (the basis for quantitative analysis) of relevance to the study. One limitation of the survey is the type of reply it demands—levels of difficulty. Using levels of difficulty to measure if the

patient takes a family member or friend with them to a doctor's appointment for example, neglects a host of other associated issues around accompaniment. The underlying assumptions that literacy is geared towards an individual functional literacy in the HeLMS had to be taken into consideration in how I utilised it with patients. For this reason, I generally used the survey in a dialogic fashion.

5.6.5 Generalisability

There is much variation in opinion on the function of generalisability in qualitative research. The classic definition of generalisability is that causal relationships can be predicted "which are context-free, and their value lies in their ability to achieve prediction" (Lewis & Ritchie, 2003, p 267). Generalisability is not the goal of an ethnographic approach to research. However, as Lewis and Ritchie (2003) concede "a study which cannot support representational generalisation may still generate hypotheses which can inform and be tested in further research. It may yield material about a particular individual case which is of interest in its own right" (p. 266). This is a position supported by Maxwell (2012), "indeed the value of a qualitative study may depend on its *lack* [italics his] of external generalizability in a statistical sense; it may provide an account of a setting or population that is illuminating" (p. 142). I concur with Maxwell, and Lewis and Ritchie that the value is in the illumination of context under study which can lead to further research. It can provide a *thick description* (Lincoln & Guba, 1985).

Providing a thick description of the context and shadowing the patient as occurred in this research, coupled with conversations, amongst semi-structured and unstructured interviews curbs the concern around data that is just generated from interviews and therefore decontextualised. Taking an ethnographic perspective on data collection allowed deeper description of the context.

Looking at the informal grounded theory methodological approach and thematic analysis approach taken in this research, Glaser (2007) tackles the question of generalisability in qualitative research, dismayed that it is seen as dangerous. He maintains that using formal grounded theory, generalizing is safe to do because of how these core categories are generated in the first place where data

codes evolve to become substantive themes which in turn can have wider implications when viewed against other data and studies in similar substantive areas. This may be the case, however, there is a difference between findings being generalisable in the formal sense of the word, and having wider implications. The two are not interchangeable. In addition, I did not use a formal grounded approach.

5.6.6 *Credibility*

Credibility in this thesis is a term used interchangeably with validity. In qualitative research credibility examines aspects like adequate familiarity with the topic and well supported claims that are logically linked with sufficient evidence to support the reader following the tenor of the analysis. Maxwell (2012) however, is helpful in his treatment of credibility in qualitative research, or validity as he prefers to call it, debunking any calls for a check-list approach to credibility stating that that approach is “seriously flawed” (p. 129). Maxwell maintains that such an approach is a realist approach to validity because validity “pertains to the accounts or conclusions reached by using a particular method in a particular context for a particular purpose, not to the method itself” (p. 130). Heath and Street (2008) contend that researchers must lay out what they call decision rules: the decisions the ethnographer took in the location so that anyone else returning to the same situation would get a sense of the approaches taken. These decision rules, Heath and Street consider to be a vital part of validity. Previous chapters go to considerable lengths to outline the particular methods and contexts for studying the specific questions at hand. The previous sections on limitations as well as the detailed discussion of the research sample incorporate the decision rules used in this research. Many of these rules were guided by the protocol developed for the ethics applications as well as other ethical questions evolving as the research progressed.

5.6.7 *Dependability*

Reliability or dependability is closely related to generalisability and validity. It considers whether or not with a similar study using the same methods, similar descriptions, interpretations and conclusions would be drawn. Crotty considers

the naturalist researcher will give a useful interpretation but it will not necessarily be a “valid interpretation” (Crotty, 1998, p. 47).

This means that description and narration can no longer be seen as straightforwardly representational of reality. It is not a case of merely mirroring ‘what is there’. When we describe something, we are, in the normal course of events, reporting how something is seen and reacted to, and thereby meaningfully constructed within a given community (p. 64).

Being aware of these issues of subjectivity as a qualitative researcher is imperative hence the importance of outlining researcher subjectivities outright so that the reader is clear on researcher perspectives and beliefs as well as research methods.

5.7 Conclusion

This chapter’s description of the methods employed in my research has given an important context to data collection and data analysis. As well as providing detail of the practice of data collection, it has also discussed the application of generalisability, credibility and dependability to the style of research methodology I used. However, all of these are a reflection on the earlier chapters, especially my discussion of axiology and ontology.

Chapter Six: Findings – Patient Texts and Contexts

6.1 Introduction

The chapter begins with a broad description of the physical positioning of written text designed for public or patient consumption in the hospital environment. The physical placement of texts is an important element in establishing the context of literacy events and practices. To recall, a literacy event or activity in which a written text plays a role is used to understand a literacy practice which is “both the social practices of reading and writing and the conceptions or *models* [emphasis theirs] of literacy that participants use to make sense of them” (Street & Lefstein, 2007, p. 193).

A description of a selection of texts that were peopled during the research using the matrix in Appendix 2 follows. An account of the texts intertwined in the story of the patient-user and the health professional mediating them is contained in the following chapter. That account is a narrative of events—what was told for a specific purpose at a specific point in time in a specific context. That account also includes the mediation of the text by any health professional as well as the patients’ responses to the texts and reflections from the HeLMS tool. The developing themes around access to knowledge, patient agency and mediation of text take shape in both of the ensuing chapters and are examined in depth in the final chapter, Chapter Eight. Figure 6 is an overview of the people taking part in this study along with the major reason for their admission to hospital.

#	Cause	Sex	Age Range	Pseudonym
1	Heart attack	M	50–60	Mr Cox
2	Heart attack	M	60–70	Mr Ray
3	Atrial Fibrillation	F	60–70	Mrs Roberts
4	Heart attack	M	60–70	Mr Dan
5	Heart failure	F	70–80	Mrs Trent
6	Angina	F	80–90	Ms Lewis
7	Chest pain	M	60–70	Mr Frost
8	Heart failure	F	80–90	Mrs Newton
9	Heart investigation	M	65–75	Mr Shaw
10	Chest pain/ heart attack	F	60–70	Mrs Burns
11	Ischemic heart disease	F	60–70	Mrs Hunt

Figure 6: Patient participants with medical conditions

6.2 Physical location of patient texts

Consistent with Scollon and Scollon's (2003) view of physical spaces, it is pertinent to scrutinise the hospital landscapes that patient texts appear in to gain insight into how the texts are woven into literacy events and practices. Spatial positioning is a reflection of hegemonies and therefore examining the context from this perspective is important in deciphering the institutional and hegemonic processes at work. Flowerdew's (2014) discussion of context confirms the need to adopt a model of context which suits the particular goals of the study. The work done by Scollon and Scollon (2003) provides a scaffold to examine this aspect of text in context which they call *emplacement*. This is just one aspect of analysing a linguistic landscape, the calling attention to "language in the environment, words and images displayed and exposed in public spaces" (Shohamy & Gorter, 2009, p. 1). This section provides an overview on the location and positioning of written patient materials and details the spaces patients were located in when they took part in the research while in the hospital.

6.2.1 Assessment unit

There is a small space as you enter the AU from the front side of the hospital. Though this area is a hallway it presents as a small sitting area with a television on the opposite wall and some chairs for anyone to use. A television screens health educational programming at various times during the day. The space does not *belong* to anyone (Scollon & Scollon, 2003) in that it is not near an established office or room that would have patients waiting outside. It could be deemed to be *neutral space* although it does have a curtain at the end of the area, which is the first patient cubicle curtain (see the curtain rail in the corner of Figure 7).



Figure 7: AU hallway and the first patient cubicle

Curtains in these contexts denote privacy required. On the wall behind the position of the photographer in Figure 7 above is a notice board with staff related issues that have relevance for patients, for example, patient satisfaction survey results.

A common sight in many healthcare facilities is the wall hung pamphlet holder. This hospital was no exception. The photograph below illustrates the variety of texts available and the manner of display. This particular holder was hung to the right just at the entry to the unit by the AU reception desk.



Figure 8: The AU pamphlet holder

There are up to sixty different written texts offered on a vast array of topics, for example, immunization information, medical alarm advertising, health insurance, patient rights, pharmaceutical information, condition management information—especially for cardiac conditions, procedure information, advice on what to do when someone dies, and details of risk factors for illnesses. By and large the texts are offering passers-by technical and condition-specific information for patient procedures which are highly technical, for example, “ERCP [an endoscope procedure] at medical day stay,” “Atrial fibrillation,” “Cardiac catheterisation,” “Endoscopy,” “A guide to your PICC” (a peripherally inserted central catheter). There is scope for a lot of information with sixty filled pockets. The pamphlets with top and bottom borders are in-house publications—often simplifications of text produced by external health organisations or publication houses e.g., the Heart Foundation. There is limited use of pictures and images that demand eye contact with the public. They demand eye contact by giving the viewer/reader direct eye contact from the photo.

The pamphlet holder appears to be intended as a service for the public. It has information available for various groups who may care to stop and browse or

those who recognise the name of the specific condition and need the information. There are no signs directing the user how to interact with the information or any other form of mediation to a potential user. The position of the holder, in a neutral hall space with no obvious signs of ownership, may help the unaware passer-by assume that one can help oneself. The positioning of the pamphlet holder here is not likely to violate any expectations of users. A member of the public walking in would not be surprised to see this information available in this format in this place as written information is often presented this way in public hospital or health spaces. In this regard, according to Scollon and Scollon (2003), it does not *transgress* any community expectations of where “signs or messages may appropriately appear and where they may not” (p. 149).

Similar pamphlet holders are in other corridors and thoroughfares. The one in the cardiac unit (Figure 9) is in a controlled access area that one could only get to if admitted by the receptionist who is responsible for vetting visitors and unlocking the door.



Figure 9: Cardiology area hallway pamphlet holder

There are no chairs or other reasons to stop on the way down this corridor and, therefore it may not be appealing to the loitering family member or visitor as in other areas of the hospital. Again, the space is neutral—it is a thoroughfare. The positioning of both of the boards could be described as discrete in that there are no signs to direct passers-by as to what or how they may interact with the pamphlet holder. It is assumed that passers-by understand the information is free for the taking by whoever has the inclination or need to, perhaps the active seeker or reader—the passing patient or family member. It assumes a question or reason to be picked up. The patient needs to have a degree of agency to access them. A patient or family member needs to know the name of their condition to find the right leaflet, and as the data reveals, that is not always readily accessible.

There is another pamphlet holder in the family/patient lounge outside the locked doors of the ward. This area is a true lounge or sitting area where patients can go with their family or support person. That pamphlet holder was just being set up when I was on-site so the administrator was making decisions about what ought to be on display. By being in a room where patients and family gather, the space may encourage a different type of interaction with the written material to that of the hallway pamphlet holder. The patient and family room may be called *a special use space* (Scollon & Scollon, 2003) where the comfortable seating and tea making facilities allow different behaviours to that of what Scollon and Scollon would call *a passage space*, as in the previous examples.

The texts in Figure 10 below are located in an open shelf above the health professional's desk in a clinic room which is used to see out-patients. The room is used by both specialist nursing and medical staff and could be designated as a special use space. Added to that designation, the location of the patient pamphlets above the main desk implies that they are under the ownership of the office user, the health professional. There are no signs mediating the information to the patient or giving advice on how the pamphlet holder can be interacted with.



Figure 10: Patient texts in a hospital out-patient clinic room

Aside from texts given to patients by health professionals, the physical placement of written patient texts in the hospital environment has no other mediating signs or messages accompanying it. Scollon and Scollon (2003), when looking at public spaces and how discourses and social interactions are located in this “material world” (p. 169) identify a continuum between “highly designed and controlled places where only certain clearly defined social actions and interactions may occur . . . and much more loosely designed and loosely controlled places” where a variation of interactions can take place (p. 169). The locations of pamphlet holders, except in the out-patient office, are in predominantly neutral spaces with no other surrounding signage. A user would need to have enough background knowledge of what the behaviour expectations of the hospital were in order to recognise how to interact with the pamphlet holders. In areas where there is a seat or chairs near the pamphlet holders, there is perhaps more incentive to browse as the space moves on the continuum towards a special use space.

6.2.2 Other text occurrences

Apart from these public displays of varying information leaflets and booklets located in the pamphlet holders, written patient texts were, by and large,

entrenched in specific health care practices. As Papen (2010) found, patient texts were used as part of a nursing ritual. Within cardiac services of the hospital, the ritual was that the medical specialists deliver the diagnosis and a nurse specialist follows-up, usually with some sort of written text to give the patient. As evidenced by the pamphlet holders, the availability of written health information for patients is often controlled, requiring a more knowing other to mediate the contents of the booklet to the patient. This is another practice which provides insight into the context of literacy events in this hospital.

6.3 Written text administration

To explore other external contingencies regarding how and who made decisions on what printed information was available in the pamphlet holders, I spoke to administrators and nurses. One cardiac specialist nurse (CNS) was responsible for regularly checking what was available in the assessment unit and in the ward where many cardiology patients were transferred. She had been unable to do this work over the preceding months due to staff shortages and the low priority of the work. The pamphlets that she did take responsibility to stock in publicly accessible holders were the “Angina, Are you at risk?” pamphlet, and in the ward, the “Healthy Activity” pamphlet sourced from the Heart Foundation of New Zealand. She did not have anything to do with the pamphlets in the two other areas of the hospital used for cardiac patients. Her impression was that the cardiac pamphlets went quickly and she was not sure that it was actually the patients themselves who took the pamphlets or what they did with them.

Another CNS was aware that there were four major pamphlets available publicly—one concerning angina management, another on preventing heart attacks, another on exercise and another on heart failure. She initially said if people did not need to know, then why provide them. She then reconsidered and decided that if they were available and people were interested, then they could learn if they wanted to. Conversations with a senior nurse concerning the role of written text perceived it to be “fill(ing) holes.” She also had concerns whether the readers perceived the information the “right way.” Considerable effort had gone into updating and rewriting pamphlets for the public spaces and for use with patients. Any cardiac pamphlets with dark borders were produced in-house by the cardiac nurse

specialist team and were often intended as simplifications of previous more detailed, complex or out-of-print brochures.

Both administrators of the AU and cardiac unit had the responsibility for keeping the pamphlet holders stocked with all leaflet types and genres. In one area, a nurse had been assigned to help with the decision-making around this task, but worked part-time so had made only limited progress when this study took place. It was reported that other nurses would also request pamphlets if they noticed gaps or had a particular request. The administrators, neither of whom had clinical backgrounds, reported they were guided in pamphlet selection by their intuition, their institutional knowledge and the occasional requests from clinical staff. Occasionally a member of the cardiology medical team would request that a specific pamphlet on a cardiac procedure be made available. Conversations with an administrator from a different area of the hospital revealed similar experiences. The administrator, also from a non-clinical background, had had little guidance as to what should be displayed. She had ordered and stocked one 60-pocket holder in the corridor (see Figure 9) and did it according to what she felt were important to the hospital, using her own institutional knowledge. She had then sought approval for her choices from the charge nurse manager. She had been asked by a cardiac nursing professional not to put out all of the pamphlets pertaining to heart care as the nurse specialist considered some patient booklets needed to be given to patients by a nurse or other health professional. This was the case with the “Staying Well with Heart Failure” booklet. The most popular items in the pamphlet holders from the administrator’s perspective (she kept a tally of numbers) were the booklet giving advice on what to do when someone dies and the pamphlet on suicide. The next most popular was the ETT (exercise tolerance test) and TOE (trans-oesophageal echocardiogram) pamphlets (both about patient procedures) then Heart Foundation booklets, followed by Accident Compensation Commission (ACC) information and travel assistance. She had noticed that families, not patients, traditionally had used the pamphlet holders but now with the new cardiac unit layout, patients themselves did wander about more and were picking up some reading material.

One administrator felt she was doing the ordering of the pamphlets by default and felt it was rare for her to stock up the holder. When asked what was missing from the four gaps in the pamphlet holder, she was not sure as the types of written material available were not part of any information strategy, but whatever was at hand. So there seemed a degree of convenience in the pamphlet inclusion or exclusion.

The process for ordering from a range of potential pamphlets or information leaflets presented barriers. The administrator needed to know the specific name of the pamphlet she wanted to order. She searched for example, under the term 'cardiology' and had a nil return on any printed matter available on the system she was using. Consequently, the administrator was not sure what was missing, and what was potentially available, making what was in the pockets very changeable. There was access to an in-house design and print centre as part of the hospital where *.pdf* documents could be formatted and printed. The unit had just recently completed the production of an in-house welcome leaflet which healthcare assistants endeavoured to put on the bed pillow for each new patient. The text was not mediated by anyone so did not form part of the text data set. One of the initial patients in the study had to have an ETT soon after admission and received oral instructions and descriptions about what was going to happen to him, but at that stage there was no written material to back up this information giving session. Soon after, a simple ETT pamphlet appeared which had been produced in-house once the absence of a text had become apparent. Figures 8 and 9 show a large number of in-house publications.

6.3.1 Additional insights from corridor conversations

Other insights into the broader context of written text came from various conversations with individuals I met while on site during data collection. A nurse educator from a different area of the hospital who had heard about my research wanted to give me her thoughts and experiences. She felt strongly that the written information provided in the booklets and leaflets was far too general, and did not include enough meaningful, specific examples that readers could relate to. She wanted to know what it meant to say to a 30-year-old that smoking would decrease their life by 5 years. She maintained that for a person of that age, this

did not mean a great deal, Rather, calculating the cost of smoking for example over a month made it more real, or relating smoking to a specific health problem the person was having and explaining its relationship made more sense. She also recounted patient reactions to the glossy, colourful patient information booklets she was dealing with in her sector, comments like, “Oh, looks too flash for me.” She had witnessed patients who did not seem to have faith in the written material, despite the “sweating of blood” which went into their production. Her approach was to break the booklets down to one page or one key paragraph when mediating them to the patient. Patients she came across who could not read would tell her they would get family members to read it to them.

She felt strongly that there were many missed learning opportunities in acute settings where doctors and nurses under-estimated the huge impact they could have on a patient’s learning and understanding of their health and their condition. She believed there was a lot of evidence to support this meaningful impact on patients by health care professionals in the acute setting. Research by Flocke and Stange (2004) support this observation. They concluded that, “patient recall of health behaviour advice is enhanced by longer duration of advice and by linking advice to visit contexts that represent teachable moments” (p. 343). This thesis is exploring text from a patient’s perspective rather than the practitioners, but the corridor conversations did serve to give further insight into the context written patient texts were being used in. It is to the text themselves that we now turn.

6.3.2 Written text given to patients

As previously evidenced, the amount and scope of cardiac patient information available in the public hospital setting was variable, often difficult to access and, for most patients, was mediated by nursing professionals. Appendix 1 is a list of the written texts given to patients during the study and which therefore became part of this research. Some texts given to patients by health professionals were not available in any other setting or place in the hospital aside from that consultation.

This section will look at a selection of those texts given to a patient which held some significance for that patient. It will use the matrix in Appendix 2 to examine

the texts. It will also look at the availability and mediation of the texts. Other particular texts will be examined in the following chapter as a part of a patient's story.

6.4 Staying well with heart failure (2010)

6.4.1 Text availability

The "Staying Well with Heart Failure" booklet was not available to the public from a wall-hung pamphlet holder. However, there was one similar called "Living with Heart Failure" in a pamphlet holder in the cardiac unit corridor. The absence of the booklet, "Staying Well with Heart Failure" from publicly available holders reflected the view articulated by the lead cardiac nurse specialist that it was a text they should give to the patient. The reason offered was that the booklet was both instructional and informational with interactive text that sought both patient and clinician involvement. Examples of how the booklet was actually used are outlined in Mrs Trent and Mrs Newton's stories in the following chapter. One of the patients was a hospital in-patient while the other had been an in-patient but received the booklet in her follow-up outpatient appointment session. I was present in this outpatient appointment and recorded the proceedings. The other mediation of the book was recounted to me later by the in-patient.

Prior to looking at the broader literacy practices surrounding the use of this text, an analysis of the text itself is required to ascertain the nature of the text, its features and its literacy and numeracy demands.

"Staying Well with Heart Failure" (2010) is a 52-page, A4 booklet developed by the Heart Foundation Heart Failure Guideline Team and published in 2010. The team has acknowledged and drawn extensively from a booklet entitled "Heart Failure Intervention", which was developed in 2007 by medical related personnel at three North American universities. The booklet was available on-line until mid-2012 when a new and longer version of the booklet was introduced.

6.4.2 The text

This booklet's primary function is to inform its assumed audience, the patient, how to *stay well* with heart failure, assuming perhaps that the patients are already

well. The booklet is a hybrid of genres—primarily informational and instructional (Bax, 2011, p. 53), but with large segments of the text designed to be filled in or notated by the reader/s. The 2010 edition states “Ask your doctor or nurse to go through this booklet with you and if there is anything that you do not understand, they can answer your questions” (p. 4). The booklet beckons interaction from both the patient and the healthcare provider with the inclusion of space, questions, tick boxes, and empty lines calling for information. For example, the text directs the reader to prioritise their information needs by reformulating the contents page into a ranking of the things most important to the reader to find out about. In another example, guidelines on medication give a lot of information about managing pill taking, what the pills do, dosage rates, for example, and then it tests the reader’s understanding with an agree/disagree set of questions with answers elsewhere, e.g., “It can be dangerous to suddenly stop taking your pills” (p. 19). The constituents, understanding the condition and understanding care are managed across eight chapters, covering a plan, condition explanation, medication, diet, daily condition management, living guidelines and getting further help. The booklet uses coloured tabs to organise the different sections making it easier to navigate.

6.4.3 Pictures/visuals

The simplified semiotic systems I used to analyse the use of pictures in the patient texts were taken from Scollon and Scollon (2003). See Chapter Five, section 5.5.3.1.

The booklet uses line and block colour illustrations with the front cover featuring a woman holding a child’s hand, and a man walking a dog on a leash. The man and the dog are walking behind the woman and the child. The scene itself is credible but the modality of the illustration is limited because of the abstract way that the characters are presented. It is not engaging as nothing is demanded of the reader because the of characters’ positions. There are few clues of the interaction the participants have with each other except that the woman and the girl are in bare feet, and the man is not. The dog is carrying a stick in its mouth which could suggest someone is playing throw and chase games with it. Little is also being

offered by the picture except that a heart failure sufferer may still perhaps hope to go for a walk on the beach or walk their dog with their family.

Other stylised illustrations are used throughout the booklet with varying levels of interaction between participants and with the written text. A cartoon strip is also used to illustrate lifestyle management. It depicts direct speech between a man and his family on a topic that is real to life, for example, “The family feel more relaxed when I take my mobile with me when I go for a walk” (p. 37). The illustrations are pen and block colour but linked so closely to the accompanying text, they have a high level of modality—“the truth value or credibility of (linguistically realized) statements about the world” (Kress & Van Leeuwen, 1996, p. 155). Headings are consistent and colour coded with each chapter having a different colour. Illustrations seldom allow for identification of a particular ethnicity. Varying skin colours are displayed, perhaps sending the message that heart disease affects people from every walk of life.

6.4.4 Lexical choice

It is immediately apparent that there is a considerable focus on the second person singular. *You* is the second highest occurring word in the booklet of 8367 words, occurring 307 times (in either subject or object position). *Your* has 253 appearances. This focus on the other participant (the patient) is typical of text in instructing mode where the second participant is “typically silent and implied” (Bax, 2011, p. 77). The genre expectation for this booklet is set-up by the title—“Staying Well with Heart Failure.” It is an instruction booklet on how to do this. It is also strongly interactional. It does invite and display participation with the spaces and questions for dialogic interactions and what appear to be direct quotes, e.g., “You can have more energy for the things you enjoy doing by making small changes to your daily routine. Use the ‘Plan for change’ on page 6 to help you make changes to your daily routine” (p. 39). This text is directly supported by a comic strip story relaying a patient’s experience of planning his daily routine as well as a direct quote from a supposed heart failure sufferer which states “I used to feel exhausted after my shower. Now I put on my towelling dressing gown to dry myself and sit down to get dressed. Then I can enjoy breakfast.” These patient voices often acknowledge patient stresses or difficulties in dealing with

heart failure and offering support or reassurance: “I couldn’t believe the difference that cutting down salt made to me. I was able to cut down on my water pills” (p. 21).

Nearly 80% of the vocabulary used in this over 9000-word booklet is within the first 1000 words of English (Nation, 1990) with a further 11% of the vocabulary being low frequency words. Many of those vocabulary items pertain to the human body or are medical terminology needed to understand the condition, for example, *ankles, wheeze, heaviness, angina, or symptoms*.

6.4.5 Transitivity

Examining the verbs used in the booklet, and categorizing them according to Hallidayian transitivity or verb processes, as interpreted by Janks (2010, p. 68), it is useful to note that over two-thirds of the verbs used in the “Staying Well” booklet are *material* verbs which in Hallidayian terms means they are action verbs or types of doing verbs (e.g., *plan, pack, stay*), with the bulk of the remainder of the verbs being relational: the verbs *be* and *have* are used to establish relations of identity and possession. The high use of material verbs suggests an expectation by the writer of the reader being able to act, to be active, to have agency, to be involved. This analysis supports the aim of the text, that it is instructional and interactive.

6.4.6 Assumptions

The booklet assumes the presence of supportive family or friends and access to an available nurse or doctor who “can help you to make the ‘Plan for change’” (p. 5). It does not assume that the reader has knowledge of specialised medical terminology as it defines such vocabulary items as they are introduced by reformulating the technical term into plainer language, “cardiomyopathy (disease of the heart muscle), abdomen (tummy)” (p. 9). It appears to make an assumption of limited comprehension ability on the part of the reader as it uses a mix of simple, compound and complex sentences where necessary and layout techniques of bullet points and illustrations to help comprehension (p. 26).

The Staying Well with Heart Failure booklet presents as a patient text which is actively promoting patient engagement and providing encouragement to the reader.

6.5 Managing your angina



Figure 11: “Managing your Angina” in a pamphlet holder

6.5.1 Text availability

Aside from being available from the cardiac nurse specialist team, the pamphlet also featured in the publicly available pamphlet holder in the hospital. However, according to reports from the administrators who were responsible for re-stocking these pamphlet holders, this pamphlet was not mentioned as one taken by many people from the public areas.

6.5.2 The text

The “Managing your Angina” pamphlet is an A4 eight-sided fold-out styled leaflet. It is produced by the Heart Foundation of New Zealand. The pamphlet follows an established information constituent pattern (see Appendix 2) including elements from both the understanding of condition and understanding care. The

heading structure chosen begins with a conversational style with the question and answer format but this is not consistent across the pamphlet and in fact only four of the twelve headings use this format. The remaining subheadings position the patient as the recipient of the information, the reader who needs to know and is told. The text is a mix of genres, primarily instructing (Bax, 2011, p. 92) and informational (Smith, 2003).

The representation of “social actors” (van Leeuwen, 2008) in the text is interesting because of the degree of the exclusion of the agent, or sufferer of angina and the foregrounding of angina, the condition, as the central agent.

6.5.3 Lexical choice

The prevalence of passivisation (lines 2, 6, 10, 11, 16, 21) brings an impersonal representation to the angina sufferer. It places the disease in the subject position perhaps to maintain the author’s authoritative voice or as a reflection of a deeper theoretical position on disease where a disease is itself an entity (Cassell, 1994, p. 93, p. 138) and the person suffering from the disease is a silent participant. Cassell considers that if diseases are given entities, and if viewed ontologically, with “the patient . . . at best an unlucky and unhappy container of the sickness—it would not matter much who had it, the effect would be the same” (p. 93). When the central agent, the angina sufferer, is featured in the text, he or she is obscured by generic references to *people* and indeterminate references to *some people*. Both of these position the sufferer as the unknown other. The choice to use the definite article (line 10) to describe an angina patient’s chest centre again removes

What is angina?

1 Angina is a common symptom of heart disease. It
2 is usually described as a discomfort or unpleasant
3 feeling (sometimes like indigestion), tightness,
4 pressure or weight on the chest and sometimes a
5 feeling of breathlessness. Angina usually only lasts
6 a few minutes and can be relieved by rest and/or
7 medication.

8 *Angina can affect people in different ways*

9 The symptoms may differ at various times, but it is
10 usually felt across the centre of the chest. It may
11 also be felt in either or both shoulders, the neck or
12 jaw, down the inside of one or both arms and in the
13 hands. Some people experience it in only one of
14 these areas and not in the chest at all.


15 *What causes angina?*

16 In most cases, angina is caused by coronary artery
17 disease. This occurs when fatty deposits build up
18 under the inner lining of the coronary arteries,
19 which supply blood to the heart muscle. As a
20 result, these arteries become narrowed and the
21 blood flow to the heart muscle is reduced.

the focus away from the sufferer of angina. The use of the third person (line 1, 10) also creates a sense of objectivity, despite the high degree of uncertainty surrounding the recognition of angina symptoms and the difficulty a sufferer may have in identifying their own angina symptoms. There is a sharp contrast in the next section (see Figure 12) where the constituent switches to understanding care and the patient is directly addressed in a switch from third to second person. There is also frequent use of imperatives (e.g., *stop, sit, take*) reflecting an instructional voice from the writer. Beside this action plan is a photograph of a man and woman, both wearing day packs and resting after what looks like a climb or walk up a hill. They are smiling and are sitting against a backdrop of blue sky and sunshine. Their carefree image seems at odds with the patients I saw using

this text (as is discussed later). There is very little modality in this section and what is there is deontic (obligational) modality (Fairclough, 2003).

The lexical density (Clerehan, Buchbinder & Moodie, 2005 & Appendix 2) of the second sentence is 4.5 when the goal is to be under 4. Lexical density is the number of content-bearing words per clause. The choice of vocabulary is also interesting. The writer has chosen *resume* over *begin* and *persists* over *carry on* or *continue*, lexical items that are less frequent and likely to be less well-known.



Angina symptoms (occasional)	Action
<p>When you get angina, stop what you are doing, sit down and take action.</p> <p>When the angina is relieved by rest, or by your GTN spray or GTN tablet, you can resume your activities gently.</p>	<p>Take 1 puff of your GTN spray or 1 GTN tablet, under your tongue. If the angina persists, you can repeat the dose safely every 5 minutes.</p> <p>But, if the angina is not relieved after 2 doses in 10 minutes – call an ambulance. DIAL 111 IMMEDIATELY.</p>

Figure 12: Angina action plan

Below are the instructions for the use of glyceryl trinitrate (GNT) spray (which is actually nitroglycerin) taken from the pamphlet.

- 22 GNT spray gives a metered dose each time the button is pressed. The spray
 23 droplets are absorbed quickly and give an almost immediate effect. When
 24 you use your GNT spray, remember:
- 25 • Do not shake the canister
 - 26 • Hold the canister upright
 - 27 • Spray 1 or 2 puffs on, or under, the tongue
 - 28 • Close the mouth

This extract of text is instructional and positions itself as knowledgeable. There are no devices used here that introduce any subjectivity or modality. The imperative voice is used in directions with no modality in other verb phrases. There is a continued back grounding of the agent with the continued exclusion of

the central actor in the first two sentences. The choice of *metered dose* (line 22) reinforces the gap between the institutional voice of authority and the everyday discourse of the patient.

Using Pavlenko and Blackledge's (2003) theory of positioning, the identity given to the reader here is imposed. The expected reader is someone with angina who is reading how to manage angina, the information contained in the pamphlet. There is perhaps some softening in the extract above for example, with the use of the conditional clause *when you use...* and the use of the second person pronoun, *you*, which could have a softening effect, prior to the imperative *remember*. However, by and large, the pamphlet is instructing (Bax, 2011, p. 92) and informational (Smith, 2003, p. 252).

6.5.4 Visuals

The text (see Figure 11) has three photographs. The front cover features a photo of a man and a woman walking along the beach in bare feet, shorts and t-shirts. They are looking at each other's faces, oblivious of the camera, and seem to be sharing a joke. There is a noticeable height difference between the two of them. The couple are not engaging or confronting the reader and the style of the photo is high in modality, as it suggests trustworthiness and credibility. The picture on page one of the pamphlet again features a man and woman's head and shoulders. They are both wearing sunglasses and wearing a backpack. The man has a t-shirt on and looks to be in his late 50s, with grey hair and a grey beard. The woman has a singlet on and looks of a similar age. The whole of page one is printed onto the sky behind the couple, suggesting they are on top of a hill or mountain. There is a wind blowing their hair to one side. They are smiling and looking at the camera. The photograph is of a normal scene. There is nothing about the scene, or the setting or the participants which is out of the ordinary. It seems credible. The engagement with the reader by directly looking out of the photo is softened by the tinted sunglasses, thus softening any demand they may have on the reader. Rather, the photo could be offering vitality and happiness from one or both people managing their angina conditions. The third photograph used in this pamphlet is that of a grey-haired man holding a two or three year old child around her middle. He is looking at her and laughing (we cannot see his eyes) and she is happily

looking into the camera. The relationship between the two participants seems to be one of mutual enjoyment and happiness. He could be her grandfather and he could be tickling her. The coat she is wearing is the same colour as the red of the pamphlet. Again, this is a situation that we would normally see. The engagement of the child with the reader could be an invitation to also enjoy the moment she is having with her grandfather. All of the participants in the photos are smiling or laughing. This could be an offering made by the pamphlet writers that happiness is still available to people with angina. This offering using photographs of normal people doing normal things could add to the sense of truthfulness and credibility the pamphlet seeks to bring.

6.6 A Guide to recovery after a heart attack (2011a)

6.6.1 Text availability

This booklet was not mentioned as being publicly available in pamphlet holders for the public and I did not see it available publicly. The booklet was part of the hospital acute coronary pack given to patients who had had a heart attack. It came with leaflets on food label reading, a risk factor action plan, an at-home plan, a questionnaire about healthy diets, an invitation to the cardiac rehabilitation classes, healthy eating for your heart, further contacts for regional cardiac support groups, an exercise diary, what's in a label leaflet (a how-to on food label interpretation), and a course evaluation questionnaire. This pack was sometimes given to patients when a nurse specialist visited them in hospital or at the rehabilitation classes if they attended.

6.6.2 The text

The text is a 42-page booklet which is both informational and instructional in its genre (Bax, 2011, p. 53). It achieves these functions in a number of structural ways. It is divided into three chronological sections. The first is entitled *your stay in hospital*, the second is *planning for home*, and finally, *welcome home*. The introduction states the booklet has been written to “help you and your family understand what a heart attack is and to assist you on your road to recovery” (p. 2). It adopts a predominantly information approach, with headings and sub-headings which seem to follow an inconsistent hierarchy in terms of heading

colour and size. The structure has a mix of questions and answers throughout the text, as well as some opportunity for readers to interact with the text through answering questions or filling in charts monitoring dietary intake or physical activity. There is a quiz which tests the patient's understanding of their heart condition and space with invitations to readers to write in the book. The colours used in the booklet (the Guide) are black for text and shades of red for headings and alert boxes.

6.6.3 Lexical choice

It is interesting to note that for the first section of the Guide, over 76% of the first 2470 words are in the first 1000 English word list (Nation & Waring, 1997), another 8% in the 1000-2000 word list and 11% are technical vocabulary and/or low frequency. For a closer examination of the discourse used in the booklet, the stopping smoking section (p. 39) is analysed below.

Stopping smoking

Stopping smoking is the most important thing that you can do for your health. Stopping smoking is something you can do for yourself, your family and friends.

Where's the harm in smoking and second-hand smoke?

Smoking and exposure to second-hand smoke is damaging to your heart health as well as your general health. It:

- Damages the lining of blood vessels, causing narrowing of the arteries
- Reduces the ability of the blood to carry oxygen
- Makes the blood stickier than it should be.

All of these changes can lead to blocking off the arteries to your heart and brain.

jargon alert: second-hand smoke

About two thirds of the smoke from a cigarette is not inhaled by the smoker but is released into the air. That smoke mixes with smoke exhaled by the smoker and the combination is called second-hand smoke.

If you don't smoke you may still be exposed to second-hand smoke, therefore it is recommended you avoid being in smoky indoor and outdoor spaces.

What are the benefits of stopping smoking?

It is never too late to stop smoking.

- Stopping smoking reduces the risk of having another heart attack by half within the first year of stopping
- Within just one day of quitting, your chance of a heart attack decreases
- Within two days of quitting, your smell and taste are enhanced
- Within two weeks to three months of quitting your circulation and lung function improves
- The risk of having a heart attack reduces to the level of a 'never smoker' within 5 years.



hot heart fact

Stopping smoking is the single most important thing you can do to manage coronary heart disease.

Figure 13: Excerpt from “A guide to recovery after a heart attack”

This excerpt of text attempts to persuade the reader to stop smoking. The writer wants to encourage the reader to give up smoking or those around them to give up smoking if they are exposed to second-hand smoke. Persuasion, according to Bax (2011), uses lexical resources, verbs, nouns, metaphor and pronouns to motivate or argue. There is also the use of structures typical of description, according to Jeffries (as cited in Bax, 2011). These structures include the subject/predicate/complement clause structure especially with the use of the verb *be*. We see this in the first three sentences of the page: *Stopping smoking is...* The text then moves on to using verbs of change: *demand*, *reduce*, and *make*. There is also the use of the simple present tense throughout, another feature of descriptive texts.

The section on the benefits of stopping smoking is clearly persuasive. Again, there is strong use of verbs of change: *reduce*, *decrease*, *enhance*, *improve*. An acknowledgement of why someone would not want to give up smoking, or the challenges of giving up is positioned in a less direct way in the following page (see Figure 14) where the text changes to become more instructional.

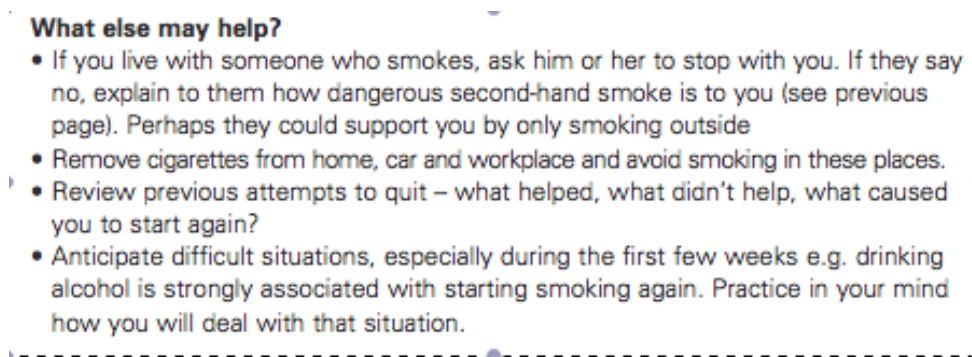


Figure 14: Excerpt from “A guide to recovery after a heart attack”

Figure 14 gives an example of one of the ways the text makes use of the interacting discourse mode by the use of questions which is part of turn-taking strategies (Bax, 2011, p. 87). Obviously the text continues and answers its own question thus continuing the instructing and describing modes. The answers to the question are in an instructing discourse mode, as can be seen in the use of imperative forms of the verb: *remove*, *review*, and *anticipate*, for example.

The text also attempts to position itself with the person giving up smoking by giving directions for managing resistance to asking any smoking co-habitant to smoke outside. The “bureaucratic objective” (Fairclough, 2003) of the authors is to inform the reader with the view to changing their behaviour from smoker to non-smoker, to bring them “into line with what is medically ‘correct’” (Dixon-Woods, 2001, p. 1419). Using Dixon-Woods’ *patient empowerment/patient education discourse analysis*, this booklet sits more comfortably in the patient education discourse. However, the framing of the information is done in a way that could on the surface facilitate the empowerment of patients. The three stages—*in hospital*, *preparing to go home* and then *at home* are a realistic representation of a patient journey. However, there are not many avenues in this booklet for the patient to be anything other than a recipient of knowledge.

6.6.4 Intertextuality

Intertextuality examines texts for their dependence on other texts, or the way other texts can be seen to have contributed to the knowledge within the particular text. In the section on *while you are in hospital*, the discussion of assessment includes a description of tests that a patient is likely to have and these include “a regular check of your pulse, blood pressure and temperature” (p. 7). Pulse and blood pressure and temperature (Figure 15) are then defined but no information is given concerning interpretation of the results. The discussion assumes reader knowledge of what a good blood pressure reading looks like, or what the average body temperature and the average pulse rate should be. Or, the text assumes patients do not need or want to know this information.

This booklet is more in keeping with the hospital experience where a patient’s temperature is taken and recorded in patient notes, which are available to the patient only if he or she requests. This is further evidence of the booklet being categorised in Dixon-Woods’ patient education discourse category.

Tests are likely to include:

A regular check of your pulse, blood pressure and temperature.

- Pulse - the number of times your heart beats each minute
- Blood pressure - the pressure in your blood vessels. This helps assess how hard your heart is working. A blood pressure reading gives two numbers, **for example** 120/80

When the heart pumps, it produces pressure inside the blood vessels and moves the blood forward (this gives the top number known as 'systolic' pressure).

120 / 80

Then the heart relaxes as it fills again and the pressure falls (this gives the bottom number known as the 'diastolic' pressure).

- Temperature - your body temperature may be a little higher than normal for a day or two after your heart attack.

ECG (Electrocardiogram)

Figure 15: Extract from “A guide to recovery after a heart attack”

6.7 Atrial fibrillation: Information for you, and your family, whānau and friends

6.7.1 Text availability

This text was used in response to the cardiologist’s diagnosis of atrial fibrillation in Mr Ray. It was not available in public pamphlet holder in the areas of the hospital I frequented as part of my study. However, the simplified version produced in-house as an A4 folding leaflet was on display. As was the established practice, the nurse specialists provided this particular text to Mr Ray. In this instance, the text became part of a chain of texts that were used as the patient’s diagnosis changed and as more tests were carried out.

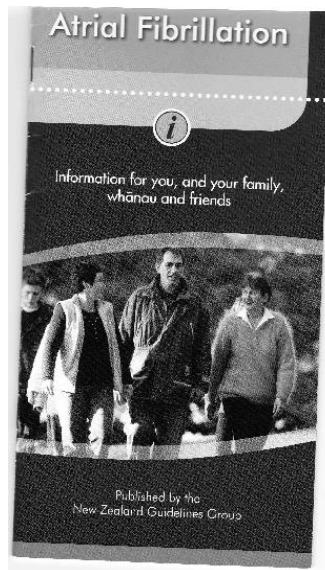


Figure 16: Atrial fibrillation leaflet

The comprehensive booklet was published by the New Zealand Guidelines Group (NZGG) in 2006, which went into voluntary liquidation in mid-2012. NZGG when producing the booklet, based it on an evidence-based guideline on atrial fibrillation published in 2005. When queried about these two versions of the same information, the nurse using the information booklets said she decided which one was best suited to each patient, depending on her perception of their inclination to read.

6.7.2 The text

The text is an 18-page booklet of around 2400 words which begins with a list of contents and a definition of the condition. It moves to a stated purpose for the booklet, “to help you better understand your condition and how it is best managed” (p.1) and the major risk factor. The text then moves to a deeper understanding of the condition, using labelled diagrams of the heart, one with and the other without atrial fibrillation, with a more in-depth definition of the condition following. A question and answer format is used throughout most of the booklet. Description of the condition continues with comment on its prevalence, causes, symptoms, and effects. At that point the booklet moves to understanding care or management of the condition and the safety or risks of the proposed interventions. There is a summary of use, side effects of medication, when to seek medical advice and sources for further information. It follows

closely the understanding condition and understanding care constituents outlined in Appendix 2.

This snapshot of the patient booklet displays the one invitation to the reader to write something in the booklet as it suggests to the reader to “fill in with your doctor” the INR or International Normalized Ratio, which is a measure of blood thinness:

The image shows a page from a patient booklet. At the top, the title reads "WHAT IF I NEED TO BE ON WARFARIN?". Below the title, there are several paragraphs of text. The first paragraph states: "If you are taking warfarin, you will need regular blood tests to make sure that your blood is thin enough to protect against stroke, but not so thin as to cause bleeding problems." The second paragraph explains: "A simple blood test will check how thin your blood is and calculate your International Normalized Ratio or INR. Your doctor will advise you what your target INR range is. A common target INR is 2.5 with an acceptable range of 2.0–3.0." Below this text is a form box with the heading "My target INR is: (fill in with your doctor)". The form has two input fields labeled "Value" and "Range". To the right of the text, there is a highlighted box that says: "It is important to let your doctor know if you might have trouble getting to the laboratory or clinic for your blood tests." Below this, another paragraph discusses home monitoring: "Home monitoring of INR using a personal monitoring device is easier for some people than getting to a hospital or clinic, but the device and testing strips will cost money. Even with home monitoring, you will still need to have your warfarin dose managed by your doctor. For more information about home monitoring of INR, ask your specialist." At the bottom of the page, there is a small photograph of two people, a man and a woman, looking at something together.

Figure 17: Extract from “Atrial Fibrillation: Information for you, and your family, whānau and friends”

The writer has adopted a descriptive narrative in this section. The subject of the action is often removed from the patient. For example, “Your doctor will advise you what your target INR range is” and further on, “Your doctor will adjust the dose of warfarin according to your INR results.” Both of these events place the patient in a passive position, the receiver of the doctor’s knowledge or the doctor’s action. The box to record the target INR is the only place in the book that invites reader interaction. The highlighted box requesting that the patient inform their doctor of any laboratory access difficulties is followed up with advice on home monitoring and informing the reader that warfarin management is the doctor’s responsibility. “Even with home monitoring, you will still need to have your warfarin dose managed by your doctor” (p. 14). However, elsewhere in the booklet discussing management of the condition, the assumption is made that

there will be a professional/patient partnership when deciding on management. “It is important to balance the benefits and risks of blood-thinning treatment. These vary between individuals and are a matter of judgement. Your GP or specialist will help you to decide which treatment is best in your case” (p. 10). There is a diagram of a set of scales to help the reader see the decisions needed to judge the risks of different treatment options.

The voice of the writer is one of friendly authority. The section entitled *warfarin dosing* begins with “It is very important to take warfarin just the way your doctor advises. If you miss a dose, call your doctor for advice. Do not change the dose of warfarin on your own” (p. 16). The theme of doctor as knowledge gate-keeper continues, with no mention of any other health professional able to give any advice to a patient. For example, one would expect a pharmacist to be able to help with advice on the management of warfarin. There is frequent use of imperatives in the condition management section of this pamphlet, especially around compliance in medication management: “Do not change the dose of warfarin on your own and do not make up for a missed dose by taking more than the prescribed dose” (p. 16). Here, compliance is key and the use of the imperative voice conveys that authority.

The grammatical complexity in this booklet is variable. The text has a range of simple, compound and complex sentence types with frequent use of conditional clauses. Sentence complexity is often associated with the writers restating complex information in a more simple way. The following compound complex sentence is an example: “These include having a procedure known as ablation (which prevents the abnormal electrical signals travelling into the ventricle), and the surgical insertion of a pacemaker (which provides regular electrical signals to make the heart pump at a controlled rate)” (p. 13). The insertion of relative clauses in the brackets makes the entire sentence longer and places more demands on a reader, perhaps contrary to the intention of the writer.

6.7.3 Numeracy

The extract above also displays numeracy dimensions where the reader is required to make sense of numbers, specifically their INR. The leaflet helpfully explains

the meaning of a decreased or elevated score. The writer assumes the reader is familiar with the mathematical concept of range. There is very little space given for further patient engagement in this domain, with the patient reliant on the doctor for an appropriate INR target. The reader also has an opportunity to interpret an ECG graph in this booklet. The graph shows normal ECG results and those of someone with atrial fibrillation and has been used to helpfully illustrate the booklet's explanation of atrial fibrillation.

6.7.4 Lexical choice

The booklet has a vast new vocabulary describing the condition. Annotated coloured diagrams attempt to assist readers to understand the technical aspects of the heart function with and without atrial fibrillation. The information is for the reader to understand and manage the condition of atrial fibrillation. Rather than use the technical term in the text, the authors have chosen to reformulate in brackets with the medical terminology. "Instead of a regular electrical signal starting from the sinus node, multiple random signals *fire off* from the heart muscle in the atria. This causes the atria to quiver (fibrillate) in a muddled way" (p. 7). An analysis of the text reveals 77% of lexical items are in the first 2000 words of the English language with 18% of lexical items (Nation & Waring, 1997), being low frequency. This high number is also a reflection on the approach the text has taken to introducing medical terminology to the reader (by reformulating text to gloss medical terms). This is a larger proportion of technical vocabulary than other leaflets profiled in this chapter. Interestingly, when new vocabulary is introduced it is still reasonably infrequent which would make this text very challenging to a reader.

6.7.5 Visuals

The photograph on the front cover is the predominant personalisation of this booklet. The male is the central figure, who is looking at the camera and demanding from the reader. The two women to either side are staring at the central figure, keeping him as the central focus. The photograph has a high degree of modality. It is set outside and uses out of focus greenery as a backdrop. The man is wearing a warm jacket. The same people are used as a background in

other pages throughout the booklet. As has been discussed, several diagrams are used to provide illustration of the text.

6.8 Patient information on SVT

6.8.1 Text availability

The supraventricular tachycardia (SVT) leaflet (Crozier, 2000) was given to Mrs Hunt by a junior doctor. It was the only written patient information on a condition given to a patient by a medical doctor during the study period. The text was not available in any public pamphlet holder.

6.8.2 The text

The leaflet covers a number of constituents—understanding the condition (definition, demographics, causes, symptoms and effects), and understanding care, (interventions/responses, pharmaceuticals, risks, monitoring, constraints). It uses a question and answer format to structure the sections and cartoon-styled pictures, one of which depicts the human heart (see Figure 18). The sequence of moves in the text progresses from understanding the condition to understanding the care.

The leaflet uses simple, compound and complex sentence types and technical vocabulary, so it assumes that readers have the skills for decoding and understanding these features.

6.8.3 Lexical choice

An example of vocabulary complexity using research on vocabulary frequency in English (Nation & Waring, 1997) on the following extract is indicative of the style of the pamphlet.

What causes SVT?

Patients with SVT are usually born with an electrical abnormality of their heart. Although the racing may develop during childhood years, they may not start until the teenage or even adult years. Apart from the electrical abnormality the heart is otherwise normal.

What if the turn does not stop?

If the turn does not stop, or if you are feeling dizzy or develop severe chest pain or shortness of breath, you should see your own doctor or attend the casualty department of your hospital immediately. A medicine administered into the vein will almost always correct the rhythm disturbance. Occasionally you may require cardioversion. This is a very safe procedure performed under a brief general anaesthetic and involves delivering a small electric shock to the chest to correct the rhythm disturbance.

Both of these paragraphs have around 85% of their vocabulary represented in the first two thousand words of English, leaving the remaining as low frequency English words. Examples of such vocabulary items are *administered*, *anaesthetic*, *cardioversion*, *rhythm*, *dizzy*, *vein*. The writer assumes a reader is able to decode these items and does not provide a glossary or definition for them. However, other devices are used to support understanding of new vocabulary that the reader needs to learn as part of describing the condition. Terms are defined e.g., “Supraventricular tachycardia (SVT) is a heart rhythm disturbance commonly referred to as a ‘racing turn’” (p. 1) or explained by means of a relative clause e.g., “electrocardiogram (ECG), which records the rhythm of your heart” (p. 2).

6.8.4 Visual features



Figure 18: Drawing depicting electrical abnormality of the heart

There are no labels or direct references in the text to the drawing, so the assumption is made that the reader is able to make the link to the surrounding text. The text closest to the drawing is subtitled, “What causes SVT?” (p. 1). It begins, “Patients with SVT are usually born with an electrical abnormality of their heart. Although the racing may develop during childhood years, they may not start until the teenage or even adult years” (Crozier, 2000, p. 1). The reader is left to wonder what the abnormality in the picture is and what it all means.

6.9 What is supraventricular tachycardia? (SVT)

6.9.1 Text availability

This in-house patient condition pamphlet was a shortened version of the previous leaflet profiled. It was not available in any public pamphlet holders. It was given to the patient by a cardiac nurse specialist.

6.9.2 The text

The A4 folded leaflet is 334 words in total. This written text was part of Mrs Hunt’s story who was diagnosed with this condition. The aim of the text is to provide information on understanding condition and understanding care. Its constituents are limited to symptoms, causes, risks, management, and prevention. It uses a question and answer format to engage with the reader, and features the same heart picture seen in the example above. The shortened length of this document reduces the amount and type of information. However, while the intention of the pamphlet writer is no doubt simplification, the writer uses many of the same complex sentence structures.

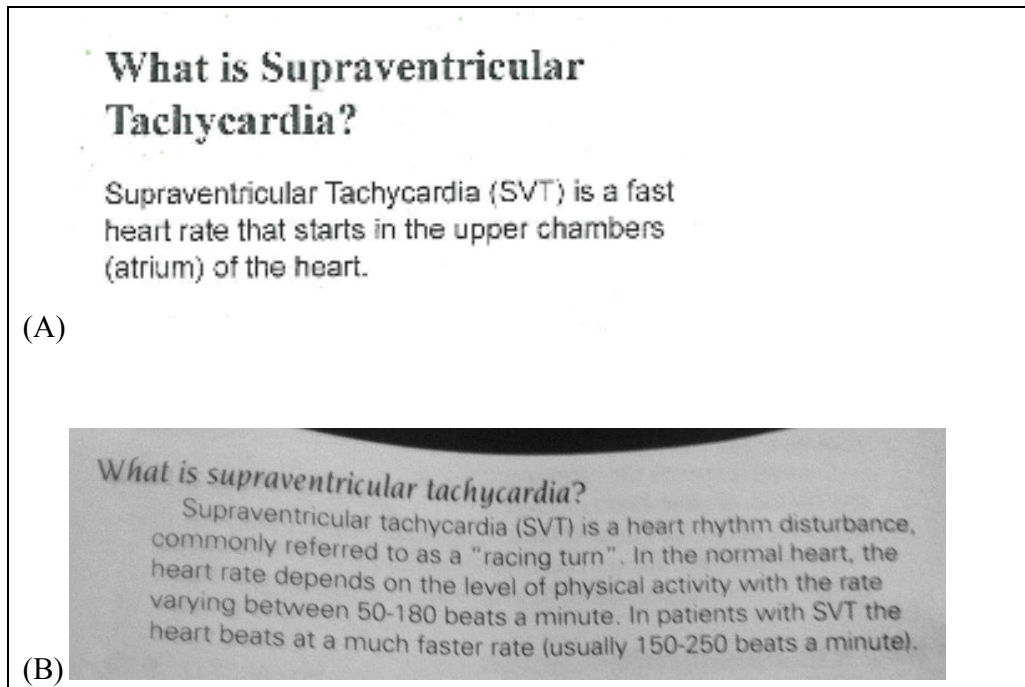


Figure 19: Excerpts from (A) “What is SVT?” and (B) “Patient Information on SVT” leaflets

In the extract (A), the writer assumes that the reader requires only a brief definition of SVT, can decode the word *chamber* and understand the relative clause. The two lexical items, *atrium* and *chamber*, have been added, both of which are technical terms. The additional information about what *faster* may mean in relation to a normal heart rate is not included in the shortened version.

In the extracts featured in Figures 20 and 21, 9% of words are low frequency words (Nation & Waring, 1997) but in the second sentence alone, that rises to 12.5%, leaving 78% of the words in the first two-thousand word lists. Compared to the original version of this sentence in the longer leaflet on SVT, where 89% of words are in the first two-thousand word list and 7% of words are low frequency, this increase in difficulty of vocabulary in the shortened version is of interest. In the original text, the directions to stop a turn were accompanied by an illustration which restated and summarised the steps and used numbering to guide the procedure for stopping an SVT episode. The shortened, simplified version retains the long compound conditional sentence listing the steps to take to stop STV without teaching the specialised vocabulary. These features of the shortened version are less likely to empower patients to understand their condition and care.

How can I stop an episode?

The SVT may stop by itself or you could lie down and relax for a minute or two. If the SVT persists, try taking a deep breath and 'bear down' (as though having a bowel motion) for 15-30 seconds, then relax and breathe normally. This is called a Valsalva manoeuvre. Alternatively try washing face with very cold water.

Figure 20: Extract from “What is supraventricular tachycardia?”

How can I stop a turn?

Many patients can stop a racing turn themselves. The best way is to lie down flat and relax for a minute or two. If the racing turn has not stopped, take in a deep breath, hold the breath and bear down (as if you were having a baby or passing a bowel motion) for 15-30 seconds then relax and breathe normally. This is called a Valsalva manoeuvre and often the racing turn will stop in the 30 seconds following relaxing. Alternatively, fill a large bowl with cold water (and if possible place some ice cubes in it), then place your face in the water for as long as you can comfortably hold your breath. For a small child, placing a bag of frozen vegetables over the face for a minute or so, taking care not to obstruct the child's breathing, may also stop a racing turn.

4 BEAR DOWN
5 RELAX & BRE

The image shows a cartoon character with a large head and small body, lying on its back with its arms and legs extended, illustrating the 'bear down' step of the Valsalva manoeuvre. The character has a large, pointed nose and a small mouth.

Figure 21: Extract from “Patient information on SVT”

6.10 Conclusion

This analysis of texts provides an understanding of the nature of text given to patients. It has discussed their features and provided insights into the literacy and numeracy demands of the text. Analysis so far of texts in a decontextualised manner confirms Franken and Hunter's (2012) constituent analysis approach to healthcare texts where they found a lack of consistency across texts concerning what aspects of understanding of condition and understanding of care were

included (see Appendix 2). Use of technical vocabulary varies, but for the most part it is either glossed or defined in the text. It is the use of other less frequent but non-technical vocabulary which can create more difficulty for readers.

Authors choosing more difficult vocabulary over more common words can raise unnecessary barriers to comprehension. There is a difference between technical vocabulary a patient needs to learn and less frequent lexical items that have more common synonyms available. Analysis referred to earlier by Rogers and Street (2012, p. 161) maintain that adults are well able to learn to read and write words that have meaning to them “irrespective of their apparent complexity” (p. 161).

An important feature of these texts is the way that patients are positioned. The majority of texts reviewed are patient education texts, designed to move patients from deficit to credit in their knowledge of their illness. The “Staying Well with Heart Failure” booklet however is different in its approach, inviting participation in different forms from the reader and thereby courting active reader engagement. It could be classified as a patient empowerment text rather than positioning the patient as a primarily passive recipient of knowledge. The “Atrial Fibrillation” booklet also displays a positive reader-writer relationship, with personalised directives that facilitate patient decisions and assumptions of a professional/patient partnership.

The physical positioning and selection of written text in the hospital context revealed an institutional expectation of patients or readers of the literature to be able to access the appropriate texts from the pamphlet holders. What was and was not available in these public pamphlet holders was significant as it revealed the style of patient information policies in place during the time of the research. These policies were minimal in their codified presence but were part of the cultural knowledge of the hospital. Opportunities for patients to access sanctioned written texts about their condition or care were mostly restricted or controlled, with much information for patients delivered orally. This physical availability and access to patient texts is discussed further in Chapter Eight in a fuller treatment of access, which is a theme within the research findings. How text was mediated and how patients responded to the text and the context is contained in the chapter which follows.

Chapter Seven: Findings – Patients, Mediators and their Texts

This chapter explores nine of the participants' interactions and experiences with patient texts. Despite a bigger sample of eleven, I have restricted intensive analysis to nine, reflecting the saliency of the participants' experiences and their degree of engagement. Personal details which would in any way identify them have been changed to protect their privacy. The pseudonyms are Mrs Newton, Mrs Hunt, Mrs Lewis, Mrs Roberts, Mrs Burns, Mr Cox, Mr Shaw, Mrs Trent, and Mr Ray.

In the chapter, time is taken to build the context of the patients and their interactions with their own health, the hospital system and the patient texts. Some analysis and interpretation are included in this chapter, but predominantly, the latter is reserved for the following chapter, where the themes emerging from the data are further discussed. These themes of access, agency and mediation thread through the stories that follow and the texts already examined in the previous chapter. In this description, some patients feature more prominently than others reflecting the fact that relationships which developed during the period of data collection varied between myself and different participants. This is also a feature of the story each patient brought to the study and the centrality of the patient text involved in their story. Italics are used in this chapter for transcribed dialogues to give prominence to the voice of the participants. There is variation in the amount and type of written patient texts given to the participants. The patient texts reviewed in the previous chapter are positioned here as part of the patient experience. How the patient responded to the written material is also described in detail here.

Responses to the Health Literacy Management Scale (HeLMS) survey tool are examined in light of each patient's journey with the general theme emerging that the survey questions themselves provoked rich descriptions and stories of patient health journeys when the questions were used as part of a semi-structured interview. However, the actual measures (levels of difficulty) used in the HeLMS survey seemed to capture practices that patients did not do rather than practices

they did do to manage their health. Capturing what patients did do is also the reason patient agency is used as an organizing feature in this chapter as during data analysis patient agency emerged as a theme in the data. It is for this reason that some dialogues are analysed in terms of their moves and agentive turns to explore how those patient agentive turns were realised in language.

7.1 Mrs Newton

Mrs Newton was an 88-year-old woman who lived independently. She knew she had angina and had been recording her blood test results and her weight every morning to monitor her fluid levels. She believed she had had angina for over thirty years. She arrived at hospital in an ambulance and was admitted to the AU, seeing the cardiologist and then the cardiac nurse specialist. These were consecutive events which were common practice. Mrs Newton was a patient who displayed a variety of types of agency. There were many factors that contributed to these agentive changes. The description that follows presents in some depth these contributing factors along with her own context and experiences.

7.1.1 Text mediation

Mrs Newton was not given any written material in either of the consultations with the specialist or the nurse specialist. Later in the afternoon of her arrival, she was given the “Staying Well with Heart Failure” (2010) booklet (see Chapter Six) by the student nurse who had accompanied the nurse specialist in the consultation. I was not informed prior to the nurse consultation with this patient and therefore it is unclear whether the booklet was part of the nurse-patient consultation, but it is unlikely. The patient said that no book or written information was given during the specialist nurse-patient consultation. The following dialogue took place as recounted later by Mrs Newton.

30 Nurse: [Nurse specialist’s name] *said you might like to have a look through*
31 *this book.*

32 Mrs Newton: *Thank you, I will.*

The simple mediation of the text, in this particular context, is in keeping with other broader literacy practices evidenced in this hospital. The written patient information material available in large pamphlet holders in various thoroughfares

around the hospital was completely self-access, there for the taking by anyone who may have been interested. The phrasing used in the mediation, as reported by Mrs Newton, could also suggest it was an afterthought, and a reinforcement of the previous discussion with the nurse specialist. It did not appear to be a usual practice that written patient information was given to patients to reinforce or augment previous discussions. Generally, it was up to the health professional's own practice when dealing with a patient. The absence of direct mediation of the text also suggests that the text was not being used as an education or teaching tool during the nurse consultation, even though this particular booklet is written with multiple opportunities for the health professional and the patient to engage together in learning about and managing the heart failure condition. Further exploration of this text is in Chapter Six.

A background to this activity was Mrs Newton's initial comments to me that she avoided reading and writing even though on later visits to her home and the hospital, she had reading material beside her—magazines and a self-help style paperback book. She also confirmed that she did not use the internet. Mrs Newton's behaviour regarding the booklet she was given however, tells a different story. Not only was she reading and understanding the information in the booklet, she was using it and her experience in hospital to begin to critically assess her health situation and her medication regime.

7.1.2 Patient response

Mrs Newton did begin to read the booklet and recounted her initial sense of relief. Her sense of relief came with great emotion.

33 Mrs Newton: *I looked at the last page of the book and read the*
34 *symptoms and started to cry. [later on] The back page is when it went*
35 *“wang.” [See Appendix 4]*

She went on to recount closing the book and crying and then picking it up again and having another read. And then defensively she said, “*I am not overacting.*” Mrs Newton recounted her experience reading the book and understanding her symptoms in a different way:

36 Mrs Newton: *When I opened the first page it was such a relief to get*
37 *some answers because I'm going to go out in the afternoon and*

38 *couldn't get my damn shoes on and think why are my damn feet*
39 *swelling up like this. . . . That book opened up a whole new a whole*
40 *new—it was like having a specialist walk in the room. It was like, like a*
41 *good old recipe book. It meant the world to me. I had this wheezing*
42 *sounds, sounds like a bloomin' old smokers' cough and I didn't realise*
43 *it was a ...*
44 R: *That was new to you? You didn't realise that the shortness of breath*
45 *was related to your heart failure?*
46 Mrs Newton: *No. I can't lay [sic] down again ever. I have to sleep like*
47 *I am now [propped up]*
48 R: *So you learned that in the book, how to manage your sleep?*
49 Mrs Newton: *Yeah*
50 Mrs Newton: *Oh and my fingers too, that was in the book too, you see*
51 *cause I can't wear any of my rings.*
52 R: *Ah cause they swell up?*
53 Mrs Newton: *Yeah*

Mrs Newton did not finish reading the booklet, losing it during her discharge from hospital which she discovered once she was at home. She did not know how to access another book and asked me, the researcher, if I could get her another one when I visited her at home a few weeks after her discharge from hospital. She then recounted her conversation with the doctor prior to her discharge from hospital having been told that from their examination of her echocardiogram, she had two leaking valves and one chamber in her heart had gone. She asked what could be done about it and was told that unfortunately there was nothing more that could be done and that she needed to go home and rest. After leaving hospital she went with her daughter and happened to see a different GP at her usual medical clinic. This doctor quizzed her and asked the following, as recounted by Mrs Newton.

54 Mrs Newton: *You do know what is wrong with you? "Yes" I said. "I've*
55 *had bad angina. I've suffered angina for years" I said, and his eyes*
56 *switched to my daughter. "Your mother has heart failure," he said.*

For Mrs Newton, this was an important point in her journey to more fully understanding her condition. She had been discharged from hospital still not fully understanding that she had more than angina, that she was in heart failure. She recounted being quizzed by her family afterward, about whether she had been told by her GP that heart failure was actually her condition, to which she answered in

the negative. For Mrs Newton, prior to her hospital admission, her GP was her sole source of information. Her family then pressured her to get a different GP. Appointment system changes at her medical clinic meant she was able to see a different GP without having to confront and leave her usual GP, something that after 18 years she admitted to finding very difficult. She was also staunchly protective of her original GP, saying *I'll have no bad word spoken of her.*

Mrs Newton recounted some of her behaviour since exiting the hospital and losing her book.

57 Mrs Newton: *And I definitely need another one because I've told so*
58 *many people about it. My doctor . . .*

59 Researcher: *Oh what did your doctor say?*

60 Mrs Newton: *She's very interested. I said, I was careful what I said*
61 *because I wasn't telling her she hadn't done the right thing. I said,*
62 *"If I had have read this book before," I said, "I would have been*
63 *saying to you that something needs to be done about this fluid, look at*
64 *the size of my legs. I've gone from 62 kgs to 71 and it was **all damn***
65 ***fluid**" [her emphasis]. That book is the most wonderful book. It told*
66 *me all of the things like getting - why I get short of breath like I do.*
67 *But my doctor is a damn good doctor, she really is. She probably*
68 *knew these things but she didn't bother telling me about it. But you*
69 *see I was doing silly things like in my garden I was doing things I*
70 *shouldn't have been doing. . . . Heavy things and I shouldn't have*
71 *been doing that. . . . I've probably done a lot of damage to myself.*

After the initial discharge, Mrs Newton ended up back in hospital three weeks later after a sudden drop in blood pressure. She collapsed while gardening and sustained an open wound and severe bruising. One advantage of her re-admission was that she asked for and was handed another copy of the book so was able to continue reading. At that point she texted me the following comment:

72 *Am up to page 15. Have had to close the book am so angry 2 not been*
73 *told what was causing swollen legs 4 1 thing didn't know shouldn't*
74 *dig garden don't think I can face my Dr who I love.*

Her emotional reaction came with her realisation and understanding what it actually meant to be in heart failure despite seeing her doctor about her heart issues for the previous 18 years and being in hospital the few weeks prior. Mrs Newton had not been connecting the swelling of her feet or shortness of breath to heart failure.

75 Researcher: *And so you'd talked to your doctor? And what had she?*
76 Mrs Newton: *Aw she'd press it like that and she gave me some*
77 *Furosemide to take and she said, "Oh you've got a bit of fluid there*
78 *Mrs Newton." And I didn't think it had anything to do with my heart; I*
79 *thought it was my legs you see, or my fingers.*
80 *And she did question me about my shortness of breath, she did say,*
81 *"You're very short of breath today." And I probably said, "Oh it is an*
82 *easterly wind or some stupid damn thing because I didn't know any*
83 *better."*

Reading the booklet made these connections for her. For this patient, her interaction with the booklet was pivotal for her understanding and using the information to improve and manage her health and thus display agency (Ahearn, 2001, p. 130). Her major challenge was not the written text, but access to the text. Her GP had not given it to her. It was not available publicly in the hospital. If it had been available, she may not have taken it because of her belief that she had angina rather than heart failure. Furthermore, the student nurse gave her the booklet outside of the regular consultation, possibly more as an afterthought. In other words, Mrs Newton came very close to not having access to this information. Literacy events involving written text in her trajectory of care were sparse. Consequently the literacy practices around those events positioned Mrs Newton as someone needing high levels of personal agency and critical health literacy to access information and understand and manage her condition and care. Literacy practices evidenced earlier in this thesis showed this text was not publicly available. Patient information text was not at the forefront of Mrs Newton's experience with her chronic illness so it may not be surprising that she did not actively seek written information. However, once she understood that there was such a thing available, and she lost it, she sought out the information again, gaining her second copy.

In terms of interacting with the book, Mrs Newton had not written anything in the book, despite the ample opportunities the book presents, nor had any health professional despite the numerous shaded areas the book offered to the health professional. This could reflect the way the book was mediated to the patient. It appeared to have been given as a matter of interest to the patient for her to look through, rather than being an artefact at the centre of a dialogue between the

patient and the health professional, as suggested by the book. (See Chapter Six, Section 6.1.5).

A major area of impact for Mrs Newton was her feelings about her medication.

84 Mrs Newton: *The thing that upset me the most was the thing on*
85 *medication . . .*

[Later on]

86 Mrs Newton: *Speaking for myself, you are in your doctor's hands—*
87 *either you do what your doctor says or. . . . You expect the doctor to*
88 *join the dots.*

[Later on]

89 Mrs Newton: *I can't wear my rings anymore. I told [doctor's name]*
90 *this, but nothing got changed. How can things go that wrong, when I*
91 *have tried so hard to be independent? I won't get back to that again. I*
92 *will be independent but not as fierce.*

During the second stay in hospital, Mrs Newton had also witnessed her weight drop nine kilograms (fluid reduction) and her breathing become more stable. She had not been short of breath since coming to hospital, a reflection of the medication she had been on since her admission.

Mrs Newton had not read the book right through but rather picked out things that were meaningful. She intended to continue dipping into the booklet.

93 Mrs Newton: *There is a lot more reading. You never finish that book.*
94 *You go to another page. . . . When I read it I thought why didn't I know*
95 *that before? I am so dumb.*

7.1.3 Patient condition management

While in conversation about the booklet and how Mrs Newton was managing her condition, I asked her whether she had a clear idea about what she was allowed to do. She recounted her neighbour quizzing her after her previous stay in hospital, whether she should actually be driving her car. Was she safe to drive? She admitted she needed to talk with her doctor but also questioned how many people drive around who do not know they will have a stroke or heart attack. She just happened to know about it.

96 Researcher: *How about ironing or other physical work you do at home?*

97 Mrs Newton: *Nobody has told me I can't do that. Nobody has told me I*
98 *can't do anything. They've just told me I got to rest. I'm too young to*
99 *sit around and rest. I was starting to get quite a lot of angina when I*
100 *was crocheting. That's made me think about that . . . I'm not to put my*
101 *clothes up on the line—put my hands above that* [motions above her
102 shoulders].

Mrs Newton was showing evidence of a critical turn. “*You expect your doctor to join the dots*” and “*How could things go so wrong?*” Wondering why she had not been told certain pieces of information was also evidence of an emerging critical stance, or critical agency, as was making suggestions about information she needed and questions she had which remained unanswered.

She felt very comfortable with some sections of the book, especially the section on diet.

103 Mrs Newton: *I eat well.* [pause] *Labels—well I've been doing that for*
104 *a long time* [reading labels p. 23].

105 Mrs Newton: *I think they've covered it all very well. I think it is very*
106 *well written whoever has put it together is wonderful. Very easy to*
107 *read. Explains it. You see, who could not understand that just by*
108 *looking at that whether you read English or not? It is very well done.*
109 *Blister pack—I've never got into that.*

110 R: *So how will you organise your drugs when you get home?*

111 Mrs Newton: *I don't know. I'll have to think about that. I don't know.*
112 *It is going to have to be a day at a time. It's frightened the bloomin'*
113 *knickers off me in a way.*

114 R: *It is a lot isn't it.*

7.1.4 HeLMS questions

The HeLMS survey was administered 14 days after she was discharged from hospital the first time. Mrs Newton scored below the acceptable range on the HeLMS survey. The interview was cut short when Mrs Newton became upset answering how difficult it was for her to find the energy to manage her health. The answer to that question was she found it very difficult, thereby scoring poorly on the scale, but that did not preclude her actually still managing her health to the limits of her knowledge. From the surrounding conversations, Mrs Newton had done what had been required of her and what she had known. For example, she said she had been recording her weight every morning since 1993 because a doctor in another hospital had directed her to do so.

115 Mrs Newton: *The same one told me before you eat anything in the*
116 *morning get up go to the toilet, get weighed and record it. So when*
117 *they tell me that, they've worked hard to become doctors—I respect them*
118 *for it—so this is the least they ask me to do. . . . If it wasn't for doctors*
119 *like that, I wouldn't still be here. So I have to play my part and do what*
120 *I am told.*

Using the HeLMS survey to have a structured conversation with Mrs Newton revealed some shifts in her approach to her own health care, despite not being measured by the survey. According to the HeLMS survey, Mrs Newton's results suggest she had health literacy challenges across four of the eight domains the survey covers. The lowest score was in the being *pro-active domain*, then *communicating with doctors*, *socio-economic factors*, and *social support*. The style of this survey reiterated the *clinical risk* approach of the survey. Mrs Newton did have financial pressures but had creative ways of managing her life, for example, keeping the petrol tank in her car full so that she could (and did) ask friends and neighbours to drive her to the doctor (and other places) in her own car thereby avoiding taxi costs. This type of strategy is not part of the HeLMS survey, and yet Mrs Newton lost points on the survey because she did have financial pressures, which according to the survey increased her chances of having health literacy challenges. In addition, for Mrs Newton, her health condition was a very private matter. Her daughter had access to her health condition details, but other than that Mrs Newton was not interested in discussing her health condition with others. She viewed it as private. She therefore scored low on the question asking how difficult it was for her to discuss her health with people other than a doctor. Much more could be said about the mismatch between the HeLMS survey questions and results and the social practices Mrs Newton displayed to access, understand, appraise, and apply health information to her situation. Thus, the survey became a useful tool for having structured conversations during the research, but it did not prove to be very helpful in capturing the actual health literacy practices individuals engaged in when accessing, understanding, appraising and using health information to make health decisions.

7.1.5 Patient agency

Mrs Newton's journey shows a gradual increase in what she came to know coupled with action, and agency. As previously discussed, Ahearn's (2001)

definition of agency describes Mrs Newton's journey of knowledge being socially constructed during her stays in hospital and her as the agent acting on what she had come to know or believe (p. 130).

When I met Mrs Newton she admitted that she did not see herself as particularly sick saying that she had not wanted to come to hospital because there were "*lots of other really, really sick people.*" Fischer and Eraut (2012) label this *entitlement anxiety* and describe it as follows: "If I go to the doctor and I'm not ill by his definition, I might feel humiliated . . . so am I entitled to present myself as ill for this reason at this time?" (p. 19). This anxiety waned during Mrs Newton's hospital journey.

- 121 R: [Do you] *get a second opinion?*
- 122 Mrs Newton: *Yes, I didn't use to but now I do.*
- 123 R: *So would you feel confident going to a different GP?*
- 124 Mrs Newton: *Today I would but last week I wouldn't have. Because*
125 *[GP's name] is my friend—18 years but I'm now having a few second*
126 *thoughts about my medication for one thing. I'll not have a bad word*
127 *spoken about [GP]. I've been doing a lot of thinking. I have got to take*
128 *responsibility.*
- 129 Mrs Newton: *I question now what they give me.* [referring to her
130 medicines she had been prescribed]. *And the nurse here, this morning I*
131 *was telling her I said, "I've done a lot of thinking. This has been so good*
132 *for me. I've done a lot of thinking." I think now I've **really** [her*
133 *emphasis] got to take responsibility. I've got to stop expecting too much.*
134 *I'm very hard on myself. If I want something done I just do it. I just*
135 *yeah—but I said, I'm concerned now as my doctor has become my friend*
136 *and I'll not have her hurt in anyway and I will not have her criticised in*
137 *any way. And this nurse said to me "You know Mrs Newton sometimes a*
138 *new pair of eyes is good so you might need to think about these things."*
139 *Now wasn't that a lovely way of putting things.*

Mrs Newton displays acts of contestation in her care. We witness an increase in her enactment of individual expertise and control as well as her negotiation of her care. Her statement (line 128) that "*I question now what they give me*" is a clear indication that she has adopted a more critical agency. Her reflections on her approach to her health which had meant she had expected her doctor to join the dots suggest this. In addition, she was questioning how things could go so wrong when she was in her doctor's hands and had been doing what the doctor had told her to do. Her sanctioning of a doctor in the hospital after her perceived bad

treatment also evidenced this more critical stance. Mrs Newton told the nurse that she was refusing to see the doctor who left her waiting for four hours with an open wound. On Mrs Newton's second admission to the hospital, rather than expressing entitlement anxiety as previously expressed, she began to challenge the compliant patient identity.

140 Mrs Newton: *The doctor came . . . and he said, he didn't like the look of*
141 *it [her leg wound] 'cause it swelled again and he'll just go away and*
142 *check with his boss and then be right back. . . . I told the nurse. She said,*
143 *"Right, the doctors come to see you." I said, "I'm not even speaking to*
144 *him" [her emphasis]. "Oh," she said, "really Mrs Newton?" "No," I*
145 *said. "If I tell a person—you know this, if I send you off a text*
146 *immediately saying you come this way, you do that, I tell you I will be*
147 *there, I'm there when something big happens. You see what I'm saying?*

Here Mrs Newton contested her care. She displayed agency in banning the doctor from her bedside and using the attending nurse as her messenger to deliver the ban. The doctor duly came.

148 Mrs Newton: *So when he came he said, "I believe you are not speaking*
149 *to me," and so she told him, and I said, "No I'm not." "What have I*
150 *done to offend you?" Wasn't nasty. I said, "You said to me, you*
151 *uncovered my leg," I said. "I've got to be so careful with infection." You*
152 *said, "It is quite alright, like that, like it is now," 'cause you were just*
153 *going to pop away and see your boss and you'd be right back to tell me.*
154 *"That's right," he said, "and I never came back did I."*
155 *I said, "No you didn't."*
156 *I said, "Meantime people are going past. Nothing's ruder than people*
157 *who don't put a hand over their mouth when they cough and then*
158 *[emphasis] I had a neighbour who's down here, who has just gone, come*
159 *to see how things were going. She said 'Oh you've got your dressing off'*
160 *[in a high pitched voice] and whipped this straight back to have a look at*
161 *it . . . and I said, 'Excuse me, keep away because of infection.' 'Oh*
162 *nothing wrong with me,' she said. I said, 'Stay away if you don't mind.*
163 *I'm very nervous about infection.'"*

In the dialogue with the doctor, Mrs Newton enacted her own expertise (lines 148-155) as she explained the situation from her perspective and negotiated an apology from the doctor. She also displayed oppositional agency in managing her neighbour's unwelcome interest, negotiating her privacy with the visitor. The following recount by Mrs Newton may also be displaying elements of oppositional and critical agency.

164 Mrs Newton: *So this one that came in [the nurse] said, "I've just learned*
165 *that you can have something to eat." Been nil since yesterday. And I*
166 *said, "Right I'll have bacon and eggs and mushrooms and coffee."*
167 *"Oh I can't guarantee that," she said.*
168 *I looked at her and laughed: "I don't mind, just a cup of tea would be*
169 *lovely."*

In lines 148-166, Mrs Newton revealed a knowledge of the community of practice in which she now found herself. Patients do not generally ban doctors from visiting them while in hospital, and nor do public hospitals serve bacon, eggs and mushrooms on demand, which both the nurse and patient knew. Mrs Newton's critical turn then involved taking a course of action uncommon in the hospital context. Asking for bacon and eggs may be construed as further oppositional agency: perhaps a reaction to not being told directly by the doctor that she was not going to have surgery and so could therefore eat and drink. Instead, the message was brought to her by the nurse, the intermediary. This happened again later in the conversation and Mrs Newton contested it.

170 Nurse: *And he said you can walk to the toilet. You can get up and walk*
171 *to the toilet*
172 Mrs Newton: *He didn't tell me [in an upset voice]. Why didn't he tell me?*
173 Nurse: *No, that's 'cause I asked him. I asked, "Does she need to stay in*
174 *bed or can she get up? Can she eat?"*
175 Mrs Newton: *Praise you Lord for that or I . . .*
176 Nurse: *So you can walk to the toilet but not, don't go wandering around*
177 *any further than that.*

Mrs Newton's contestation (line 172) brought a quick clarification from the nurse and a sense of relief from Mrs Newton that the nurse had actually asked.

The transcript below (lines 178-194) of an interaction which took place between the nurse and the patient is salient because in this dialogue the patient who has shown a critical turn by refusing to talk to the doctor, now displays fear (line 184) about the possible ramifications of her action. She enlists the support of the nurse, which is not readily forthcoming (lines 185-192).

178 Mrs Newton: *Now when he explained it, "No we cannot operate because*
179 *this [points to her heart] won't take it," the nil by mouth is still up there.*
180 *He said, "I was going to take a skin graft and clean all of this off here*
181 *[pointing to her open wound]." I said, "Oh I've had people walking past*

182 *coughing, no hand over their mouth; I was scared silly yesterday I was*
183 *going to get an infection of some kind.”*
184 Nurse: *You're on antibiotics to cover it just while the wound is still open.*

Being told why she was on antibiotics came as a result of an earlier move by Mrs Newton to report a problem. This in itself required sufficient agency to make her concerns salient to the nurse. The conversation then takes an abrupt change in direction.

185 Mrs Newton: . . . *I'm glad I am at peace with the other doctor because I*
186 *don't want to be out of anything with people.*
187 Nurse: *I'll see you a bit later* [doesn't leave]
188 *Mrs Newton: I better learn to zip* [motions to her mouth] *in case they put*
189 *me out if I say too much. . .*
 [No comment from nurse]
190 Mrs Newton: *At least I said what I had to say.*
191 Nurse: *Yep*
192 Mrs Newton: *And to wait from 1 till past 5 is too long leaving me. I just*
193 *get the feeling they are treating me like I'm an old lady.*
194 Nurse: *No. It is good that you said something 'cause a lot of people*
195 *wouldn't have and then they think it is acceptable to do that.*
 [Interrupted by another person]
196 Nurse: *We can take that sign down and get you some breakfast. I can't*
197 *promise what it will be. I don't think bacon and eggs is on the menu this*
198 *morning but it is almost morning tea.*
199 Mrs Newton: *I know what I was, I'll have a double dose of . . . prunes. I*
200 *didn't go yesterday and I always go every day.*
201 Nurse: *Ok. It is probably the painkillers we are giving you. They can*
202 *bung you up.*
203 Mrs Newton: [Inaudible] . . . *tells me these things.* [Implied—she wishes
204 she had been warned.]
205 Nurse: *Unfortunately, the majority of painkillers will make you a bit*
206 *constipated because of the way they work.*

In lines 185 to 192 Mrs Newton goes beyond entitlement anxiety to a fear of getting off-side with the doctor for which she perceived she could suffer. This is perhaps a further acknowledgement of Mrs Newton's perception of hospital hegemony. Her self-description (line 193) concerning her identity as “*an old lady*” may also be an acknowledgement of an over-arching hegemony she perceived to be pervasive in the broader context.

For Mrs Newton, if health literacy is to access, understand, appraise, and apply health information to make decisions about your own health, then she should have passed any health literacy assessment. Aside from the displays of agency already discussed, she had faithfully acted in accordance with her knowledge of her condition and care. She relied on her GP for health advice (“*You are in your doctor’s hands.*”) and took her questions to her GP for answers. Information she was given, she used and acted upon, for example, daily early morning weight measurement. Until that point, she had taken everything doctors had told her to do and done it: “*So I have to play my part and do what I am told.*” However, as noted earlier, she had expected her doctor to “*join the dots.*” The decrease in her swelling from medications administered in hospital prompted her to take a more critical stance on both her medications and on responsibility for her health:

207 *“I’ve done a lot of thinking. This has been so good for me. I’ve done a*
208 *lot of thinking, I think now I’ve really got to take responsibility, I’ve got*
209 *to stop expecting too much.”*

It could have been that this patient did not get any written text, in which case her understanding of her condition would not have grown the way it did. Mrs Newton had no problems decoding the text. She admitted to not enjoying reading, but still did so and her responses, emotional responses and increased understanding and application of how she could manage her condition point to a deepening understanding of condition and care.

7.2 Mrs Hunt

7.2.1 The Social

Mrs Hunt, a woman aged between 60 and 70 years, arrived at hospital in an ambulance. Her journey through the hospital followed the established path of the other patients. I met Mrs Hunt just after she had been admitted to hospital and before she saw a cardiologist. She wondered out loud if her chest pain had been brought on by stress as she was dealing with some serious family issues at the time. She had a solid fiction book beside her bed that she was reading and put it aside every time someone entered her bed space.

Mrs Hunt observed a group of people, some wearing white overcoats, moving around the AU. She was interested to find out who they might be and what they were doing, but did not enquire of the many healthcare professionals as to who these groups of people were moving around the unit. This was an established practice in this area –the *rounds* done by medical staff at various, often changing times during the day, to consult with in-coming patients about possible diagnosis. Usually it would be a senior consultant with doctors accompanying who were at varying stages in training. Most times, this was a patient’s opportunity to ask questions and seek clarification from a doctor on their condition or care.

While talking with Mrs Hunt, I happened to mention that the specialist must be just about here. Her response suggested this was new information to her. Mrs Hunt’s subsequent follow-up question (see lines 210-215) illustrated she was not familiar with the routines and practices of the AU.

- 210 Researcher: *I think you are just about ready to see a specialist*
211 Mrs Hunt: *Oh really?*
212 Mrs Hunt: *Oh is it that group, that woman that goes around talking to*
213 *everybody?*
214 Researcher: *Well it depends which speciality you are under. So they all*
215 *walk around with their registrar and house surgeon*
216 Mrs Hunt: *Oh [in understanding]*
217 Researcher: *And um, they so some of them will be different specialities,*
218 *so they walk about with their registrars so you are waiting for the*
219 *cardiology troupe.*

To understand something of the care offered in hospital, Mrs Hunt used follow-up questions to familiarise herself with the context and its practices. This pattern of clarifying what was likely to happen next continued later when I mentioned that I would be back later on that day when she was seeing a cardiac nurse. She was interested and so I explained the process that a cardiac nurse will often follow-up a visit from the cardiologist. This was new information for her. She agreed that she did not know what was going to happen next. She laughed and said she was so tired last night because of all the people she had been talking to in hospital—going over her story and preceding events and over it again. When any hospital staff member comes into the patient’s bed space and begins asking questions, there is an expectation that the patient will respond openly and not query why the

person asking the questions needs to know for example. Critical questions about what the questioner is going to do with the information or how that particular person fits in to the patient's management were not observed. In this regard, a patient's identity is assumed and accepted as being open and amenable to the health care process taking place around them. In this case, it necessitated the retelling of the same story several times.

Mrs Hunt was seen by the specialist mid-morning and then by a cardiac nurse specialist after lunch. The specialist conversation with Mrs Hunt had several moves which mirror well documented doctor-patient rituals (Bryne & Long, as cited in Ainsworth-Vaughn, 2001) focusing on the doctor's activity, rather than the patient's. The ritual begins by relating to the patient, followed by ascertaining the reason for attendance/admission. A verbal or physical exam or both is then carried out after which the patient's condition is taken into consideration before treatment or further investigations are detailed. There is then a leave-taking or ending phase to the ritual. It is not the purpose here to analyse this encounter from this perspective, but it is salient to note that the specialist-patient encounter followed this pattern. Relating to the patient, or framing (Ainsworth-Vaughn, 2001) was minimal at the onset of the encounter. Once introductions of the cardiology team were over, support for the presence of others moving with the cardiology specialists in the room was canvassed with the patient. The questioning and examination then began followed by the diagnosis and way forward. No written material was given to the patient during this session. However, written material was delivered later on that day which is why it is salient to look at the conversation which preceded the delivery of the written patient information text.

The cardiologist came to the bedside accompanied by a junior doctor, a registrar and an accompanying group of pharmacists. The specialist asked the patient's permission for the large audience, which was granted. He then proceeded with introductions.

He then moved on to ascertaining the reason for Mrs Hunt's admittance to hospital, opening with the question, "When did it all begin?" Further questions followed concerning any current illness, coffee and alcohol habits, history of

diabetes, or family heart trouble, childhood rheumatic fever, depression, allergies, and other medication. These were predominantly yes/no questions and led by the consultant. The pattern of this consultation confirmed Ainsworth-Vaughn's (2001) observation of a "lack of reciprocity (e.g. patient and doctor have unequal rights to ask questions) and regulatory responsibility (the physician has an asymmetrical right to initiate and terminate the encounter)" (p. 458). It seems that there is an element of appropriacy here—what is expected by this particular discourse community? The doctor/physician asks the questions, the patient answers until a pronouncement is made of a diagnosis or steps needed for further tests or investigations.

A physical examination then commenced with imperative directives, where the specialist pre-warned of what he would do to the patient, and told his waiting audience the findings as he progressed, e.g., "Chest is clear."

The cardiologist then addressed the Mrs Hunt with the results. He gave her his diagnosis and used the proper medical name—atrial tachycardia or paroxysmal PAT. He explained, "*Basically it comes from the top of the chamber of the heart and it is an extra little heart—extra bit of rapid conduction from the top chamber to the bottom.*" He reassured her that it was not sinister and that it does not cause heart attacks or strokes. He then talked about what triggers it and options for management of the condition. "*There are a number of medications you can use should you want to try medication.*" He advised the options, what his opinion was on each one ("*I would avoid that...*") and the option of doing nothing. Looking at the progress of this part of the consultation through the moves associated, the consultant explained the condition, explained the risks and options for management and also some of the triggers. He then invited patient participation:

220 Dr: *So did you want to give that [name of drug] a try?*

221 Mrs Hunt: *Yes I think so*

Leave-taking then commenced with two invitations for questions and an outline of what would happen next and when Mrs Hunt might expect to be discharged from hospital.

A few hours after the visit by the specialist, Mrs Hunt saw a cardiac nurse specialist and it was there she received an in-house publication on supraventricular tachycardia (SVT). Just after this appointment had finished, a junior doctor who had accompanied the cardiologist returned to Mrs Hunt's cubicle and dropped off a patient information leaflet on her condition. Mrs Hunt was the only patient in the study who received written information on her condition from a specialist/doctor. This leaflet was dropped off by the junior doctor with the words, "*Dr [name of doctor] asked me to give you this.*" This event may or may not have been influenced by my presence.

After the session with the specialist, Mrs Hunt was very relieved. Her major concern that she had more serious heart problems had been allayed during the cardiologist's visit when he had told her that it was not of any sinister significance and that it did not cause heart attacks or strokes. I asked her what the name of her condition was that the doctor had said and she was unable to recall it. I could offer her part of the name and a pen when she responded that she wanted to write it all down.

Soon after the specialist's visit, the patient was visited by the cardiac nurse specialist. The nurse proceeded to ask the patient what she understood from the doctor's visit and as discussion progressed, a literacy event occurred. It is salient that this literacy event occurred in a literacy sponsor situation. Previously uncodified knowledge was codified in the form of a written text. It is also interesting to note that the nurse specialist involved in this consultation persevered (lines 222-229) in finding the condition name the patient had already heard being used by the doctor.

- 222 CNS: *So Dr [name of doctor] this morning, and what did he have to say?*
223 Mrs Hunt: *He said a . . . atra . . . called something else and that is what I*
224 *was going to write down from you.*
225 CNS: *Right. Atrial tachycardia was what he called it*
226 Mrs Hunt: *Oh [in disappointment]*
227 CNS: *Did he call it SVT or supraventricular tachycardia? PAF?*
228 *(Patient still hasn't heard what she heard from the doctor) (the nurse*
229 *laughs), PAT atrial tachycardia*
230 Mrs Hunt: *Can you write that down?*
231 CNS: *I can.*

7.2.2 Text mediation

A pamphlet produced in-house of 334 words entitled What is . . . Supraventricular Tachycardia? (SVT) was extensively mediated by the cardiac specialist nurse. Prior to moving to the document, she had explained in detail what the heart was actually doing with the SVT condition. She used her hands and words to explain. The pamphlet was a simplified version of the leaflet the doctor was soon to deliver to the patient. The simplified picture of the heart (Figure 18) was retained. The excerpts below are the exchanges immediately preceding and following the mediation of the text. The text mediation came at the end of the consult and followed the constituents as documented by Hunter and Franken (2012).

232 CNS: *Oh, I've got it. [laughs] Ok so did he explain what it was?*

233 Mrs Hunt: *No*

The Dr had explained what it was earlier saying that she had “*a common nuisance value rhythm disturbance by the name of atrial tachycardia, or in your case paroxysmal . . . or PAT.*” The doctor had explained the condition by saying that the disturbance came for the top chamber of the heart and that it was like “*an extra little heart, extra bit of rapid conduction from the top chamber to the bottom chamber.*” The following exchange between the cardiac nurse specialist and the patient took place soon after the doctor’s visit.

234 CNS: *A big word. So your heart has top chambers and bottom chambers*
235 *and the top chamber are called your atria. Normally the heart contracts*
236 *like this (shows with her fist and hand). The atria go first and then the*
237 *ventricle.*

238 CNS: *Now this pamphlet here calls it supraventricular tachycardia*
239 *which is another name for atrial tachycardia. So atrial and*
240 *supraventricular are the same thing. So in here [pointing] it talks about*
241 *the symptoms, you might notice your heart racing for a minute, [reading*
242 *from it] you might notice shortness of breath dah dah. What causes it*
243 *mostly they don't know. Mostly we don't know. It can be triggered by*
244 *exercise and stress but those aren't reasons not to exercise. We all have*
245 *stress . . . but just to point out we don't know what causes it.*

246 Mrs Hunt: *Is it dangerous?*

247 CNS: *Is it dangerous? Not usually. That is to say, if you let it carry on*
248 *and your heart rate is going at 140 beats for a week or so then it could*
249 *impair your heart a bit because you are making it run a marathon with*
250 *your feet up, so you don't want to be all the time.*

251 CNS: *How can you stop it? Did he suggest any way of stopping it?*
252 Mrs Hunt: *No [inaudible] only medication.*
253 CNS: *Okay. Something I would suggest that you could try is putting your*
254 *thumb in your mouth and blowing on it as though it was a balloon*
255 *[paraphrased from text].*

Here the CNS reformulates the text, with actions to show the learner/patient exactly how to do the manoeuvre (there is no support picture or diagram in the CNS text). In lines 265-270, the reformulation of the ice water example provides more understanding of why a particular procedure (ice bucket) is effective. This is a benefit of having a more knowing other in the mediating position; she is able to enlarge understanding of the patient text.

256 Mrs Hunt: *Mmh ok, that's what I/they did down there*
257 CNS: *Right and it didn't alter it at that time?*
258 Mrs Hunt: *I don't know. I was on my back. Couldn't see*
259 CNS: *If we do that when the palpitations first start then it can be quite*
260 *effective. The longer you leave it the harder it is to revert your heart back*
261 *to normal rhythm. So if you feel like it is starting to raise, just sit there*
262 *you can blow for about 10 or 15 seconds while holding your pelvic floor*
263 *so **that** [her emphasis] actually stimulates the heart to stop impulses.*
264 Mrs Hunt: *Ok*
265 CNS: *Mmh [pause] um and the other thing it says here is to wash the face*
266 *with very cold water. The textbooks tell us to immerse the patient's head*
267 *in a bucket of ice water.*
268 Mrs Hunt: *Oh really*
269 CNS: *So anything that makes you suddenly breathe in can alter that*
270 *heart rhythm.*
271 Mrs Hunt: *Oh ok.*
272 CNS: *So it can be really effective, best as soon as it starts 'cause once it*
273 *has been a couple of hours and ... in a cycle, it can be very hard to turn it*
274 *around [still in the book]. Do that straight away. Um here, should we*
275 *ever develop chest pain is because it is racing you do need to go and see*
276 *a doctor. If the palpitations carry on, 15 minutes you do need to go and*
277 *see your GP*
278 Mrs Hunt: *Ok*
279 CNS: *How can I prevent it from happening? Well sometimes you can't*
280 *do anything. That's the unfortunate thing. Sometimes you can if you are*
281 *aware that some things trigger it, so for some people it is alcohol, some*
282 *people it is coffee, some people it's family hassles. Can be a number of*
283 *things but often it is nothing. If you find you are stressed and you*
284 *thought it was stress that was triggering it, um do you have good ways of*

285 *dealing with stress or has it been getting on top of you?* [more
286 conversation on stress]

287 CNS: *So the ongoing thing for you is to take your tablets and if you*
288 *notice they are no longer controlling you go back to your GP and if you*
289 *are having palpitations or chest pain then you need to come and see us.*

Refer to Appendix 5 for a further transcript of this part of the conversation where mediation of the patient information text continues. The cardiac nurse specialist in this dialogue was actively engaging the patient with the leaflet, (lines 265, 274, 279) asking her questions (lines 257, 285), paraphrasing (lines 278-284), and waiting for understanding (lines 257, 265, 278). This particular mediation was lengthy and did act to make the new knowledge more accessible to the reader—the patient. The nurse used the leaflet as her guide while talking through it, interacting by pointing and reading out loud along with the patient. The written patient pamphlet given to Mrs Hunt by the nurse did not have a picture to illustrate the bearing down (Valsalva manoeuvre) technique unlike the more in-depth pamphlet provided by the doctor. In a follow-up conversation the next day, it was the presence of the picture that Mrs Hunt used to identify and talk about the pamphlet which she preferred. What makes this literacy event more salient is that the patient later received the second piece of written text about her condition from the specialist. That leaflet contained a lot more information, despite it not being mediated in any way except that the person delivering the leaflet was doing what he had been asked to do by the supervising doctor. This is salient because the mediators, the nurse specialist and the cardiologist's appointee, made the decisions about what knowledge was mediated and how that mediation occurred. In this regard, Silverstone's (1999) observation is relevant that mediation is both epistemological (creating a definition of what is understood) and ethical in that the power in the mediating event is with the health professional.

Post-discharge, the patient's reaction to her time and hospital and her learning was very clear:

290 Mrs Hunt: *I'm really pleased I've found out what was wrong you know.*
291 *It was quite educational.* [post-discharge from hospital]

292 R: *Oh great yeah.*

293 Mrs Hunt: *I didn't really know much about the mechanics of my body.*

She had learned a great deal during her time in hospital, to the point of describing it as educational. Her understanding of her condition and care, she acknowledged, was limited prior to her hospital visit. When asked which leaflet she preferred she stated,

294 Mrs Hunt: *I think the second one [pause] the one with the picture of the*
295 *person laying in it [pause] the other one was very simple– although it had*
296 *it all there.*

The second leaflet had more information in it than the one given to her by the CNS. Interesting, too, is how she remembered the difference between the two leaflets was through the use of a picture. Her reading motivation was to answer her question, how bad was the condition going to be.

297 R: *And [pause] what was the thing you were most interested to read when*
298 *you were reading, when you picked it up. What did you most want to*
299 *know?*

300 Mrs Hunt: *I wanted to whether I had Wolfe-Parkinson-White syndrome.*

The leaflet tells the reader what to do to prevent rhythm disturbance: “In some cases, cutting down on substances that stimulate the heart may help prevent racing turns. These include caffeine (coffee, tea, chocolate or cocoa), alcohol, asthma medications and cold preparations.” However, this left Mrs Hunt wondering what she could do instead.

301 Mrs Hunt: *Also preventing maybe and I don't know what they think I am*
302 *going to drink but everything is off except water . . .*

Mrs Hunt had also used the leaflet information to reflect on the decision she had made with the doctor concerning how she was going to manage her condition, her treatment options and the possible interventions.

303 Mrs Hunt: *I was interested that second sheet went over the options you*
304 *had, you know when the doctor explained about the different drugs.*

305 R: *Yes*

306 Mrs Hunt: *Treatments that*

307 R: *Yes it did. And how did you feel after reading that, did you think ah*
308 *I've made the right decision? What was your reflection?*

309 Mrs Hunt: *Well definitely that the operation part was out and um 'cause*
310 *when you first go in you just want to know, is this going to cause a*
311 *stroke? . . . and I was told no it will not, so that was fine.*

7.2.3 *HeLMS survey*

Completing the HeLMS survey with Mrs Hunt as part of a conversation again highlighted some of the limitations of the Likert scale used by the survey. For question 3 (see Appendix 6), Mrs Hunt responded that she had never gone for a second opinion for example on a health matter because she had never felt the need to seek one.

Therefore, for her it was more about appropriacy of response than being able to do it if she had to, whereas the survey sought to measure the difficulty a patient may have undertaking this task. Mrs Hunt scored above four in all of the health literacy domains the survey tool purports to measure thus giving no cause for health literacy concern or risk according to the survey. She recounted information she was given by her health professional for a previous condition was very thorough so that she had not felt the need to pursue further information on the internet or any other sources. This is a comment which could reflect a similar sentiment to that expressed by the previous patient, in which she had trusted the advice she had been given by the health professionals and that if she had needed to know additional information, she would have been informed. Mrs Hunt's experiences had so far found this position to be accurate.

7.2.4 *Patient agency*

Mrs Hunt's desire to know if she had Wolfe-Parkinson-White syndrome occurred after she had seen both the specialist and the nurse specialist. It was a question which arose in response to the more in-depth reading material given to her by the junior doctor. Mrs Hunt's opening comments in this conversation were that she was really pleased she had found out what was wrong with her and how educational the experience had been. She added that she had not really known much about her body. This may reflect the intense personalisation and mediation of knowledge that she received from both the specialist and the nurse. The written text from the specialist reiterated and reinforced some of what was said in that consultation, but the mediation of the second text was highly personal and highly interactive. These literacy practices surrounding the literacy events were instrumental in Mrs Hunt's learning.

7.3 Mrs Lewis

Mrs Lewis was in her mid-80s and had been diagnosed with angina ten years previously when she was admitted to hospital. She lived independently and still volunteered in the community. She was involved in social clubs and kept a vegetable garden and hens. Once admitted to hospital and into the AU, she was seen by a geriatrician, then a cardiologist, and then finally by the cardiac nurse specialist. These visits took place beside the patient's bed. The curtain between Mrs Lewis and the neighbouring patient remained permanently closed the whole time I visited her. The curtain at the front of the bed when open, looked straight into the pod's nursing/medical station where consultants and their juniors congregated and prepared before launching into ward rounds.

Mrs Lewis' opening conversation with the cardiologist reflects how Mrs Lewis presented just after admission to hospital. It shows how she understood her illness at that point, especially line 318 where she surprises the doctor.

- 312 Dr: *So how are you today?*
- 313 Mrs Lewis: *I am well thank you.*
- 314 Dr: *You're well.*
- 315 Dr: *So you got a bit of angina yesterday?*
- 316 Mrs Lewis: *Yes*
- 317 Dr: *Bit longer than usual?*
- 318 Mrs Lewis: *Um, I've never had it before.*
- 319 Dr: *Never had angina before?* [surprised]
- 320 Dr: *I thought you had ah stents put in before previously.*
- 321 Mrs Lewis: *Yes, but I had TIAs.*
- 322 Dr: *Ok*
- 323 Dr: *You never had chest pain before?*
- 324 Mrs Lewis: *No*
- 325 Dr: *Ok. No heart attack before?*
- 326 Mrs Lewis: *Um I think I did.*
- [Later on]
- 327 Dr: *How bad was this, on a scale from 1 to 10, how would you rate this*
- 328 *one? Ten being the worst pain ever and.*
- 329 Mrs Lewis: *Oh about [pause] six.*

- 330 Dr: *Six? Ok so it was moderate.*
- 331 Mrs Lewis: *It was more, it was, I [pause] I've had a heaviness and I*
332 *didn't know what it was so I put up with that.*
- 333 Dr: *For how long?*
- 334 Mrs Lewis: *On and off, off and on, for some weeks.*

Mrs Lewis had been experiencing moderate pain intermittently for weeks. It had become severe so she had used her angina spray for the first time in the eleven years she had been carrying it around.

- 335 Mrs Lewis: *And then the heaviness got a bit more severe and I thought I*
336 *had better use my puffer . . . for the first time ever [great emphasis]*
- 337 Dr: *The red one?*
- 338 Dr: *Yes?*
- 339 Dr: *Under your tongue?*
- 340 Mrs Lewis: *So I used that.*
- 341 Dr: *Ah ha*
- 342 Mrs Lewis: *And then after 5 minutes the pain was still there so I rang an*
343 *ambulance and had another puff.*
- 344 Dr: *And then it's easing? Easing?*
- 345 Mrs Lewis: *Went away.*

The consultation continued with a physical examination, questions about Mrs Lewis's social situation and then a declaration that she had had a tiny heart attack. She was told that she would not be able to drive for at least two weeks because of New Zealand law prohibiting driving after a heart attack. Mrs Lewis's response, after the long pause, was a challenge.

- 346 Dr: *After a heart attack you are not allowed to drive for two weeks.*
[Silence for 4 seconds]
- 347 Mrs Lewis: *When was I told that? [Emphasised]*

Mrs Lewis was visibly upset by this news, which was not surprising given the full and active life she led. The conversation progressed with Mrs Lewis asking pertinent questions of the doctor when she either did not understand or wanted to query what she was being told.

- 348 Mrs Lewis: *You said something in my carotid artery.*

349 Dr: *Yeah, a noise is there. It's due to the narrowing of the carotid*
350 *arteries. Yeah, with a history of mini stroke um it is likely due to the*
351 *narrowing of the arteries, narrowing of the arteries everywhere at your*
352 *age. If you have no symptoms, no treatment needed.*

Mrs Lewis here moved in the conversation to seek clarification and understand her condition more fully by understanding what had caused it (lines 347-351). She then moved on to understanding her condition's care and her treatment options as well as furthering her understanding of her condition's causes (lines 352-362).

353 Mrs Lewis: *Can you put stents in there?*

354 Dr: *Can do. But a risk of stroke.*

355 Mrs Lewis: *Do you think it was a clot?*

356 Dr: *It is a small clot. Heart attack is due to the plaque rupture in the*
357 *arteries.*

358 Mrs Lewis: *So these injections will stop it?*

359 Mrs Lewis: *And dissolve it?*

360 Dr: *Yeah, prevent it from getting bigger or the tablets and the tablets.*

361 Mrs Lewis: *And why do I have to stay for two days?*

362 Dr: *Because you need to have two days of injections.*

363 Mrs Lewis: *Oh, I see. Yeah*

The consultation with the nurse specialist occurred an hour later. In this particular session with the nurse specialist, the nurse was sitting on one side of the bed, close enough to touch the patient. The nurse closed the curtains. This consultation began with the following dialogue.

364 N: *How have you been? This isn't a new thing for you is it?*

365 Mrs Lewis: *Well I didn't know what angina was. I knew I knew what*
366 *caused it.*

367 N: *Yes*

368 Mrs Lewis: *Cause I worked for a doctors.*

369 N: *Yes*

370 Mrs Lewis: *So I know a bit, a little bit... .. But I didn't know, I thought*
371 *that when you got an angina attack you went ah [exhales breath and*
372 *clutches her chest], you know?*

373 N: *Yes, like the movies.*

374 Mrs Lewis: *Like this, a really sharp pain, but it is not like that. I've had*
375 *this dull ache, here [points to her chest], for some time. I just thought I*
376 *was over doing it, so I stopped digging, have rest for a few minutes, it*
377 *would go away, I'd do a bit more and*

Despite the nurse opening her conversation asking whether the angina was new to Mrs Lewis, it *was* actually a new thing for the patient, reinforcing how she presented to the cardiologist an hour earlier. By the time Mrs Lewis talked to the nurse, she realised her recognition of her angina pain symptoms had not been accurate and was able to explain her mistake. This was in contrast to her declaration to the doctor an hour earlier that she had never had angina prior to the event which had brought her to hospital. As she described to the nurse, she thought it was a huge pain and as the interview progressed and different things were volunteered it seemed that the patient had actually had angina. So the nurse was right—probably from reading the patient notes, but I was not privy to them. However, the patient had not recognised that she had had angina because she was not recognising the symptoms. She recounted going to see her GP—doctor and being asked if she had chest pain, to which her answer was always in the negative. Below is an incident where the patient previously had described waking at night with an indigestion type pain and how she managed this with her general practitioner.

378 Mrs Lewis: *And I went to my doctor about a month ago, for my three-*
379 *monthly check, told him about it, and I said, "Do you think if I took*
380 *Losec at night as well as [Inaudible, but the name of another drug], that*
381 *would help it?" And he said, "Yes" and he prescribed more. But then I*
382 *thought, no I'm going to manage this myself. I don't need Losec at night.*
383 *I will just eat a bit earlier and let my food digest before I go to bed.*

384 N: *So does it all work?*

385 Mrs Lewis: *Well I came in here. [laughter]*

"*Coming in here*" meant that she had ended up in hospital. The nurse in this situation went on to explain what the Losec actually does and why it might be helpful, but she also went on to explain what could have also been going on (and what the nurse thought was going on, but softened the message), that after dinner the blood supply of the body centres around the tummy (the word the nurse used) to distribute the nutrients and this concentration of blood away from the heart can

cause angina. She went on to advise if burping did not help with the pain, the patient should use her spray. The patient responded,

386 Mrs Lewis: *I didn't realise that I could use it like that.*

7.3.1 Text mediation

This patient got the information she needed to manage her condition in hospital, not from her GP, but from a cardiac nurse specialist. The nurse carried with her an angina pack, prepared for angina patients by the cardiac nurse specialist staff for use with in-patient angina patients. The pack was an A4 cardboard folder. Details of written material found in the folder are in Appendix 1. The A4-legal-sized pamphlet, "Managing your Angina" (Heart Foundation, 2011b), was part of the pack and is profiled in Chapter Six.

The relationship between the angina pack and the health professional's conversation with Ms Lewis loosely followed some of the content covered in the pack. However, the nurse did not give the angina folder to the patient and the patient did not ask for it either. Despite this, the topics covered during the conversation could be found in the pack. There was some oblique reference to the written information during the 30-minute conversation in that the nurse made decisions and justified why she was not giving Mrs Lewis the contents of the angina pack which dealt with risk factors, diet and other topics covered in the angina pack (see Appendix 1):

387 CNS: *Back to your doctor in a couple of weeks. Um, as far as looking*
388 *after yourself when you go home, I tend not to talk to you um-need-I*
389 *don't think I need to talk to you about risk factors, changing diet,*
390 *modifying, all that sort of stuff really, because you're, you're the grand*
391 *old age of whatever. You, you don't need to be making huge changes*
392 *now. But it is a good idea to when you get back home, to rest for a little*
393 *bit for a few days, not be doing too much rushing about, um not be doing*
394 *too much heavy lifting and that sort of thing, and you know, vacuuming,*
395 *making beds.*

Prior to talking directly about the written text, the nurse had explained how to react to an angina attack, what the patient should do (sit down, wait, spray, wait five minutes, try again etc.) to manage it. The conversation then moved to responding to Mrs Lewis's questions about her indigestion, the problems the patient was having with her GP, and how to change GPs. How much exercise

Mrs Lewis was doing and why, and how she should continue, as well as how she should ease back into her life without heavy lifting were the next topics of conversation, followed by a question from the patient about how many eggs she should be eating. Mrs Lewis was then invited to attend a cardiac rehabilitation class, but she declined stating she had already attended such a class previously. The conversation around “Managing your Angina” text and the giving of the text came right at the end of the nurse-patient conversation. However, the nurse was very deliberate and careful about even giving this pamphlet. The nurse selected from the folder which booklet to give Ms Lewis rather than giving the folder to allow the patient to look through it. She expressed her reservations as she leafed through the pack.

396 CNS: *I'm going to leave with you—I'm just debating actually whether I*
397 *should give you—I think I might just, have a look at that. That's your,*
398 *that's about angina, okay.*

399 Mrs Lewis: *Thank you.*

400 CNS: *In the middle is about the um action plan. So that's what I was*
401 *talking about with the spray. So when you um have a spray and think*
402 *“Oh gosh, that hasn't gone away. What did that nurse say?” That's what*
403 *I said. Basically too, if you have, if you have a spray, cause you've dug*
404 *the heavy garden. So you have a spray, everything's fine then, and that's*
405 *what you need to do. If you become, realise that you're actually having to*
406 *have the spray more often each day, um or it's waking you when it didn't*
407 *used to, or you know it's becoming more um frequent, then you need to*
408 *go and talk to the doctor and say, “This isn't quite right.” They might*
409 *need to increase the medication a bit. Okay?*

410 Mrs Lewis: *Yes well that'll be very helpful thank you.*

This leaflet used here by the nurse at the end of the conversation reinforced parts of her previous dialogue with the patient, and the conversation ended straight after this. Mrs Lewis was discharged from the hospital a few days later with a discharge letter and a handwritten summary of each drug she was on with what it was for and how to take it. This was given to her by the nurse looking after her at the time of discharge. However, the medication summary and the discharge letter had been foreshadowed by the geriatrician who had attended Mrs Lewis when she was first admitted into the AU. The geriatrician had said that when Mrs Lewis did go home, someone would explain her tablets, and it was usual that she would also get a copy of the discharge summary. He explained that this was a copy of the

letter that goes to the patient's GP that lists tablet changes as well as other patient details. An excerpt of the letter is in Figure 22

7.3.2 Patient response to the text

I asked Mrs Lewis how she found the "Managing your Angina" pamphlet. Her response was emphatic.

- 411 Mrs Lewis: *I think it is a marvellous paper.*
412 Mrs Lewis: *It explains everything I need to know.*
413 Mrs Lewis: *I didn't know anything about angina mmh. I hadn't been*
414 *told anything about it. The um type of pain, I knew it was chest pain and*
415 *I knew it could travel down your arms and I've got something upon my*
416 *fridge that, that tells me when people are having a stroke , you know,*
417 *speech, and arms out, and [pause] all that sort of thing you know [pause].*
418 *I know all that.*
419 Mrs Lewis: *But I didn't know for myself [small laugh] you know, pain,*
420 *that wasn't pain really, this heaviness [pause] was angina. But now*
421 *reading this it's really helped me.*
422 R: *Oh good, so that has been most helpful in identifying your symptoms.*
423 Mrs Lewis: *Yeah.*

When asked if Mrs Lewis had anything that she would like to see added to the pamphlet, she responded:

- 424 Mrs Lewis: *But the thing this doesn't tell me is, for instance, I'm a*
425 *member of [the name of a local social action club]. It doesn't say in the*
426 *future how I should, how I should manage my life socially say.*
427 R: *Yeah yeah*
428 Mrs Lewis: *Should I go or not?*
429 Mrs Lewis: *Yea, I will get excited. When I say excited, you know I'll be*
430 *stimulated, and is that going to bring on an angina attack?*
431 R: *Mmh, yeah well those are good questions to ask.*
432 Mrs Lewis: *Well I think it might say there, it is hard for me to think it*
433 *through um. Perhaps it should tell you how to pace yourself, knowing*
434 *yourself.*
435 Mrs Lewis: *Knowing your capabilities, and how you react to certain*
436 *situations, whether to avoid them or embrace them.*

Once again, timeliness of information and access to text was highlighted as well as her relationship with her own GP. In lines 437-460, Mrs Lewis described her habit of seeing her GP every three months and a typical visit. It is pertinent to

note how Mrs Lewis reported the questions the GP asked of her and the mismatch between what her perception of chest pain was and what she now understood about angina pain.

- 437 R: *When do you think you should have got it?* [the leaflet]
- 438 Mrs Lewis: *I should have got that in 2004 when I had stents put in my*
439 *heart. I was given a lovely book, a beautiful book and I was given a*
440 *picture of my heart before and after the stents went in. I've got that at*
441 *home, . . . but it just says how to manage after a heart attack. But it*
442 *doesn't talk about angina.*
- 443 R: *Did you know you had angina in 2004?*
- 444 Mrs Lewis: *No. I thought angina was, my idea in my head, I thought*
445 *angina was a huge pain. I didn't ever know it was just a dull ache but I*
446 *know now.*
- 447 R: *No. And you've seen your doctor every three months since?*
- 448 Mrs Lewis: *Yes I do. And all he says to me is "Have you had chest pains?"*
449 *and I say "No."*
- 450 Mrs Lewis: *Yes, and I think that this doctor is interested, . . . but only for*
451 *20 minutes. The next time I go he says to me, "What are you here for?"*
- 452 R: *Mmh*
- 453 Mrs Lewis: *You know, I only go every three months. I'm I'm just, I'm*
454 *just, I'm just another 20 minute gap, that's how I feel. But he is pleasant*
455 *to me. He is very nice—a very nice man.*
- 456 R: *But not up to scratch?*
- 457 Mrs Lewis: *Well not up to my expectations. I don't feel that he's, I don't*
458 *think that he even thinks about what he said to me last time he saw me*
459 *which I suppose is understandable, but he doesn't look at me. He's*
460 *looking at his screen mostly.*

Despite Mrs Lewis having diligently seen her doctor every three months, and kept her angina spray up to date, her access to meaningful information about managing her angina only occurred after her admission to hospital which resulted from a change in her angina condition. Her comments about her own GP reveal something of the journey Mrs Lewis took while in hospital to re-evaluate how she was managing her health when back in her community.

7.3.3 Discharge letter

Standard operating procedure for discharge from hospital is that a patient gets a copy of the discharge summary sent to their general practitioner. This discharge summary is a summary of the patient's notes. I did not have access to patients'

notes as I did not specifically request it as part of the consent procedure and ethics applications but Mrs Lewis shared her copy with me. In addition, none of the patients I worked with, to my knowledge, saw or requested to see their patient notes so in this regard, it was not part of the written texts patients were exposed to. Patient notes in a hospital are not shown to patients but patients can request to see their notes. I was not privy to the mediation of this letter to Mrs Lewis. It is, as the specialist said, a copy of the letter sent to her GP. The patient is not the intended audience for this document and its vocabulary, layout, and abbreviations make it inaccessible to a non-specialist audience. However, it is the only written summary Mrs Lewis was given which recorded her hospital journey in any form. Being given a copy of a letter intended for somebody else positions the receiver into a passive role at worst and perhaps a mail carrier at best.

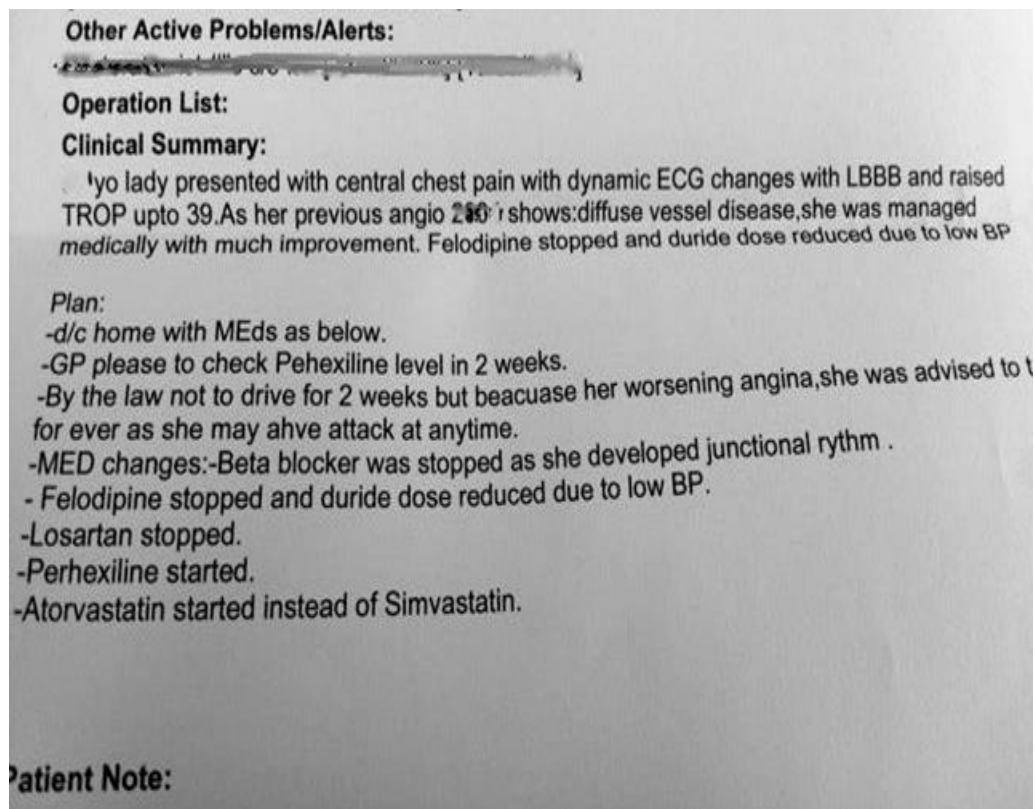


Figure 22: Extract of patient discharge letter

Mrs Lewis' story did not finish with her discharge from hospital. About twelve days later she was re-admitted with further heart problems. She once again saw the specialist and a nurse specialist and was discharged six days later. She said she received no written materials during this second stay in hospital.

7.3.4 HeLMS Survey

Talking through the HeLMS survey with Mrs Lewis and using it as a structured conversation along the way, brought deeper insights into many more aspects of her health journey and condition. Her scoring was well within the health literate range, according to the survey. However, reflecting on Mrs Lewis' journey reveals a prolonged period of time where her understanding and management of her condition had had major impacts on how she lived her life. She had been very pro-active. She had gone to her GP asking about her indigestion and even suggesting to her doctor what treatment she thought would be helpful, to which the GP complied. The GP did not realise Mrs Lewis was displaying further angina symptoms, so again could not help Mrs Lewis understand her condition any further. Mrs Lewis on the other hand was caught not knowing what she did not know and therefore answering the GP's questions according to her current knowledge and understanding of angina.

7.4 Mrs Roberts

Mrs Roberts was an 80 year old woman, self-identifying as Māori whose first primary language was Māori (referred to as Te Reo Māori) and whose second was English. She had collapsed in the community and been admitted through the ED. She had a moderate to severe hearing impairment. Mrs Roberts was in a small cubicle in AU. The cardiologist came into the cubicle with two other more junior doctors and the patient's nurse. The nurse was backed up against the curtain as it was a confined space. This patient was also an angina patient. Her exchange with the specialist cardiologist resulted in a change to her medication (as it transpired it was her medication that had caused her collapse), and a request by the specialist for her to go to see her GP for follow-up. Mrs Roberts left the hospital without any written material from any source or any cardiac nurse consultation. The nurse in charge of mediating any written material was not working that day. At this time, Māori and non-Māori services were delivered separately. No Māori cardiac nurse specialists were available that day. The patient was discharged by the nurse on the ward, but did not receive any written information to support any discussion of her condition or care. Nor did she or any member of her family seek out any information from the pamphlet holder in the AU. As the researcher, I intended to

have a follow-up visit with Mrs Roberts at her home to talk further with her and also to go through the HeLMS survey but I was unable to contact her. Her hearing impairment precluded any telephone conversation with her.

While I was talking with this patient in hospital, she admitted that she had sent her husband home because he did not cope very well with sickness and hospitals so it was better for him not to be with her there. At the time of data collection, if a patient self-identified as being Māori when they were admitted to hospital, they were automatically streamed into any available Māori services available at the hospital. Māori cardiac nurse specialists was one such service.

The lack of written patient information/text was something as a researcher I reflected on early on during my time at the hospital. The following excerpt from my reflections speaks to this.

461 *There is so little written text. . . . It places the patient in a perpetuating*
462 *passive position. They don't know what they don't know a lot of the time*
463 *maybe. However, for some they may be glad because nothing is*
464 *demanding of them in terms of reading or numeracy ability overtly.*

However, later that day, I witnessed a discussion with a patient about risk and that risk was expressed as percentages, with the example being a 7% blood clotting risk, weighed against the 1% bleeding risk. This required a reasonable understanding of the measurement of risk in order for the patient to understand what these percentages meant in her particular context.

7.5 Mrs Burns

Mrs Burns was in the 65–75 year old age bracket and was admitted to hospital after suffering a minor heart attack. I accompanied her on her initial first few days after which she withdrew from the study. Mrs Burns's use and interaction with the texts given to her by the cardiac nurse appear to be very limited. It would appear at the end of her treatment that she did not understand what her condition was nor how it had been and was being treated. The literacy events surrounding her journey appear to be limited to the written texts the cardiac nurse specialist gave her. During the cardiologist's visit (attended also by his team) Mrs Burns had been informed that because of other potential neurological complications associated with her recent falls (*"You've had a little bit of bleeding inside your*

head.”), there was a conflict, “*The treatment for one [the heart attack] is a bit of a problem for the other.*” The specialist regarded this as a problem and proceeded to explain it to Mrs Burns that stenting required the use of good anti-clotting medication which would make any further falls or internal bleeding a disaster. He concluded:

- 465 Dr: *At this stage it is time to do a complete overhaul of your complete set*
466 *up and tackle you as a person rather than each problem that crops up.*
467 Mrs Burns: *Alright*

The specialist needed more information about Mrs Burns’s home context before taking a decision on her treatment so requested further assessments. There were no written texts used with the patient during the fifteen minute consultation.

7.5.1 Text mediation

Mrs Burns was transferred later that day from the AU to an intensive cardiac unit, a smaller unit where beds are in a single line. The cardiac nurse specialist visited her the following day. She sat beside Mrs Burns in the coronary care unit where patients are intensively monitored. The cubicles are individual, walled on three sides with a privacy curtain on the forth side. The cubicles all face outwards in a row towards the clinical staff station.

The nurse followed a pre-established order for her conversation with Mrs Burns. She began by explaining how the heart operates and what had happened to the patient’s heart. The nurse used her fist and words to explain the workings of the heart.

- 468 N: *Your heart is a pump about the size of your fist that sits in the middle*
469 *of your chest, so it is a very strong pump because it pumps blood all*
470 *around your body.*
471 Mrs Burns: *Yes [nurse continues her explanation].*

She then moved onto the patient’s risk factors which mirrored a sheet in the Angina Information Pack folder the patient was given at the end of the session. The risk factors were listed as cigarette smoking, high blood pressure, high cholesterol and fat levels in blood, overweight, diabetes, family history of heart disease, over 50 years of age, stress, and physical activity. The nurse proceeded

to go through each of these risk factors separately and then went on to point out the “Food Label Reading” leaflet, and the “Healthy Eating for your Heart” leaflet. The conversation then moved on with the patient wondering if her vacuuming of her house had caused her heart attack to which there was no response. The mediation of the text was a discrete action, separate from any of the dialogue that had taken place previously. At the end of the session, the nurse gave the folder to the patient.

472 CNS: *This folder here has some information in it. This sort of talks*
473 *about label reading which is ah fat content in food* [intimated towards the
474 “Food label reading” leaflet].

475 Mrs Burns: *Yes*

476 CNS: *This is about the cardiac rehab course that we run here at the*
477 *hospital so we will give you a ring and invite you to come to that . . .*
478 [more description of the classes]

479 Mrs Burns: *Mmh*

480 CNS: *And “Healthy eating for your heart” that is another little dietary*
481 *pamphlet.*

482 Mrs Burns: *Right*

483 CNS: *Guide to your, this is the one you need to read. It tells you all*
484 *about the heart attack and at the back here is the angina action plan.*
485 *That’s what I explained to you before, the GTN spray.*

486 Mrs Burns: *Yes, ok*

487 . . . [talk of mother’s health]

488 CNS: *So looking at your risk factor action plan, this is what we have*
489 *discussed this morning.*

490 Mrs Burns: *Mmh*

491 CNS: [More talk of exercise and smoking] *Ok so I will leave you with*
492 *this. That’s the pack. So you can peruse that.*

493 Mrs Burns: *Good, thank you very much.*

Mediation of text in this instance was about introducing the folder or pack to the patient and highlighting to her the content and items that she could read later. Previous descriptions and explanations of the heart and heart function did not refer to text. There was little direct mediation even of the 48 page booklet, “Guide to Your Recovery after a Heart Attack”, that the nurse requested that the patient read, except for a reference to the angina action plan. No checking of

understanding or teach-back or reformulating of the critical information needed was undertaken by the nurse.

7.5.2 Patient response to the text

In a follow-up interview with Mrs Burns about the nature of her response to the text she said:

494 Mrs Burns: *It explains everything very well, doesn't it? . . . I'd read a bit*
495 *and then I'd sort of fall off to sleep and then I'd read a bit more and then.*

496 Mrs Burns: *I think a lot of it is common knowledge but these warning*
497 *things [points to page 42 "Angina Action Plan"] yeah, no, I've got that*
498 *spray now . . . Sit down. (reading) Well that's what I did. Took these*
499 *breaths and then I decided to go to bed. And I should have pressed the*
500 *thingummy on my wrist, but I didn't.*

501 R: *Oh have you got a medical alert?*

502 Mrs Burns: *Mmh, a St Johns thing.*

After questions concerning anything she had specifically wanted to know or understand better about her condition she responded in the following way:

503 Mrs Burns: *Yeah, I think the book's got everything in it really, hasn't it?*
504 *Yes I know I've got to stop this smoking thing. It is very hard when*
505 *you've smoked for years.*

506 R: *So probably for you in here the stop smoking thing is probably quite*
507 *important is it?*

508 Mrs Burns: *Yes well I've been cutting down, trying to cut down, that is*
509 *important I know that is.*

When asked about her information on recognising symptoms or signs, she referred to her husband's heart condition symptoms and how she had remembered those. She did not refer to the book or the previous conversation with the cardiac nurse specialist concerning this. She also referred to her mother and had realised after her conversation with the nurse the previous day that her mother had probably suffered from angina but had never told her directly. She had found small pills in her mother's clothes after she died, which the nurse specialist had told her was the way angina was treated before GTN spray. Mrs Burns seemed to use her relationships with others to gather information about her condition and help with decision making.

Mrs Burns then brought up the conflict in advice she had had from the cardiac nurse the previous day and the dietician prior to that. She read from the book:

510 Mrs Burns: *And it says here, "Rather than using several protein rich*
511 *items such as cheese and meat, use vegetables to flavour main dishes."*
512 *Well the dietician lady here said to me with me it's, with this weight thing*
513 *eat plenty of cheese you see.*

514 R: *Mmh complicated.*

515 Mrs Burns: *Yeah it is you see that part of it. She said to go on the pale*
516 *blue milk not on the bright blue milk. [pale blue is lower in fat]*

517 R: *What are you going to do with that?*

518 Mrs Burns: *Well she said you need that to build*

519 R: *How do you think you will manage that?*

520 Mrs Burns: *And she said you should put grated cheese on things you*
521 *know, cheese with this and cheese with that which I've been doing and*
522 *now I read that.*

523 R: *Do you know what is actually wrong with your heart Mrs Burns?*

524 Mrs Burns: *Oh it's um something, pulpa what do you call it?*

525 R: *Palpitations?*

526 Mrs Burns: *Palpitations and something isn't it? Yes I've got an uneven*
527 *[inaudible] that's only happened in the last . . . since all of this [referring*
528 *to her stressful life circumstances].*

I did not witness Mrs Burns asking about this apparent conflict in advice concerning her condition management. She had not written in the book and when asked how she might use it once she left the hospital, her response was to stop and exclaim:

529 Mrs Burns: *Well I won't be looking at this thing!* [laughter]

530 R: *What's that?*

531 Mrs Burns: [holding the page up] *Sexual function!*

532 R: *Oh you never know. . .* [both laughing]

533 Mrs Burns: *Oh the thought of it!* [more laughter]

She then recounted information and direction she had received from her son to exercise more. After this interview Mrs Burns chose to withdraw from the study, citing that her son had expressed the wish that she withdraw because she already had too many other things to be dealing with in her life. This precluded any further discussions with her and also the completion of the HeLMS survey. She

did agree however to being contacted in the coming months by telephone for a follow-up conversation.

I spoke to Mrs Burns again some eleven months after she had been discharged from hospital. She said she had been back and forth to the hospital for various specialist appointments and that she had stopped falling and had also stopped smoking. She had used the stop smoking product given to her at the hospital and had continued on with it. She said that her general practitioner was particularly proud she had done that.

In response to a question about diagnosis for her heart, she said she was not sure what she had had. I asked if she had had an angiogram and she said she wasn't sure, but reiterated that "*Everyone looked after me so well*" although she said she was still not getting any more home help. Her neurosurgeon had discharged her but she was still not back driving. She was unsure how or when this could happen. As far as managing her dietary conflict, fat or no fat, I asked her:

534 R: *Your diet. Cause remember the dietician was saying eat lots of fat*
535 *and ice-cream and the nurse was saying no fat, no ice-cream.*

536 Mrs Burns: *I know!*

537 R: *What did you do?*

538 Mrs Burns: *Well I like a bit of ice-cream.*

539 R: *So did you go with the low fat for your heart or did you go with the*
540 *dietician's advice for your body?*

541 Mrs Burns: *Well, a bit of both really.*

She had continued on much like before, cooking larger quantities and freezing them for future meals. In response to a direct question concerning her heart:

542 R: *What do you understand is wrong with your heart?*

543 Mrs Burns: [5 second pause] *Um, [pause]*

544 R: *You can say you are not sure*

545 Mrs Burns: *I don't know [laughter]*

546 R: *That's alright*

547 Mrs Burns: *Well it was like a quiver and then I had those pains down my*
548 *arms.*

The discussion continued and then she volunteered that the doctors had put her on a drug, which she named. It transpired that the drug is used to treat osteoporosis, the symptoms of which she had described earlier in the conversation.

For Mrs Burns, her heart condition had compounded a neurological condition which seemed to have taken precedence in her view of her health. The fact that she offered the name of the drug she was on in response to the question about her heart could suggest she believed the medication was actually for her heart condition. Not having clarity about the tests undertaken as an outpatient at the hospital or her current heart status could indicate that she either had not had any more cardiac follow-up or that if she had, she had not understood or remembered what the outcome had been. Her diet had not changed significantly to indicate that she was eating for a healthy heart and she still had the same unanswered question over conflicting dietary advice. However, the fact that she had stopped smoking after so many years, was an indicator that her stays in hospital had produced change. Stopping smoking was the area in the book (p. 39) she had referred to while reading it in hospital. She had been seen by and received support from a specialist stop smoking nurse as well as received more stop smoking information from the cardiac specialist nurse.

Her comment about being so well looked after by everyone while she was in hospital contrasted with her limited knowledge of her condition and may indicate her style of patient agency. For her it seems compliance was how she interpreted and acted in her role as a patient. She had attended the necessary appointments, stopped smoking, and had recovered.

7.6 Mr Cox

Mr Cox was a participant whose journey from entry into the hospital system to exit was transformative. Not only was he caught by his GP in time and admitted to hospital for further investigation, Mr Cox himself became engaged and aware of his condition, its causes and its management. His story below recounts parts of that journey, especially where literacy events and practices were present. Mr Cox, a man in his mid-fifties and the youngest participant in the research, came to ED after being referred on by his GP who he had gone to visit because of his

constantly sore elbow. I met him just after he had been admitted to the AU and was waiting for assessment. He happily agreed to be part of the research being “*happy to help if it helped.*” This recording (lines 549-555) was taken in AU where Mr Cox was in an open area, close to the nurses’ station. He was in hospital pyjamas at this point. He had come into hospital in his work clothes which were lying beside him. During the course of his stay in hospital (over nine days) Mr Cox would often get back into his clothes rather than wear the hospital pyjamas.

- 549 R: *What made you go to the doctor?*
550 Mr Cox: *Oh just the pain there* [points to elbow].
551 R: *Was it unusual?*
552 Mr Cox: *Yeah it was unusual . . . I never go to the doctor actually. . . . I*
553 *hate going to doctors.*
554 R: *But you’ve got a doctor? You’ve got your doctor that you go to?*
555 Mr Cox: *Yeah yeah* [Name]

Later he admitted that he never actually told his doctor about his sore elbow, but rather got carried away answering the doctor’s questions about his chest. When he first came into the hospital, he came in thinking he had angina. He had asked his GP about it who had pointed to the number of cigarettes he smoked each day. He was dropping his smoking down to eight a day and was now thinking it was time to give up.

- 556 Mr Cox: *Oh yeah they say smoking’s bad for everything. Mum had*
557 *angina and she never smoked. Dad smoked like a train and died at 82.*

Soon after I met Mr Cox the newspaper trolley came along with a woman touting papers. She asked him directly if he wanted a paper to which he replied that he did not, that he never read the paper and that it is just filled with bad news. He was in the AU for most of that day, receiving a blood test and an exercise tolerance test before being transferred to a cardiac ward later that evening.

- 558 Phlebotomist: *Hello, Mr Cox, mind if I pop in and collect a blood sample?*

There was no written literature about the exercise tolerance test but a new text describing the test did appear in the hanging pamphlet holder on public display in the ward a few weeks later.

7.6.1 Questions

A doctor dropped in to visit Mr Cox in the cardiac ward and asked if he had any questions. In the background of the audio recording during this time is a clearly audible conversation that a neighbouring patient is having on the phone sorting out her personal affairs. I have included this type of description to continue to keep the context of these descriptions to the fore, as the AU was such a busy and at times noisy place, where personal privacy was sparse. Mr Cox did not have a question to ask the doctor but he said to me afterwards:

559 Mr Cox: *The worst part, hardest part is, what questions to ask. "Have*
560 *you got any questions?" You know, well, well. "Can I have a*
561 *cigarette?" You know what I mean? [laughs]*

Mr Cox's question was to illustrate that he was struggling to know what to ask; what did he not know that he should know? Up until this point he had not had any written information as the focus was on diagnosis by clinical staff to find out what had been going on. A person then came to take him away to have an x-ray.

The cardiac nurse who visited him in his 4-bed room had the "Coronary Information Pack" (see Appendix 1) with her and went through the contents with Mr Cox. She showed him the results of the risk factors sheet, which he subsequently filled in and scored himself. He discovered by doing it that he had too much fat in his diet. She gave him the "Coronary Angiogram" pamphlet, "Managing your Angina" pamphlet (which he later read through), GTN spray administering, the healthy eating chart, and an invitation to attend cardiac rehabilitation classes. Mr Cox had skim read the angiography pamphlet but said he had been told enough to feel comfortable. I asked if just hearing was enough for him and he said, "*I like to hear it then read it and then I know.*"

Mr Cox's reflection on this session with the nurse was that he had not really got a lot out of his session because it was common sense. However, he had found the information on diet useful. He reflected that he had known for a long time, intuitively, that there was something wrong but had hoped that it would go away.

Mr Cox had deliberate mediation of texts by multiple nurses—the cardiac nurse specialist as well as the smoking cessation nurse. Each text concerned procedures

that Mr Cox was about to undergo. He felt prepared for his stent and had found the book (“A Guide to Angioplasty”) most helpful. It gave him the information about what was going into his body. The cardiac nurse had asked him if he could see himself not smoking in another two years’ time. She commented to me that he had deflected her question. “I find if they can’t [see themselves smoke free], then they often haven’t fully come around to the idea of quitting long term. Hence I dropped him back the “Quit” book just to help him along this decision process.”

Mr Cox did not refer directly to this booklet in any conversations with me, although he did stop smoking. Reflecting on any reading material (apart from his angiogram results poster) Mr Cox had read since returning home, he said he had referred back to the booklet on food and exercise once. Mr Cox had not found reading the various pamphlets difficult. He said he got the gist and then went back to re-read. He wished that all the information he needed was together rather than in separate pamphlets and booklets.

7.6.2 Pivotal texts

Mr Cox had been given a patient information sheet by the x-ray nurse and said he was not interested in it but had kept it because “*I haven’t got anything else to do*” he said. He was upset because he was not at work earning money. He had just had six weeks break from work because there had not been any on offer but work had just started again, making his position in hospital rather than at work very frustrating. He suspected angina because his mother had had angina. He said his heart was good and that he had got a lot of wind, just like his mother. He had recently cut down on the number of cigarettes (from 40 per day), partly influenced by his partner who had recently given up smoking. He was currently smoking between 6 to 8 cigarettes a day. His mother was the only person he knew with angina. A couple of his friends had just died from cancer.

When I was talking to Mr Cox on the second day, he said he was pretty sure he had angina, just like his mother. This could have been why Mr Cox picked up a brochure on angina from the pamphlet holder in AU the previous night.

562 Mr Cox: *I read a bit about angina last night.*

563 R: *Ah yeah. And have you still got it?*
564 Mr Cox: *Nah, I put it back. I had a quick squiz [look] at it. And ah yeah*
565 *[laughs] cause I get, goes in one ear and out the other. I don't absorb it.*
566 R: *Oh when you read it?*
567 Mr Cox: *Yeah when I read it I don't absorb it.*
568 Mr Cox: *I think the fact is that um avoiding it I suppose ... how does that*
569 *sound?*
570 R: *Good*
571 Mr Cox: *Yeah. Avoiding it. I don't want to know. I don't want it. I*
572 *don't want it. I'm one of these people who go "I don't want to get sick."*
573 *.. I just keep telling myself that. . . . And it is a positive thing.*

Despite his own analysis, nothing in Mr Cox's scores on the HeLMS survey suggested he had trouble with reading comprehension, nor any aspect of health literacy purported to be measured by the HeLMS survey.

Mr Cox was unusual in my research in that he received a copy of his angiogram results and his echocardiograph results. It was the only time I saw this happen among the patients I followed. I was not able to witness that mediation; however, Mr Cox was able to decode the results (shown in Figure 23) especially the meaning of the 95% drawn on it by the cardiologist. Mr Cox mediated the diagrams to me when he was showing me. The specialist had gone through what would happen next which was that he would put in a stent to open up the 95% occluded artery. Mr Cox said he was also told that the artery which was 20% occluded would heal itself if he gave up smoking and exercised. The impact of the visual representation of Mr Cox's heart on him was important. The 95% blocked artery was vivid and salient.

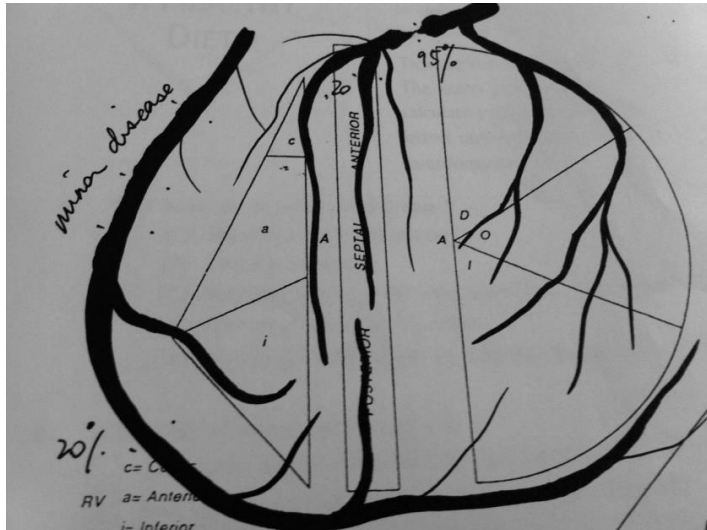


Figure 23: Angiogram results

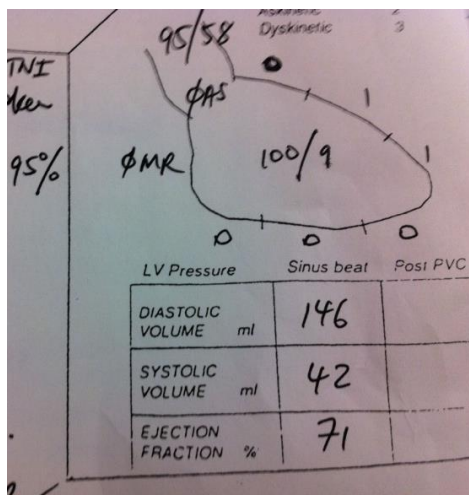


Figure 24: Pictorial angiogram results

The patient's reaction to this picture which was mediated to him earlier by the specialist was as follows:

- 574 Mr Cox: *Here's the blocked artery there . . . Pretty blocked isn't it?*
 575 R: *Yeah, it really is.*
 576 Mr Cox: *Oh shit that's me. That's inside me!*

He did not talk about or interact with the second picture (Figure 24), which I assumed was because it did not hold any meaning for him. Eight weeks later when Mr Cox had received a clearance from the cardiologist to continue on with his work and life, we reviewed his health journey. Mr Cox's angiogram print-out reappeared in the conversation.

577 Mr Cox: *Last thing I can remember was this feeling of something going*
578 *through my chest like someone poured water across it and that was*
579 *it. Right you can go now and then they come back with that horrible*
580 *photo* [laughs].

581 R: *Oh yeah that's a great photo though*

582 Mr Cox: *Yeah, yeah I've got that pinned on my wall* [laughs heartily].
583 *Oh no! When I think about a cigarette, I look at it.*

Mr Cox took a patient text which had been mediated and written on by a more knowing other (the cardiologist), which was highly personalised and not only used it to understand his condition more fully, but also re-framed it to become an artefact important to his condition management post-surgery. In this regard, the annotated patient text by the cardiologist was effective in increasing Mr Cox's understanding of his condition and application of that knowledge to the decisions he took subsequently in his every-day life concerning his health.

7.6.3 Bloods, numeracy and agency

Mr Cox was also given a copy of his blood test results (Figure 25) by the laboratory person who took the blood sample. Part of Mr Cox's interpretation of his results follows.

584 Mr Cox: *Cholesterol, the ultimate op-op-optimum is 3.4 and mine's 4.2.*

585 R: *Oh yeah*

586 Mr Cox: *And ratio total is 4.5 and I'm 5.1. So I'm only a little bit over.*
587 *A couple of years ago I was 14. . . .*

588 R: *And do you know like all of these symbols?* [pointing to greater and less
589 symbols]

590 Mr Cox: *Nah, I just know that, that's where it should be* [laughs] *and it's no –*
591 *that's all it means to me.*

The meaning of *range* and the *less than* and *greater than* symbols did not feature in Mr Cox's reading; in fact he admitted he was not aware of their significance. He was however, motivated to seek clarification on the aspects of the results he did not understand.

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	Ref Range	Units	
Cholesterol	< 5.0	mmol/L	6.0
Triglyceride	< 2.0	mmol/L	1.5
HDL Cholesterol	> 1.0	mmol/L	1.17
LDL Cholesterol	< 3.4	mmol/L	4.2
Total/HDL Chol Ratio	< 4.5		5.1

Figure 25: Blood test results

This dialogue portrays Mr Cox’s attempts to understand what the numeric results meant in Figure 25, remembering that part of the numeracy definition used in this research is “to be competent, confident, and comfortable with . . . what the answer means in relation to the context” (Coben, 2000, p. 35). Clearly here the patient struggled to not only decode the results himself, but also understand what they meant in relation to his condition and care. He displayed a pro-active stance by enlisting the registered nurse on-duty to assist him. This following interchange took place at the bedside in a ward dedicated mainly to cardiac patients. The registered nurse (RN) sought initially to minimise the conversation with her opening line (line 592). Mr Cox countered by pointing to the text and intimating he wanted help. The RN reiterates what is written, assuming Mr Cox understands the numerical concept of *range*. He did not understand it and expressed uncertainty in his reply (line 595). This was not addressed by the RN (line 596).

- 592 RN: *Oh Okay . . . So you are not going to record much* [laughs]
- 593 Mr Cox: *No, it’s just really what what ...* [pointing to paper]
- 594 RN: *These are the normal ranges*
- 595 Mr Cox: *Okay?*
- 596 RN: *Yeah. And this is what your range is like* [points to his result]
- 597 Mr Cox: *Which is . . . good or bad?*

- 598 RN: *Ah, you check your, the normal, against what your current reading*
599 *is, yeah.*
- 600 Mr Cox: *Yeah ... so that is just one point above isn't it?*
- 601 RN: *Exactly*
- 602 Mr Cox: *So that's not super bad, is it?*

Mr Cox in line 599 was still seeking clarification. He received some clarification but there were no attempts by the RN to reformulate, check for understanding or ask Mr Cox questions which may have provoked further learning. In this regard, the questions all came from Mr Cox, who was displaying a great deal of agency in continuing to seek clarification from the health professional. In line 600, Mr Cox sought meaning of the number in the context. In terms of his numeracy, he needed to know what the numbers meant for him. He received limited interpretation in return. In this dialogue there was potential for a lot more learning to take place. It was a teachable moment in terms of Mr Cox's results and the use of *greater than* and *less than* and *range* concepts on the blood test result, which Mr Cox was oblivious to.

After this dialogue between the nurse and Mr Cox, we talked about the impact of my presence as a researcher on him. He said that it had had an impact on him-it had made him more aware of what was happening to him, but he credited his partner with teaching him to be more aware of what was going on around him.

Another numeracy issue that arose for Mr Cox was the reading of food nutritional labels in his new quest to change his diet. His strategy was to remember the amounts he should be under (e.g. 400 for sodium) and focus on eating low amounts of salt, low fat meats, and more beans and grains. When quizzed about his maths in the supermarket when deciding on buying, Mr Cox used these strategies to keep it simple and just checked sodium and fat contents.

7.6.4 The outcome

Mr Cox eventually got his angioplasty and stent after a nine-day wait in hospital and then attended some of the follow-up cardiac classes run by the cardiac nurse educators. He was an active participant in the classes he attended, asking questions and reporting on his journey to recovery to the nurses in attendance. In that final appointment nearly two months later, the cardiologist gave Mr Cox the

clearance to return to work that he was after. He also gave him a copy of his clear echocardiograph results, pointing to his heart rhythms in Figure 26.

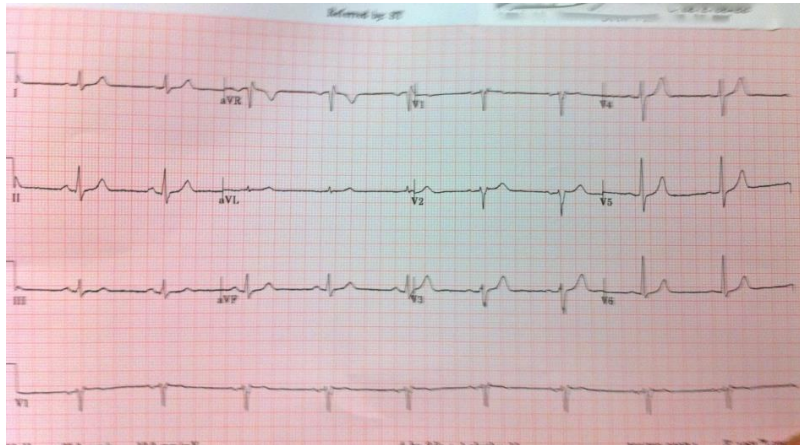


Figure 26: Echocardiograph

He asked if Mr Cox had had any angina, to which Mr Cox answered in the negative. This was a question which assumed Mr Cox knew what angina felt like and could identify it. The specialist then went through Mr Cox's medications to check against his records and to warn him about the pharmaceuticals he was taking. Mr Cox told the doctor that he was proud of himself for having given up smoking, and that he had bought a cooker so that he could get rid of the fat in his cooking, and about his now extensive exercise regime. The specialist took Mr Cox's blood pressure and Mr Cox asked for the result. Mr Cox was told he needed to follow up on his cholesterol with his GP. Mr Cox thanked the doctor for keeping him alive.

7.7 Mr Shaw

Mr Shaw, a man in his early sixties, arrived into ED via an ambulance. He had chest pain which prompted the admission to hospital. He had had a by-pass operation several years previously. This occasion was the first time he had managed this chest pain with an angina GTN spray, and found that it had actually worked. Mr Shaw was a participant who made large changes in his health literacy during his hospital and out-patient journey. His motivation increased as did his understanding and application of health information about his conditions. His case is briefly presented here and discussed further in the following chapter. Upon arrival to the hospital, Mr Shaw was transferred through to AU and saw the

cardiologist who arranged for further tests, as initial tests had come back inconclusive. At the end of the consultation, the cardiologist went through leave-taking and asked if the patient had any questions as he was exiting the area:

- 603 Dr: *Ok, see you later with that* [and goes to leave]. *Any questions?*
604 Mr Shaw: *No* [mumbles something unable to be heard]
605 Dr: *Alright, we will see you later.*

Leaving-taking utilises a highly conventional pattern; the use of ‘Ok’ winds up the conversation or is a pre-closing, and the ‘See you later with that’ a conventional formula for the closing. The invitation for questions by the doctor was an afterthought in this dialogue and was the only time the offer was made during the consultation. In fact, Mr Shaw did have questions, but for whatever reason, he chose not to ask them of the specialist or the nurse specialist. In a conversation with me after the doctor departed, Mr Shaw admitted to being concerned about the life-span of his earlier heart by-pass. I raised it with the nurse, who advised he would need to speak to the specialist about that.

After the specialist consultation, Mr Shaw saw the cardiac nurse specialist (CNS) prior to further tests as she felt it was important to go over a few things with him, especially risk factors given his health history. She asked him about his angina, to which he admitted having used his (expired) GTN spray for the first time. She then asked about the drug he was on for cholesterol management and whether he knew his cholesterol levels. He was not exactly aware of them so she proceeded to go through the blood results with him as well as other risk factors, especially diet and exercise. During the nurse-patient consultation, the nurse gave Mr Shaw a patient information leaflet entitled “Managing your Angina” (see Chapter Six). Prior to giving this booklet, the nurse checked Mr Shaw’s use of GTN spray—that he knew how to work it. She revised with Mr Shaw how to use the spray and gave the advice on the use and availability of aspirin and other tips to help with managing his angina.

She said she would give him a pamphlet about it.

- 606 CNS: *Ok, so I have got some information here for you called “Managing*
607 *your Angina.” There’s a little pamphlet and here’s your cholesterol*
608 *results, your latest results, and there are your levels there, written there.*

609 Mr Shaw: *So it is actually a little bit high.*

610 CNS: *It is a wee bit high still yeah and this good cholesterol, the HDL*

611 Mr Shaw: *Yeah*

612 CNS: *That obviously needs to come up to over 1 and now a good way to*
613 *get that up will be all your exercising, so that is a really good way.*

614 Mr Shaw: *Yeah*

615 CNS: *But another thing is fish oil, omega 3.*

616 Mr Shaw: *Omega 3*

617 CNS: *Yeah*

618 Mr Shaw: *I buy olive oil actually so*

619 CNS: [3 sec pause] *You have got to be a bit careful though 'cause if we*
620 *are using olive oil you might be using too much oil*

621 Mr Shaw: *Yeah*

622 CNS: *And then it will convert to fat and so that will then increase your*
623 *LDL.*

624 Mr Shaw: *Yeah.*

625 CNS: *Or your lousy cholesterol. If you use fish oil supplements or*
626 *omega 3 supplements, as in fish oil capsules.*

627 Mr Shaw: *Yeah*

628 CNS: *That just gives you a smaller amount of omega 3 which is safe for*
629 *your heart.*

630 Mr Shaw: *What about um tuna,*

631 CNS: *Yeah, tuna, and salmon,*

632 Mr Shaw: *I buy those little tins of tuna*

633 CNS: *Yeah, that's good. The deep sea fish have got lots of omega 3 so*
634 *that's good. And it is probably better if you buy the ones that are in*
635 *spring water rather than in brine.*

636 Mr Shaw: *Oh yeah*

637 CNS: *But if you are already using um your tuna and having salmon and*
638 *the deep sea fish, this is still only .86 so I think an omega 3 capsule*
639 *would still probably help.*

640 Mr Shaw: *So, what would that be, one a day sort of thing?*

641 CNS: *Two [pause]*

642 Mr Shaw: *Two a day?*

643 CNS: *Two to three a day*

644 Mr Shaw: *Okay, so what, spread them out or?*

645 CNS: *Yep have them all for breakfast or all in the evening and just buy*
646 *them at the supermarket*

647 CNS: *Yeah, [brand name] is probably one of the cheaper ones. So I'll*
648 *just put that in here as well [writes information into a leaflet in Mr*
649 *Frost's information folder].*

650 CNS: *Ok, So any further questions?*

Note in lines 616-634, the CNS realised that the patient thought fish oil was a cooking substance and went on to clarify and reformulate the fish oil into talking about capsules (line 625). The talk continues with Mr Shaw asking about what will happen that day, about the hospital process, what will happen next in his diagnosis and management and whether he will have to spend another night in hospital.

The nurse's reflections were on Mr Shaw's management of his condition and commitment to his wellness. She wondered whether he would continue to make the lifestyle changes he needed to make, given that he had also been diagnosed with pre-diabetes which he had also chosen to manage through lifestyle changes.

651 CNS: *He's had this by-pass and they think they are invincible after that*
652 *and so they use butter, and he said he was being slack with salt and now*
653 *he is pre-diabetes. Yeah, and he says he wants to use salt. Well you*
654 *can't go like this [motions with her hands] to them. You can only say*
655 *what, you can only, it's hard sometimes.*

656 R: *Are you left feeling like this man will spiral?*

657 CNS: *Yeah, well no, it depends. Hopefully we will capture him if he*
658 *wants to look after those grafts.*

The nurse then reflected on whether he had attended any cardiac rehabilitation classes and whether he might be interested in doing so. She determined to return and ask him.

When I followed up with Mr Shaw the following day, he admitted that he had not bothered to read the booklet:

659 Mr Shaw: *It covered things I already know at any rate.*

660 R: *Oh is that from previous angina?*

661 Mr Shaw: *Yeah, yeah, I had the same pamphlet from previous . . . pretty much*
662 *everything that we discussed yesterday.*

And later talking about angina...

663 Mr Shaw: *This was a completely different type of pain and stuff.*

664 R: *Yeah*
665 Mr Shaw: *So no I didn't expect it to be like that?*
666 R: *Mmh*
667 Mr Shaw: *But as I said, once I took the spray it actually started realising it is*
668 *most probably an angina attack.*
669 R: *Yeah, and did the doctor actually say to you in the end that it **was** an*
670 *angina attack?*
671 Mr Shaw: *No, they are still investigating it. They've actually changed my*
672 *medication.*

As it transpired, Mr Shaw did attend all six cardiac rehabilitation classes. When I spoke to him a few months later, he had journeyed some distance in his understanding of his conditions.

673 Mr Shaw: *Yeah, no, it's been quite good. Some of it is really interesting. The*
674 *main part was that I actually learned what created, what caused and what*
675 *cures, that it basically it was a little bit more informed than I knew about it*
676 *in the first place.*
677 R: *Yeah, Like the anatomy and physiology stuff or?*
678 Mr Shaw: *Yeah*
679 R: *Or actually understanding?*
680 Mr Shaw: *What the heart attack was and what the by-pass were doing.*
681 R: *Ah ok*
682 Mr Shaw: *So that was actually quite informative. And I asked a lot of*
683 *questions so 'cause I didn't know [laughs], 'causes nobody tells you.*
684 R: *Ah I'm interested so if you think back to the information you were given,*
685 *you know, like the information you were given.*
686 Mr Shaw: *Well in the beginning there was no information at all, it was all*
687 *guess.*
688 R: *For your by-pass?*
689 Mr Shaw: *Yeah it was all guess.*
690 R: *So it was—it was all oral by the bedside?*
691 Mr Shaw: *So there really wasn't a lot of um information there. But if I'd*
692 *come to a course like this I would have known a lot more about it and most*
693 *probably done it a lot differently as well.*
694 R: *Managing yourself through that time?*
695 Mr Shaw: *Yeah, yeah*
696 R: *Yeah*
697 Mr Shaw: *But um, um, yeah, it's been quite informative, quite interesting.*

698 R: *Cos I remember when you left the hospital last time, you left with*
699 *“Managing your angina” information and I remember talking to about it*
700 *afterwards when I talked to you last time, you weren’t that much interested in*
701 *it [laughter]*

702 Mr Shaw: *No I wasn’t.*

703 R: *And I’m interested in that because, is it because you had already read it*
704 *and it wasn’t giving you any new information?*

705 Mr Shaw: *It was more, yeah pretty much—it wasn’t giving you—all it did was*
706 *cover the basics it didn’t give you the information you needed to follow. If*
707 *you understand what I mean I thought yeah, it’s just old hat, nothing’s going*
708 *to happen again, but this time it did. It led to other tests.*

His re-admission into hospital, his subsequent follow-up by the cardiac nurse specialists and his attendance at the cardiac rehabilitation classes produced change in Mr Shaw’s personalised understanding of his condition and care.

7.8 Mrs Trent

Mrs Trent was a woman in her early 70s who had been in hospital two weeks previously and was back to attend an outpatient appointment. She had multiple other chronic conditions which she was managing, as well as her heart failure. I was introduced to her in the outpatient waiting room area. While talking with Mrs Trent in the waiting area and gaining her consent to being involved in the research, she had several questions about why she was at that particular clinic, what it was about, and what they wanted to talk to her about. The patient had been referred to the clinic by her general practitioner; however, Mrs Trent did not understand why she had to come to the outpatient appointment. She was there because she had been told to come. The nurse specialist saw Mrs Trent first in an office which looked much like a GP’s room with a desk and small bookcase for the attending health professional. The bookcase is featured in Figure 10 (Chapter Six). Mrs Trent was accompanied by her partner who, as it transpired, also had a heart condition. The nurse specialist opened the conversation with questions.

709 CNS: *What do you know about your heart function at the moment?*

710 Mrs Trent: *He sort of explained to me that the heart had trouble resting and*
711 *ah when it was resting it is supposed to fill with blood and it only half filled*
712 *you know . . . to pump around again so I guess that is why I was retaining*
713 *fluid.*

714 CNS: *Did they tell you about looking after yourself?*

715 Mrs Trent: *They didn't really.*

7.8.1 Text mediation

Mrs Trent did not show any interest or curiosity towards the texts in the small pamphlet holder in the office she saw the nurse in. Mrs Trent received the booklet the nurse had decided to give her. There was significant discussion before the cardiac nurse got to the “Staying well with heart failure” booklet during the appointment. She then proceeded to refer to the book extensively during the consultation. Here is an extract from that consultation which specifically deals with the mediation of the text by the nurse specialist. It is noteworthy the nurse in this instance used a question to check comprehension.

716 CNS: *So when people have heart failure, it is all about a fluid balance which*
717 *is why we get you to weigh yourself because that's the easiest way of seeing*
718 *whether the fluid is staying in your body or not.*

719 Mrs Trent: *Yes, yes*

720 CNS: *That make sense?*

721 Mrs Trent: *Yes*

722 CNS: *. . . Now, I'll give you this book to take home. It is a truly wonderful*
723 *book as far as helping you understand what's going on with your heart. It*
724 *fully describes heart failure, um now this generally covers both kinds of heart*
725 *failure are shortness of breath . . . wheeze, this um you know, the symptoms*
726 *[reads them out loud]. It has a part here on medications. So, doing the daily*
727 *checks is important, weighing yourself every day. What would you do if you*
728 *noticed your weight go up from 86 to 88?*

729 Mrs Trent: *I don't know. I guess I would know that's fluid. Is that right?*

730 CNS: *Yep.*

731 Mrs Trent: *I don't know what I would do.*

732 CNS: *So that's when we would get you to . . . who is your GP? In the back*
733 *here it's got some key things, the green is for when you are feel well, that's*
734 *good, you know what is happening. When you don't feel well – if your weight*
735 *is up two kilos over one to two days, that's when you call me [nurse puts her*
736 *number in there] or your GP, and these might be the things you are feeling.*

The nurse here was facilitating the patient to interact with this booklet. She referred to areas in the book, pointing to it and directing the patient to engage as she was talking through parts of it. The questions the nurse asked checked patient understanding and used the booklet to supplement and support her answers to the patient to help Mrs Trent understand her condition and care more deeply.

A few days after her appointment, I followed up with Mrs Trent and asked her about the booklet. She said she had read the book but had not really absorbed it and decided she needed to re-read the book in order to answer my questions. I then visited her at home a fortnight later. This later interview revealed the patient had used the book like a reference book, one that she would leave out and come back to. She had not written on or filled in the book at all. Mrs Trent felt glad the information was all together in one booklet and not spread out over several easy to lose pamphlets. She said the most important part of the book was the section on understanding her condition.

737 Mrs Trent: *This was very good and that's what happened to me.* [reading] *If*
738 *the right side of your heart is not pumping well fluid can leak into your legs*
739 *and abdomen, fluid in your legs, I mean it just confirmed it all, it just., and*
740 *the pain in my legs, I wondered if that was [the reason] (or) not, and it is.*

The timing of when Mrs Trent received the booklet was noteworthy. When asked if she had received the booklet while she was in hospital she replied,

741 Mrs Trent: *"No, it would have been good if I'd had it in the hospital where I*
742 *could really lay [sic] and read it."*

743 R: *Did you get any written information when you were in hospital?*

744 Mrs Trent: *No I **didn't**.* [emphatic] [pause] *I wished I could've read it even*
745 *before I'd seen the cardiologist, you know, I would have been clarified,*
746 *clarifies things that I could ask questions about.*

Mrs Trent had been in hospital around three weeks prior and wished that she had been given the book then when she had time and more inclination to read it rather than having to wait for the follow-up appointment some weeks later. It is noteworthy as well that her GP also had not given her any written information.

This patient's initial reaction to the text was that she had found it *so helpful* and *so clear*. She had read the book but despite the intensive mediation by the nurse, she had not interacted with it. There were no markings in the book when we went through it some days after her hospital appointment. Like others in this study, Mrs Trent was managing her condition in a way that did not involve paper and pen. She had given it to several of her friends to read and her summation of the value of the book for her was that, *It was marvellous. Excellent, very clear. Best book I've seen - you can just pick this up and take it around with you* (rather than leaflets). The book was important for her understanding of her condition—why she

had fluid and swelling and how her heart worked. However, with the intense mediation of the book by the cardiac nurse specialist, it is unclear whether Mrs Trent felt this strongly because she had had help to interact with the book by the nurse specialist or because she had taken time to read and reflect herself on the book and its contents. It provided her with clarification on recognising symptoms by understanding more about the causes of her symptoms, especially pages 10-11. Mrs Trent checked her feet visually every day for swelling and weighed herself first thing in the morning. I left her with questions over what an enlarged heart was.

Mrs Trent's HeLMS survey results confirmed many aspects of our conversations together. Mrs Trent found managing her health a challenge. Question 2, making time for things that are good for one's health and changing her lifestyle to improve her health (question 7) were both areas that she said had *been very hard, but you do it*. Consequently her answer dipped her score for that area of the survey below the acceptable range. From a clinician's perspective, this would highlight a potential risk factor in Mrs Trent's management of her condition and care, whereas from Mrs Trent's perspective, she was making time and changing her lifestyle, but admitted to finding it a challenge. Why this would place her below the acceptable range in the survey results perhaps highlights the underlying hegemony of the HeLMS survey. It is designed for health practitioners, rather than patients. Further discussion of the HeLMS survey takes place in the following chapter.

7.9 Mr Ray

Mr Ray, of European descent, was in his mid-sixties and had been admitted to hospital with a heart attack. He had multiple other health issues as well, most noteworthy being diabetes. He admitted that his concerns about his health had been growing with several new symptoms—one was unexplained weight-loss, another was unsatisfactory sexual function, and also tiring easily.

7.9.1 The cardiac nurse specialist session

The description that follows is a summary of the twenty-minute session the nurse specialist had with Mr Ray. I have outlined it in order to give the reader an

appreciation of the complexity and amount of information being transmitted during this session and others recorded like it. At its conclusion, I will examine how Mr Ray dealt with this information flood. During his session with the cardiac nurse specialist, he received the Acute Coronary Information Pack, a pack compiled by the DHB cardiac nurses (Appendix 1). The nurse specialist spent over twenty minutes with Mr Ray and his family who were also at the bedside, explaining the difference between angina and a heart attack, the use of troponin to identify whether a heart attack had occurred and how and why that hormone is released. She referred to a diagram of the heart in A Guide to Recovery after a Heart Attack booklet to explain the workings of the heart and then proceeded to go through the contents of the Information Pack, pointing out what was inside it rather than interacting with each text in a personalised manner. She especially highlighted the Heparin/Clexane leaflet, telling him that is what was being injected into his tummy, and then went on to assess his risk factors (diet, cholesterol, smoking, blood pressure, overweight, diabetes, family history of heart disease, age, stress, physical inactivity). Mr Ray was unsure how healthy his diet was, so the nurse gave examples of fats in the diet so he could decide on his answer. She explained the use of the GTN spray which he had on the bedside table beside him, opening with:

747 CNS: *That GTN spray is your new best friend—take it with you everywhere*
748 *you go.*

The nurse's mediation of the central book in the folder, "A Guide to Recovery after a Heart Attack", was encouraging but not personalised:

749 CNS: *This book contains all the information you will need about your heart.*
750 *It is a good idea for you to read it and your family as well.*

She asked if he had any questions, admitting that there was a lot to take in but that she would follow up the next day. She then explained about the cardiac rehabilitation classes and answered questions Mr Ray's family had about those classes, encouraging them to do the classes *because you get to understand more about your heart*. She also explained that owing to Mr Ray's heart attack there could be no driving for two weeks. Mr Ray's response was one of surprise.

751 Mr Ray: *Oh gosh—oh I didn't realise that. Who is going to drive me?*

She then encouraged the patient and his family to write down any questions they had for tomorrow and then handed over the folder: *Here is the folder with all of the information in it.* The remainder of the session was leave-taking. The nurse did explain in response to questions that it was a step-by-step process and the results of the angiogram would determine what happened next.

The reflections of the nurse from this session were she wondered how much he had taken in and remembered: *Some patients—I know I have told them certain things and they come to cardiac rehab classes and say they were never told, and I know they have been told, but there is a lot going on.*

After diagnostic tests, he was placed on stand-by for an angioplasty/stent procedure which at that stage meant he had to be transferred to a larger hospital some 80 kilometres away.

7.9.2 Patient response to text

Conversations with Mr Ray revealed a holistic approach to the written material given to him by the specialist nurse. Part of that reason may have been that he did not have his reading glasses with him and found the font size of the booklets and pamphlets given to him too small. His HeLMS survey results did not reveal any areas of concern either. Another reason may have been the presence by his bedside of several family members, and his wife who seldom left his side. Any text given to him by the cardiac nurse specialist was passed on to his wife and extended family to read and digest. It was after discussion with his wife that Mr Ray asked me to go back to the risk factor sheet the nurse had filled out with him and change his answer about a healthy diet to a no. He and his family/whanaunga had been reflecting on the food that they ate and admitted to too many fry-ups.

Mr Ray also made use of other resources around him. Being in a 4-bed room in a cardiac ward gave him access to other patient's stories. He ended up rooming with another man who had had three stent operations and who gave Mr Ray a full description of everything that went on. Mr Ray referred to this when asked if he had any questions:

752 Mr Ray: *Ah No I think I understand. I had a talk to the fella over the in the*
753 *other bed who has had 3 stents and told me all about it.*

In later reflections seven weeks after the hospital event, Mr Ray reiterated the importance of having other patients around him in the ward who had had the procedure he was having and who could advise him. Both Mr Ray and his wife attended all of the six cardiac rehabilitation classes and had made changes, more for management of the diabetes than the heart, but in doing so also catered for heart health. They did comment on the lack of written resources available in Te Reo (the Māori language) as Mr Ray's wife was of Māori descent.

7.10 Conclusion

Each patient's story profiled in this chapter brought a different perspective to the context of the literacy events and practices operating within the hospital space and within the lives of the patients. The accounts of patients reflect the variability I encountered during data collection of accessibility, timing and comfort in terms of the richness of the data I was able to collect. The interaction of patients with written patient information texts was also highly variable. For some patients, new knowledge was gleaned from those around them while for others the text was pivotal in increasing knowledge of condition and care, particularly in preparation for diagnosis or treatment procedures patients faced while in hospital. Written texts were also important for providing guidance to patients moving forward with their condition. Having something to refer back to or having all of the information together in one place was salient for some.

Other common themes emerged across the data sets and they will be explored in the next chapter. The accounts in this chapter also reflect salient points in the participants' journeys. Points are salient in this research when they relate to the literacy events and practices of the context, the mediation of texts, and broader descriptions of the local and global context. A broader discussion of the data in relation to the questions this research seeks to answer is in the following chapter.

Chapter Eight: Discussion and Conclusion

My research began with a fundamental question concerning literacy and what it looked like in a hospital setting. My experience in India had demonstrated to me that the activity of decoding words on a page was not necessarily a pre-requisite for patients to gain personalised knowledge and understanding of their health. I wanted to find out about how texts were used with patients in a New Zealand health care context. The questions I asked concerned:

- the nature of patient information texts given to patients in a hospital-based cardiovascular health service: the literacy and numeracy demands and the relationship of those demands to the patients' health literacy ;
- the opportunities patients have to engage with texts: how texts are embedded and mediated in the context;
- the nature of patient responses to the texts.

Previous chapters have described the different texts used with patients in the study and the ways that patients engaged with and responded to those texts. We have seen how varied patients' engagement with texts was and how varied the texts themselves were in how they positioned the reader and patient. This chapter will discuss the understandings that evolved in response to the research questions and the contributions that can be seen to make to our understanding of health literacy.

Specifically, these contributions are around the notions of access, mediation and patient agency. Documenting the opportunities that patients had to engage with texts and how those texts were embedded and mediated in the hospital context led to examining access more deeply. The physical and linguistic aspects of access are discussed in this chapter, as well as access to knowledge through an examination of what knowledge is codified in the hospital context. The mediation of texts in the hospital created further questions around the nature and significance of mediation within the data. Mediation is examined in light of its contribution to personalising patients' knowledge in the hospital context. Patient stories of their responses to the patient information texts and to their condition and care positioned agency as also requiring further examination. The contributions this

research can make to further the conceptualisation of health literacy and implications and recommendations conclude the chapter.

8.1 Access

In the course of this research, access evolved as a salient theme. It became apparent from the physical availability of patient information, the linguistic analysis of texts, the literacy events and practices, and the prevailing hegemony concerning written patient information in the hospital. The notion of access requires a more nuanced conceptualisation than just being seen as a skill residing in an individual as it is portrayed in most health literacy definitions. Further discussion of these definitions in relation to the findings of this research follows. Specifically, the findings on access discussed in the following section are

- Access in health literacy is more than an individual skill; it is a systems skill;
- Spatial design and positioning of patient information is important;
- The overriding moral order or hegemony concerning the role of a patient in the hospital space does not facilitate open access;
- How knowledge is codified for patients determines access;
- Diversity of patient information offerings enables broader access;
- Health care organisations need to develop their role as health literacy sponsors.

Health literacy definitions, as we have seen in Chapters One and Three, have the notion of an individual being able to *access* health information as key to having health literacy. At first glance, this seems a straightforward proposition, but if we look at the convergence towards positioning health literacy as a whole-of-system issue rather than an individual deficit, then the notion of access becomes more complex. For a patient to be able to access pertinent information about their condition and care makes certain assumptions about information availability and applicability. There are features beyond the control of the individual patient which are part of the local and global contexts that the patient or individual is found in. The spatial environment, the physical availability of texts, the prior knowledge assumed to decode texts, the type of knowledge that is encoded and

therefore available, the linguistic and discourse features of the texts, the hegemonies operating in the context, and, the mediation of the text, all have been found in this research to be factors influencing patient access to health information. These are factors that are for the most part outside of the control of the individual, being part of the local and global context. The following discussion will look at each of these factors further.

8.1.1 Self-access and the spatial environment

One assumption in patient access to information on their condition and care is that the information is physically available. As the findings demonstrate, this was not always the case. The physical location of texts, their organisation and range, and their placement in the patient experience of the cardiology service across the health system revealed some gaps. Moreover, the social practice around the selection, display and maintenance of publicly available patient information suggests that written patient information was not part of a comprehensive patient information strategy. The absence of key written patient texts in publicly available pamphlet holders signifies the disjointed nature of patient information text availability. The degree of fluidity that existed in how the pamphlet holders were managed characterises the absence of a coherent underlying patient information strategy.

Physical access to written patient information was also dependent on the nurse equipping herself with the relevant documents and deciding to give the documents to the patients. In that regard, a strong element of control existed over the information, even though this may not have been the first impression. What was given to patients in the cardiac area was pre-determined by the cardiac nurse specialist group but the giving of these texts did not seem to be mandated. Rather, it seemed to be dependent on each nurse and the patient concerned. As Mr Cox pointed out in section 7.6.1, when asked whether he had any questions, he did not know what he did not know. In this regard, the power to inform lay with the more knowing other, the health professional.

In addition, many texts available publicly required patient knowledge of medical terminology or abbreviations of medical procedures. There were no mediating

signs near the pamphlet holders inviting patients to take the information nor any advance organisers indicating grouping classifications to aid selection. It seemed to be assumed that people understood how to interact with the displays of printed patient material and would take the information as required. It displayed a passive approach to patient information availability and engagement.

Both pamphlet holders were in areas that had to be accessed through a locked door so, in that way, the audience was assumed to be users of a particular service delivered in a particular location. The printed patient information text in the consulting room was positioned in such a way that it was under the control of the health professional. Access then was restricted physically to a degree for patients and in the case of the consulting rooms, was dependent on a patient's agency to ask for written information because of its location in the consulting health professional's space (see Figure 10).

Patient reflections from the data show a clear expectation that if they needed the information, they would be given it and in the depth that they required. Only one patient in the data was found to have made use of the pamphlet holder information offerings. Patients' expectations for information places onus on the literacy sponsor, in this case the hospital health professionals.

8.1.2 *Linguistic access*

Once a patient gets written information on their condition and care, the linguistic features of the texts come to the fore. As has been discussed previously, the nature of written patient text can be alienating for patients or readers and make access to the information challenging. The data revealed a wide variation in ease of accessibility in terms of the linguistic and discourse analysis. The positioning of the condition sufferer, the choice of modality and voice as well as mathematical symbols can present barriers to access (see Figure 25 for example). The instances of the use of passivisation, where the central agent of the action (the affected one) is excluded or minimised, (see Chapter Six for a full discussion) effectively backgrounded the sufferer and foregrounded the ailment, or objectified the condition. Generic references to the sufferer were features of texts used with patients in this research. In addition, how patients were positioned in the texts

varied. Patients were addressed from a biomedical stance where their health knowledge moved from deficit to credit, to an empowerment stance (Dixon-Woods, 2010) where information was available that enhanced choice and equipped them in their decision-making as a patient.

There is a high degree of complexity in the range of semiotic systems operating in the hospital environment. Patients are just one part of this and their designated role influences their responses to linguistic features of patient texts. Patient responses to the language of the text were muted in the research, with more comments being offered by patients on the look and layout of the patient texts. The discharge summary written for patients' general practitioners and written in medical language was not commented on by patients who received them, perhaps being seen by them as another ritual found in the hospital context. No patient raised a concern about the level of linguistic inaccessibility it presented to them, perhaps because the letter was plainly not addressed to the patient and it was not written for them.

8.1.3 Access to knowledge

Hospitals are learning contexts for patients. Patients generally come in with a problem that needs to be resolved. During this process, learning on many levels takes place. Understanding the condition and learning how to manage the condition during and after the hospital visit are part of being a patient. Knowledge for a patient in this context can be codified, usually by being in a written form, or cultural and tacit knowledge that is not necessarily codified (Eraut, 2004, p. 201). Codified knowledge in the hospital for a patient may be in the form of an overhead sign reading *nil by mouth*, patient notes kept by the health professionals, written patient information texts, consent forms and other *in-between pieces of text* (Kell, 2011, p. 613) which form part of the procedures needed to be part of a hospital organisation.

Learning through the literacy practices and events is part of the social practice of situated learning in the hospital environment. For some patients in this study, codified patient knowledge in the form of written patient text was a significant part of the literacy events facilitating their learning of condition and care.

However, where these texts were available, they were not necessarily accessible either because they were not given to the patient or the patient was not able to effectively select a relevant text from the pamphlet holder. For other patients like Mr Ray, learning about his condition and care did not use as much codified knowledge available in the context, but rather the uncodified knowledge residing in interactions with those around him. Learning for him and other participants occurred informally through conversations with roommates and spontaneous occurrences of information grounds with health professionals.

By viewing the hospital as a social place of learning for patients, it follows that every interaction a patient has with a health professional, the navigation of the spatial structuring of the hospital, the reading of signs and leaflets, the answering of questions, the conversations with any room mates, visitors or family, is all part of the learning *work* of being a patient and coming to understand their condition and care more clearly. This particular social space has literacies to be learned and knowledge to be gained. This learning of both codified and uncodified cultural knowledge happens in a way that learners are almost unaware of and is, according to Eraut (2004), “a prominent feature of educational institutions” (p. 202) even though an educational institution is a context where codified knowledge dominates. The hospital or health care context is similar. There are vast amounts of codified academic or medical knowledge in healthcare for health practitioners. However, for a patient it seems the codified knowledge concerning their condition and care available to them in the hospital space is not as comprehensive, and access can be a matter of chance.

The uncodified cultural knowledge in the hospital context involves not just learning about a patient’s condition and care but also about how to be a patient in that context. For a patient in hospital, much of that cultural knowledge is about learning the local beliefs and practices of the hospital context or being socialised into the patient role. Some of that knowledge is useful for the patient’s own management of condition and care, and other knowledge has to do with how to get along in a hospital setting. Mrs Hunt’s question of who the people in groups walking around the AU were was an example of learning the context (see Section

7.2.1). Access to this uncodified cultural knowledge was therefore dependent on time and levels of exposure and participation in the context.

A form of uncodified knowledge is tacit knowledge, or instinctively knowing (Eraut, 2004a). It is knowledge that is already part of someone's repertoire, and is readily available for use. In the hospital context when confronting a new health condition, a patient's tacit knowledge is likely to be limited. No assumptions about a patient's prior knowledge including their tacit knowledge of human biology by health professionals should be made. The location of the heart in the body was central in discussions in the research. Differences between heart attacks and strokes, normal blood pressure compared to abnormal, numeric symbols, daily routines of the hospital space, there were many instances of assumed knowledge in the data which to a person working in that environment is knowledge that may or may not be taken for granted. For a patient or newcomer, it can be further knowledge that is inaccessible to them.

Another important aspect of access to knowledge for a patient is the existence of a moral order in the hospital which at times precludes a patient's involvement or access. A moral order exists in the hospital environment where there are "rights and duties attributed to various actors [which] impart expectations for what is considered to be *proper* action" (Slocum-Bradley, 2009, p. 95). A patient in this context has to acquire the "uncodified cultural knowledge . . . (where) much is so *taken for granted* that people are unaware of its influence on their behaviour" (Eraut, 2004, p. 202). This cultural knowledge positions the role of patient to be trusting, cooperative and having a good memory. Research undertaken by Higashi, Tillack, Steinman, Johnston and Harper (2013), in the context of quality and quantity of time physicians spend with each patient, frames that moral order in terms of a moral economy which is predicated on the underlying morals or ethics of the "norms of reciprocity" (p. 15). They investigated what those codified and uncodified cultural beliefs and values were. They found that "in practice patients must comply with the goals and values of the hospital system to be *worthy of care* [emphasis theirs] (p. 22), but they also found doctors who actively resisted this moral economy. The findings in my research resonate with those of Higashi et al. As the research reveals, key pieces of information about

one's condition and care were delivered orally, in a condensed time period in front of a health professional audience doing their rounds. Having that number of visitors at one time in a small cubicle could be intimidating for some patients and may inhibit questions and prolonged interaction and therefore memory of what was said. Any memory aids, for example, a paper and pen for the patient or support person were not part of the literacy practices, but should have been. There were assumptions that were made by health professionals about how newly codified knowledge about a patient's condition and/or care can be accessed. It is not surprising therefore, as I discussed in Chapter Two, that patients are often discursively constructed as passive and forgetful (Dixon-Woods, 2001). There were no literacy practices in operation which gave patients access to anything other than this construction.

In addition, the trusting role of patients was seen in the clear expectations from patients that the right thing would be done. If for example, they needed written information, they thought they would be given it and in the depth that they required; therefore, to ask for access can run counter to the fashioned role of being a patient. The access therefore to knowledge of condition and care can be challenging because of the overriding moral order concerning the role of a patient. Mrs Newton displayed this when she became concerned (line 187) that she would be put out of the hospital prematurely because she had called a doctor to account for neglect. For a patient not to be given any written information or access to any other form of information in hospital could be seen by the patient as normal or not needed and therefore not something to be discussed or challenged. However, this positioned role of the patient makes access to information and personalising of knowledge more challenging.

8.1.4 Evaluating access

These findings offer a variation to the way access in health literacy can be assessed. Access is also one of the aspects to consider if taking a critical stance to evaluating health literacy across a whole system. Presenting access as an individual competency in health literacy definitions and evaluating it as such is a simplistic approach to patient access of knowledge of condition and care. Access for a patient is dependent on the complex interaction of codified, cultural and tacit

knowledge, and participants in the healthcare environment, needing both to be present in a designed way. Data from this research reveal that accessing is not a context-free ability. Each of Sørensen et al's (2012) access categories, for example, (information on medical and clinical issues, information on risk factors and, information to update oneself on determinants of health p. 10) is socially situated, as was the case in this research. Gaining access to this level of information for a patient is made more difficult by the way that information is situated in the health care context. As the research has revealed, getting sufficient timely information on one's condition and care presents challenges in cases where that information is not readily accessible to a patient.

Theoretical work carried out by Janks (2010, 2013) and detailed in Chapter Two, evaluates access from the perspective of power and diversity. Evaluating access to literacy across a health system from the perspective of power, can highlight hegemonies or dominant discourses. As discussed previously, patients had variable access to written patient information, which partly was a reflection of the dominant hegemony of the healthcare system and the social practices. Each patient in the research brought their own agency to the situations they faced, using their own literacies to navigate their journey through their illnesses.

Power should not always be maligned, but also explored from a productive, community perspective that is not just about domination and struggle. Martin and Rose (2007) take this view and Janks (2010) takes a similar view of power. The implications of this community view on power are discussed further in section 8.3 where the notion of literacy sponsorship and mediation are explored further. Both of these are productive uses of power and both were in evidence in the data. However, the data also reveals instances where authoritative power was not always productive, where patients were unable to access information from more knowing others. This was either because there existed a moral order which precluded information sharing (Mrs Newton) or a deliberate decision by a healthcare professional on how much information a patient needed, rather than allowing the patient to be involved in that decision. Mrs Lewis, for example, was fortunate to get the single pamphlet on managing her angina.

When viewing access to literacy through a diversity lens (Janks, 2010, 2013), the diversity of information resources available (for example, the different versions or modes of information) affects access by being an enabler or a limitation. It directs who gets access to what and who can benefit from this access. In the research, access to diversity was not prevalent in the data reported by patients. There were passing references to written patient health information on condition and care being available in English only. All patients given written texts were able to decode (access) text. Translators could be called upon for oral exchanges, but, by and large the pamphlets in the wall-hung pamphlet holders and other written patient text were monolingual. The research did not specifically set out to capture the use of other languages in the healthcare context. It did capture a limited number of different modes of health information however, e.g., the use of realia in the cardiac out-patient classes and in procedure explanation (an actual stent used to describe the procedure and explain patient stent options). The texts themselves revealed a degree of diversity in that there were reformulations of texts in an attempt to simplify, or different types of authority in the writer's tone, for example, but further research is required into issues of diversity beyond just language. There was some variation in service delivery based on ethnicity. Diversity of health literacy practice has to be part of any health literacy strategy to build on and maximise the literacy practices patients bring to the bedside or to the clinic room. Rogers and Street (2012) advocate that instead of teaching adults *literacy*, "let them be helped to learn . . . health . . . directly, and include in the learning programmes the embedded literacy practices of these subjects" (p. 172). There is no better place to do that learning than maximising opportunities presented in a hospital environment. The context brings a sense of immediacy.

Using notions of access, diversity and moral order to critically review health literacy practices provides insight into both the local and global contexts. It also creates a space for social practices pedagogy of literacy to inform health. It enables us to step back and look at aspects of health literacy from an educational perspective where the central agent, the patient, is the learner. It also provides insight into what it might mean to be a patient who is critically health literate and the rich learning environment that hospitals provide for patients to learn about their condition and care.

Patients go to hospital to get a change in their condition, usually to get better and be discharged. Eraut's (2006) position that "most learning in the workplace is a by-product of engagement in new situations, where learning is not the object" (p. 6) describes the patients' hospital journeys most satisfactorily. The new situation, of being in hospital with a problem that needs to be rectified or managed creates an opportunity for learning to occur. It also creates opportunities, as referred to earlier, for power to be manifest in quite different ways including being enacted by patients. The next section discusses this concept using agency as the lens for discussion

8.2 Agency

Another contribution of my research is in the area of patient agency and its relationship to patients' understanding and using information about their condition and care and making that knowledge personal. The notion of agency, "the socioculturally mediated capacity to act" (Ahearn, 2001, p. 112) has emerged as a feature in how patients in a hospital setting interpret events or information and act on those beliefs or interpretations. There is a dialogic connection between knowledge and agency. The activity of interpreting events and information as knowledge involves participants who are socially situated and are their own agents in what they come to know (Ahearn, 2001).

However, as discussed in the previous section on access to information, often in a clinical setting, patient agency is constrained by the playing out of dominant roles and hegemony. Consequently, because of these accepted roles and hegemonies, the expectation for a patient is to be compliant or cooperative and trusting, and there were many instances of this in the data. This, however, should not be confused with patient passivity (Ainsworth-Vaughn, 1992). Patients reveal agency in different ways and places. Agency as I have approached it introduces a dynamism because it is context driven and complex. The data shows different types of patient agency—oppositional or resistance agency, complicit agency, self-advocacy, agency of power (Ahearn, 2001, p. 130), clarifying agency, and I would add critical agency, often operating simultaneously in the context. For example, Mrs Lewis's questions and Mrs Newton's critical turn were patient displays of agency which were dynamic and situation specific. These different expressions of

agency (see Chapter Seven) could also be interpreted at times as attempts by patients to negotiate shifts in their patient identity, perhaps moving from an assumed identity (compliant patient) to a negotiated identity (assertive patient) (Pavlenko & Blackledge, 2003). This was peculiar to each patient.

In terms of health literacy, the construction of agentive turns and patient identities can enrich what health information is understood and used. It could be a trajectory that some patients may embark on in their health literacy journey where displays of agency are part of a dialogic process connecting knowledge to agency. This, in turn, can assist in making knowledge more personalised.

Agency arises in the context of new learning, and learning, like developing agency, is not a linear process. Learning fluctuates back and forward and is fluid (Wenger, 1998). What takes place within the individual in terms of learning, making knowledge personal, is highly dynamic and is situated. It is set among people, in places, and in time which can be a constraint or an enabler.

There is no need to use a binary or stepwise approach to health literacy. Nutbeam's (2008) premise that health literacy can be segregated into different stages or levels in order to display growth in autonomy and empowerment in decision-making creates a metaphor of a ladder which implies a starting point and an ending point. Critical health literacy is included in the higher order, or higher stage of a health literacy trajectory (Nutbeam, 2008; Kickbusch and Marg, 2008; Manganello, 2008, Sykes et al., 2013). However, findings in this research disrupt that linear conceptualisation. For example, to be in the first stage of Edwards et al.'s (2012) model (building health knowledge) requires a level of critical literacy. It requires a patient to ask critical questions: What information have I been given? What do I understand? What would I like to understand better and where can I get this information from?

In the data, patients who had repeatedly seen their GP in an out-patient context, had scored well on the HeLMS survey, and who themselves believed they had good knowledge of their condition and their care were dismayed to find out that they had in fact not been recognising symptoms of their condition correctly until it was too late and they ended up at the emergency department. They also realised

that they had not had enough information. However, this realisation often became the motivation for a change in patient agency. Agency began to grow over time. Mrs Newton, for example, went from struggling to feel justified being in hospital to realising she needed to ask more questions and be more in control of her own health and medications. These displays of agency can be viewed as an aspect of a growing health literacy and a further personalisation of a patient's knowledge of their condition and care. Figure 27 refers to this growth in agency with specific factors in the social context which mediated these agentive changes.

However, this growth in health literacy does not follow a *levels* or *stages* representation of health literacy which struggles to take into account the wide variations in when and how patients move in their knowledge of condition and care. It also tends to gloss over the wide variations that exist in learning and the different agency of the learners/patients. Building health knowledge is about learning, and learning is an active, social process with much complexity. Flux is integral in the complexity of a patient practising health literacy. In addition, in a stages representation, how does one define or recognise a patient who is a health literate expert? Such a notion is culturally bound and context driven. Other researchers have noted these things about the fluid nature of learning trajectories (Wenger, 1998; Larsen Freeman, 2012a,b).

Figure 27 displays the interactions for the growth of a patient's personalised knowledge of condition and care. It summarises the different interactions found in the research which played a part in mediating knowledge for patients in the study. The interactions with health professionals, family and friends, written patient text, and the presence of the researcher were factors that coalesced to mediate knowledge and grow patient agency in this research. The presence of others, literacy sponsors and mediators in Figure 27 illustrates their importance in the co-construction of personalised patient knowledge in this study. I will return to this in the discussion that follows on mediators and literacy sponsors.

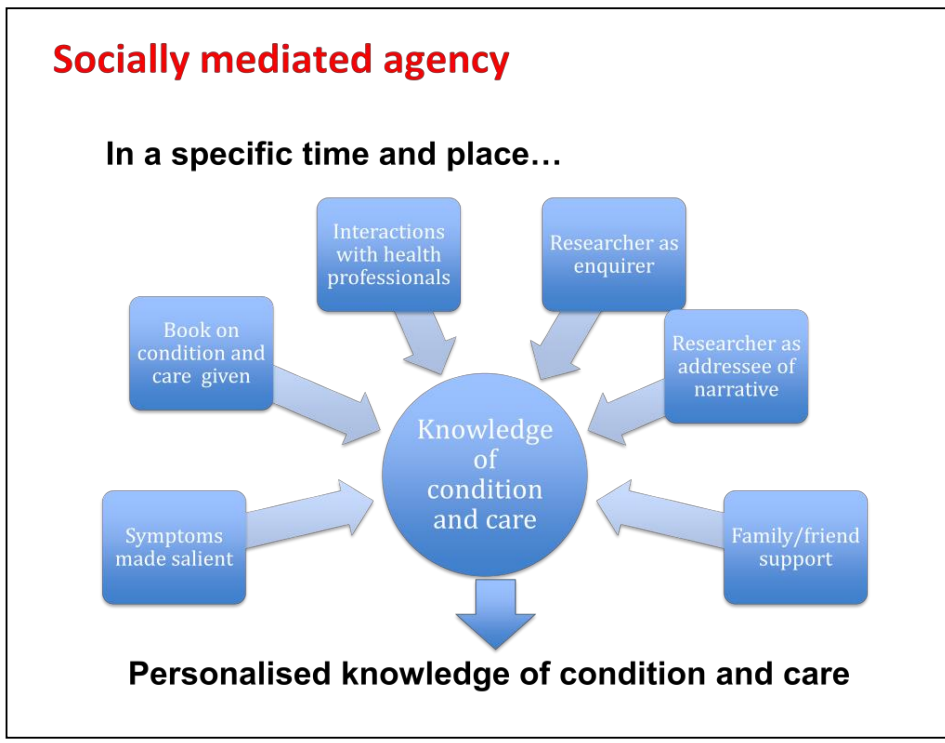


Figure 27: Factors in socially mediated agency for health literacy

8.3 Mediators and literacy sponsors

Mediation can be a complex process because the societies in which we live are constructed of many different domains networked together. “Texts are a crucial part of these networking relations—the orders of discourse associated with networks of social practices specify particular chaining and networking relationships between types of texts” (Fairclough, 2003, p. 30). Mediation of patient information text at the hospital involved what Fairclough (2003) calls *chains* or *networks* of texts, where the joining of different genres creates the possibility of transformations in action or practice. The social practice of health professionals reading patient notes before they get to the bedside, or at the bedside, and then the transformation of those texts into spoken language for the patient is one such example. We particularly see this in the doctor and specialist nurse dialogues with Mrs Lewis. There is a networking of texts in this institutional environment. The patient notes are the written text which is added to either during or after consultations by the health professional and it is a text that patients seldom see, although they can, as previously outlined, request to see it if they wish, but it is not written for them. It is the working document for a patient’s condition and care. Decisions are made by the health professional concerning

how much and which of those texts are mediated with the patient. This scenario was intimated with Mrs Lewis who had both health professionals (the doctor and the nurse specialist) open with a mediation of her notes, that she was an angina sufferer. This was not knowledge that was personal to Mrs Lewis. She had not seen herself in this way because she had not, according to her, had any angina. It was through these sessions with the doctor and the nurse that Mrs Lewis came to understand in a more personal way her condition and its care and management. Here the text being mediated was unseen by the patient and it could be argued that if it had been more accessible to the patient earlier on, she would have had a chance to understand her condition earlier and manage it differently. There are therefore different types of decisions being made in this context, made by more knowing others on behalf of the patient concerning which texts are part of the patient experience. This genre chain highlights the complexity of mediation and texts and access to salient texts and the power issues associated

Within this complexity however are health professionals who have specialised knowledge and who are, as they have been called elsewhere in this research, more knowing others. In this research, the knowing other has been configured as a literacy sponsor. Though sponsorship may result in advantage to the sponsor, this may not have been the underlying motivation for it to occur. However, health professionals in the hospital are very busy and choosing to be a literacy sponsor in that setting requires time. Ultimately that choice is a reflection of many factors, one of which may be the hegemonies operating in the local and extended contexts.

8.3.1 Personalising knowledge

At times a patient would receive pre-selected reading material with just a cursory introduction and no mediation. Mediating text with a “you might be interested to read this” or “the doctor asked me to give you this” is a shadow of what a patient may need and does little to utilise learning opportunities in a hospital context or create a learning relationship which resituates codified knowledge for patients and makes it personalised to them (See also Figure 27 above). Mediation of text does have a positive role in fostering new knowledge.

There were times when mediation, as conceptualised by Gibbons (2003), did occur. Patients were given access to key technical or medical terms and information vital to their condition and care, and at a time and place which made the meaning comprehensible. The mediator linked the text to life experiences and to teacher/nurse-learner/patient interpretations of texts and reduced the conceptual distance between the text and the patient.

There were text mediations that took place which asked deeper questions of the patient and classes where mediation of text occurred, creating active, social and co-constructed learning. Mediation by a more knowing other brought the linguistic texts and the medical concepts closer to the patient.

The role of literacy sponsor was performed by various people. Figure 27 displays the health professionals, family and friends, and the researcher as primary sponsors of literacy in the research. Literacy sponsors operated with patients and text by the bed, in outpatient clinics, in the general hospital environment, at rehabilitation classes, or at GP visits. The role sponsors played at times was pivotal to patients' learning.

With two exceptions, the passing of patient information leaflets or booklets to patients was done by a member of the nursing team and consistently toward the end of a consultation. When a leaflet or booklet was used, it was used to reinforce what had already been talked about or as an avenue for patients to learn more about what may have only been touched on in the consultation with the medical or nursing staff earlier. This practice of nurse dissemination of patient information text positioned written text away from a major centre of power in the hospital environment, medical staff. This perhaps was in contrast to what patients may have expected or experienced with their own doctor or general practitioner outside of the hospital experience and this may have impacted on the patients' responses.

In doctor initiated mediation of patient written text situations, the patients responded very positively to the texts. As well in these instances, the few annotations on patient texts by a literacy sponsor added a sense of permanence to the mediation and may have enhanced the patient's responses to those learning exchanges. The health professional, the doctor especially, is the holder of

specialised knowledge and with that comes a degree of authority and power. Papan's (2010) findings from research into the role of paperwork and non-verbal activity in doctor-patient consultations reinforces the health professional as the "party with privileged access to powerful knowledge" (p. 158) and the one who mediates medical knowledge "while the patient's access to this information depends on the doctor's willingness and ability to fulfil this mediating role" (p. 158). Certainly there were instances of this in the data, not limited to doctors or nurses. Rather the system wide approach to patient information availability and accessibility did not appear to position the health organisation as being a willing mediator or health literacy sponsor. This research does not support a conclusive link between patient response to text and perceived authority of the mediator in the hospital context, but evidence does suggest it as an area worthy of more investigation.

In the research, the out-patient cardiac classes were an opportunity for cardiac out-patients to experience the cardiac nurse specialists' community of practice (Lave & Wenger, 1991). The classes were run by the cardiac nurse specialists and provided a context for diverse learnings and shared understandings. The out-patients who attended were apprenticed in to a further personalisation of their knowledge of condition and care. Artefacts in those classes, such as models of the heart and cylindrical representations of fat content in food and blood pressure kits helped to mediate the extensive knowledge of the health practitioners to the patients. Patients became a peripheral part of this community of practice of health care professionals and were given further opportunities and options to join in a cardiac-focussed support group.

8.3.2 Patient agency with literacy sponsors

Patients actively asking for written information were not apparent in the findings. Not even when a nurse had taken more written information to the bedside and had chosen to give the patient just one of the pamphlets in the folder, did the patient ask for any of the other pamphlets. Only one patient requested that her take-home drugs be written out clearly for her so she knew what she was being given and why. Another asked for the name of her condition to be written down for her so she could remember it. Otherwise, any written patient text was volunteered by the

health professional. This may be a reflection of assumed patient identity, and patient agency—the notion that things are *done to you* in a health care environment, and coupled with that, the latent expectation that health professionals will do the right thing, and if you need information, you will be given it.

All of the participants in the research had different information needs and therefore different learning needs. The codified knowledge, the written text, used with them was mostly designed for general situations by writers located in distant places and not necessarily connected with the local context. However, for some this was immaterial because the work of the mediator brought the text near to the patient.

8.3.3 Text role in patient health literacy

The social practice for written texts for patients was designated to a particular role and a particular time, with the majority of patient information coming to cardiology patients in an oral mode with no written text associated with it. This minimised any role a literacy sponsor could have with written text as the number of literacy events were in fact very limited.

The findings reveal a wide variation in the role that written text had in a patient's health literacy journey. For some, it was not as essential as they used other modes for information gathering. For others, the introduction of a patient information text was critical to their on-going health literacy journey. The role of the text was to provide clarification and relief to gain more understanding of their health conditions and more about its management. It enabled patients to learn more about their condition and clarify its severity. Patients were able to seek further clarification about information in the written text that the nurse or doctor had not talked about. Text was important to answer patients' questions not articulated to a health professional. Written patient text also confronted patients' normal modes of operation, especially where they were not accustomed to using printed text as part of their own personal literacy practices.

8.3.4 *Patient response to text*

All of these responses were patients grappling with codified knowledge, or information that needed to be codified in order for learning to take place and to become personalised. Most of these patients with opinions were trying to translate theoretical knowledge into personalised knowledge they could make decisions on.

Data from this research bears out the findings of Barton and Papen (2010) in that patient reactions are individual. “Patients, however, react to any texts received from their doctors in a variety of ways, ranging from welcome acceptance to passive or active rejection. Leaflets can be useful and empowering . . . [or] may be of no use” (Barton & Papen, 2010, p. 176). As the previous section has outlined, written text was used differently by the patients in the study, but all patients except one did actually read the texts. This fact that patients actually read the text given to them by a health professional is worthy of further consideration as it suggests patients were either interested in finding out more about their procedure, condition or management of their condition, or complied with rituals expected of them in the healthcare context to actually do as they were told and read the text. This relates to earlier discussion of notions of patient agency and how the patient responds in the face of the moral order of the context. Interestingly, the patient who refused to read the patient information text given to him did so because he had been given it once before and saw it as being “old hat.”

The research also highlights *moments of truth* for patients or moments when the patients had a high degree of emotional energy invested in the outcome (Beaujean, Davidson, & Madge, 2006). These were points in their journeys where a piece of text was pivotal in growing health literacy. There were pivotal points in patients’ journeys where text and the patient’s interaction with that text became a moment of truth: a moment when a text bridged the gap between the current reality (the illness) and the place or position a patient wanted to get to. This destination could have been understanding their bodies or the illness, or the management of the illness. It was different for different people, but there were points when patients could be considered to have invested a lot emotionally into the outcome. Other research looking at patient response to the provision of health

behaviour advice has found patient recall of the discussion has a two to four-fold increase if the advice is associated with the diagnosis (Flocke & Strange, 2004). This may be another expression of a moment of truth where there was a high degree of emotional investment in the outcome. There were similar moments in the data where the presence of written patient information brought emotional energy to patients' learning leading to a greater personalisation of their knowledge of condition and care.

8.4 Implications

The implications of this research fall within three broad categories, which will each be explored in turn. First, there are theoretical implications for the conceptualisation of health literacy. Second, there are methodological implications for how health literacy is positioned in health care organisations, especially as literacy sponsors. These include such areas as a patient information strategy, what knowledge is coded for patients and what knowledge is assumed, and literacy practices which encourage literacy events. Finally, there are pedagogical implications for how health professionals as adult literacy educators approach the notion of health literacy and what it may mean for their professional practice.

8.4.1 Theoretical: The conceptualisation of health literacy

Theoretical foundations matter. As discussed in previous chapters, literacy (outside of health care) has moved from a functionalist or positivist theoretical perspective towards a post-positivist or constructivist position, as demonstrated by the conceptualisation of literacy as social practice. Permutations of this approach have had some influence in the health literacy debates through the work of Nutbeam (1999, 2008, 2009a, 2009b), Kickbusch and Maag (2008), and Miller and Crabtree (2005), but have been more pronounced through the work of Dray and Papen (2004), Papen and Walters (2008) and others. However, debate in health literacy is still to move on from the measurement of patient literacy (Parker, 2009), albeit of a patient's ability to access, understand, and use health information in ways that encourage good health (Nutbeam, 2008). There is a need to continue to broaden the theoretical approach beyond a functionalist approach

and move towards ways of evaluating how health organisations and systems can operate as literacy sponsors. There are implications for the notion of access in health literacy conceptualisations. It is not just about whether an individual has the skills or abilities to access information, but whether the organisation or context supports such access. In this way the previous discussion on access could provide a starting point for evaluation of health systems and their accessibility from a health literacy perspective.

More work is required on the other active verbs used in the health literacy definitions - *communicate, process, understand or appraise* and *apply*. There are implications from each of these for theoretical approaches to health literacy when viewed from a social practices perspective, and a perspective which views the health care provider as the literacy sponsor. A shift therefore is required to incorporate stronger elements of educational theory within health care. The analysis of the theoretical notion of mediation in this research supports this and the importance of positioning health literacy away from the individual and more towards the health organisation. It also raises the question of whether this shift needs to be reflected in health literacy definitions, as Papen and Walters (2008) attempted to do: “Health literacy has to do with *the social and cultural practices* that individuals and *groups may engage in* (emphasis mine), in the process of understanding, accessing and using health-related tools and services (p. 10).” I believe it does.

8.4.2 Practice: The health care system

Health care settings need to embrace their role as places of learning for patients and as mediators and sponsors of health literacy. There is a case from this research for an increase in the use of mediation by health literacy sponsors, where space is created for dialogue, learning and spontaneous information grounds (Pettigrew, 1999). It is a systems approach across the health system that will create that change. Patients in the research whose stories revealed a lack of personalised understanding of their condition and care suffered from a lack of access to crucial health information. They scored well on the health literacy measure (HeLMS) and could all decode written text, so as far as their individual cognitive skills, this was not at issue. This reinforces the situated nature of

literacy and the consideration that accessibility and mediation of patient information are needed in order to create a hospital system that itself is a literacy sponsor. Viewing health care centres and providers as learning contexts (Eraut, 2004) for patients (as well as places of healing), requires a re-orientation to what the learning opportunities are in a patient's journey. It requires consideration of what knowledge needs to be codified for patients and the most effective way to do that as well as greater inclusion of other findings from learning and teaching research and the role, for example, that feedback has in learning (see for example, Hattie & Timperly, 2007). Different learning media need to be the norm in health care contexts: interactive screens, written text, literacy sponsors, information mediators, realia, for example life-sized human models.

A shift is needed in the moral order of hospitals to socialise patients into being active learners—patients who can read their world, their condition and care. A re-examination of the physical availability of patient information is also needed as well as of the timing and scope of the information patients are given. Changes could perhaps include options of guided reading or exploring health content in hospital through pre-selected websites on mobile touchscreen devices or health programmes, letters or emails written for patients which are a summary of what happened to them in hospital, in-hospital discussion groups or learning sets, options of a note-taker or recorder in consults or other ways to equip and enhance patient learning. A shift is required in the health institution becoming a literacy sponsor.

Having a comprehensive patient information strategy which gives patients access to more modes of information and knowledge in a timely way positions the patient as the central agent. For example, having medical records (especially as these become digitalised) more easily accessible could create opportunities for the patient to be more central in discussions and decisions. It also creates a visibility to the patient journey which in the adult education domain would be deemed to empower the learner. This, in education terms, would be seen as a move away from a transmission model dominated by the educator towards a transformative learning model (Coady, 2013) where learners could be more autonomous in how they learn. Papen (2010) refers to this, saying “despite a rhetoric that professes

the opposite, the literacy practices of information provision and healthcare more generally continue to be grounded in a transmission model that privileges the institution's point of view" (p. 163). My research concurs with her summation. Written patient information content, organization, size and complexity are secondary if the texts are not made available to patients in a way that sponsors patient growth in knowledge of condition and care. Pamphlet holders are a public service, but perhaps are relics of a past era when health information was less complex because less was known and understood by the medical fraternity. There is now a lot more information known adding to the complexity and illustrating the importance of literacy sponsorship both in the geosemiotics of health care spaces and the personnel who work there. Growing a patient's health literacy occurs in socially constructed activity (see Figure 27). Information access strategies are needed that target the range of potential avenues a patient may have to increase knowledge of condition and care and utilise the literacy practices a patient brings.

A broader question is the challenge patient health literacy presents to places of medical practice outside the hospital context. This is the part of the global context often hidden in the local hospital context. The backstories of patients in the research who arrived at the emergency department and their previous interactions with other health professionals are salient. Part of the data touched on these when patients spoke of their relationships with their GPs or GP clinic. These centres are as much a place of education for patients as they are in every other stakeholder in the health system, albeit with quite different needs.

8.4.3 Pedagogical: Professional preparation

There are pedagogical implications of this research for adult literacy and language educators and for health professional educators. For the educator of health professionals, creating a shift from hospitals as places of healing to hospitals as places of healing and learning for patients could predicate teaching student health professionals how to recognise patient learning opportunities and understand the literacy events and practices in their work context as well as their underlying meanings and hegemonies. More literacy sponsors need to be created in the health care context and whether that is a separate entity as Kickbusch's (2010) professional information broker, or someone with more authority, needs to be

further investigated. Sponsoring a patient's literacy does not need to include measuring whether or not they can encode or decode a particular document. It is working with the individual's own existing knowledge and literacy practices to increase understanding. Looking at patient information strategies more closely and the current position of written patient text and other modes of information would also be a worthwhile learning outcome for health professionals. Where patient texts are used, teaching best practice in text mediation would assist with personalisation of patient information texts with patients. In addition, having a greater awareness of how power circulates in a health care organisation and what that may mean for patients' health literacy is also imperative. Practitioners therefore would benefit from a deeper understanding of potential literacy events in the health care system and approaches and practices surrounding those events.

Models of adult learning can be used to position health response to patient literacy. The claim that adults need to understand why they have to learn something before they begin to learn it and "they must move from a dependent self-concept to a self-directing one" (Tusting & Barton, 2006, p. 22) is salient in a health care environment. Tusting and Barton making use of Knowles's theory of andragogy (adult learning), claim it is important that teachers make the learning related to genuine problems or issues in a person's life, i.e., fully contextualised. This notion of full contextualisation (which learning about one's health condition in hospital must surely qualify) supports the importance of mediation of new information with the patient as learner. However, Wenger's (1998) paradoxes of design, "No community can fully design the learning of another. And at the same time: No community can fully design its own learning" (p. 234) underlies the dialogic process which is needed to grow patients' health literacy concerning their condition and care. Presenting health literacy as a non-linear, fluid and fluctuating notion could assist health practitioners to respond to the health literacy needs of patients as sponsors and engage more fully in the dialogic learning process. Keeping to the fore in health professionals' training the often considerable linguistic and conceptual variation between the patient's understanding of their body and a medical specialist's could help to position health professionals in a stronger way as literacy sponsors across the system, as well as healers.

The literacy practices described in my research can illuminate what to teach and how it can be taught (Rogers & Street, 2012). For an adult literacy educator, knowing that written patient information text may not be central in a patient's health journey, but knowledge of condition and care is, is an important distinction. The stories presented in the previous chapter and analysed through the notions of access, agency and mediation provide a starting point for educators to structure health literacy programmes, for example, equipping learners/potential patients with literacy practices which may help them access information on health conditions and care in different health contexts. Taking a social practices approach to literacy does not preclude encoding or decoding skills, but it refocuses the issue onto teaching being driven by context and the meanings and practices surrounding literacy in those different contexts.

8.5 Limitations

Limitations of this kind of ethnographic research are many if viewing the research from a biomedical, functionalist perspective. However, by considering literacy practices through the eyes of participants, texts and contexts, a different view of literacy practices can be explained. The research sits within a highly complex healthcare institution. It is a snapshot of a particular place at a particular time. It will only ever capture a part of the on-going narrative where personalised meaning is constructed through many modalities.

This study was also limited to a cardiovascular service of a hospital and it would be insightful to have it replicated across a broader cross-section of a hospital or primary health clinic's specialities. In that way, a mixture of participant ages and conditions could be included as well as perhaps greater diversity of literacy events and practices using modalities beyond the written patient information text to assist in the sponsorship of health literacy. In this regard, more research is required to actually see more of the literacy practices different people use around different literacy events (Street, 2010).

Another limitation in this research was my peripheral role as the researcher. I was not an insider so did not have a purely emic view on the context that I was observing. To have an emic perspective would have required my having a cardiac

event, since the insider in this research was the patient, not the health professionals working in the context. The patients who participated did not want to have a stranger at their bedside for the entire time of their stay in hospital and so for this reason, a true insider's perspective was difficult to capture. In addition, I was not part of the medical or health care fraternity either. I therefore could not appreciate the local and global contexts that influenced their practices. Had I had a medical or nursing background, I may well have developed a more nuanced view during the research. However, not having any specialised health care knowledge positioned me closer to the participants I was following.

In investigating the questions asked in this research, other research methods could have been used to further explore the individual decoding abilities of the participants, for example, a read-aloud protocol. In addition, my research did not highlight the effect of the language and formatting of the patient texts and this could suggest a different research approach was needed to capture this information. There were also limited focus and findings on elements of diversity in the data, for example, the influence of the participants' limited age range. Diversity is an issue in health care but not one which was evident in my research and could suggest a different approach was needed.

Research such as this could benefit from taking a more longitudinal approach so that a broader picture of a patient's health literacy practices could be examined. Having a home visit as a mandatory part of the data collection as well as a questionnaire explicitly examining patients' information seeking habits (use of internet, family etc.) would have broadening the view of literacy practices that patients brought with them into the hospital setting.

A descriptive ethnography, or textography as this is, cannot be generalised. It can however, explain the complexities of patient experience of text in the particular context. Others can then draw on the issues identified in this work and explore how they align with experiences in different contexts. The research can then serve to point towards further questions and further investigation. This is not a limitation, but rather an important slice of the ontological and epistemological research spectrum needed to engage and develop in a dynamic, complex world.

8.6 Conclusion

This thesis set out to analyse and document the nature of written patient information texts and to capture the social and cultural practices that individuals and groups engage in, in the process of understanding, accessing and using health-related texts, resources and services. I labelled this mode of exploration a *textual ethnography* where the ethnography involved itself principally with the mediating role of written texts in social encounters and events found in the hospital environment (Dray & Papen, 2004; Swales, 1998). Despite the variations in the constituents and discourse of the texts themselves, literacy events in this research have been predicated on the existence of these written texts as part of a patient's journey. However often at the bedside, texts were either absent or not central to the social context. The amount and types of text material given to patients in hospital were limited. Information about condition and care was delivered orally with an audience at the bedside. Some follow-up occurred by nurse specialists. Patients did not ask for written text either. Perhaps they responded in a way that was consistent with the moral order of the environment, a finding not dissimilar to Heath's (1983) on the meanings of questions discussed in section 2.3. Further investigation is needed into patient role designations in health care, but evidence from this research points to the need for an approach which places the patient more strongly as the central agent in their own health care.

The findings on the linguistic features of the written patient information texts themselves were subsumed in many ways in this research by the social context of the patients receiving the texts. No patient in this research was unable to decode written text that was written for patients (as compared to texts written for other health professionals), except for texts containing numeric data. Patients responded to patient information texts that they found very helpful, but no concerns or comments appeared which highlighted a particular patient's problem or concern with a text's linguistic or discourse features. These observations, as well as Rogers and Street's (2012) observations on the teaching of technical vocabulary to adult learners are areas where further research could explore how technical language in patient information texts is used with patients.

The role or place of publicly available, unmediated patient information text is another area of further interest. Are the assumptions underlying the free-to-take approach to text well founded, that if there is a need, will people take the information? In addition, Rogers and Street's (2012) claim also needs further investigation in a health context, that there is in fact no evidence for the belief that supplying written text will lead to an increase in demand for it. They assert that "it appears that demand will die without the provision of material to fuel it" (p. 160). It is another way to explore the role of mediation by literacy sponsors in the health care space, which is another area requiring further investigation. Questions arising from this research ask whether it matters who mediates patient information to patients. In addition, what are the effects on patient understanding of patient text mediation? The rich description in this research has suggested the position of the mediator and the presence of text mediation is important for the personalisation of knowledge for patients. Accessing key texts required a deliberate decision by a health professional to dispense the text items. Key texts were often not available to patients any other way, placing the patients in a somewhat passive position. Patient agency therefore came to fore in this research, by exploring what practices patients did actually use to make information personal to themselves and often their families.

Reflecting back on my experience in India in light of the findings of this research has demonstrated to me that what I saw, but did not then recognise, being effective in that place was sustained mediation of knowledge through pictures, demonstrations and the development of a community of learners in the slums where community health volunteers lived. The community health volunteer was a persistent literacy sponsor who helped personalise knowledge. In the New Zealand context, that responsibility currently rests with health care providers.

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Appendices

Appendix 1: Data summary

1a) Texts collected during data collection phase

Written Texts, Pamphlets and Leaflets				
Procedures	Style	Source	User	Given
Cardiac Catheterisation	leaflet	DHB	Pt 2	Clinical Nurse Specialist (CNS)
Healthy Eating for your heart	booklet	DHB	Pt 2 & 4	CNS
Transoesophageal echocardiography	leaflet	DHB	Pt 7	CNS
A guide to your PICC - leaflet	leaflet	DHB	Pt 7	CNS
A guide to coronary angiography	booklet	Heart Foundation	Pt 1 & 2	CNS
Condition				
Blood test results – cholesterol	page	DHB	Pt 1 & 7	Phlebotomist
What is Supraventricular Tachycardia?	leaflet	DHB	Pt 11	CNS
Patient information on SVT	leaflet	Christchurch Hospital	Pt 11	Registrar
Atrial fibrillation	booklet	NZ Guidelines Group	Pt 7	CNS
Atrial Fibrillation	booklet	DHB	Pt 7	CNS
Care				
Living with your new heart valve	leaflet	DHB	Pt 7	CNS
Take control of your cholesterol	leaflet	DHB	Pt 1	
A guide to recovery after a heart attack		Heart Foundation	Pt 2	CNS
Staying well with heart failure	book	Heart Foundation	Pt 5 & 8	CNS & student nurse
Patient Discharge Summary letter Handwritten list of medications		DHB	Pt 6 Pt 6	Reg. Nurse RN
Managing your angina	leaflet	Heart Foundation	Pt 6 & 9	CNS
Combined DHB Folders				
Cardiac rehabilitation folder used for containing leaflets and information from the cardiac rehabilitation classes	Folder with leaflets inside	Heart Foundation folder Leaflets all	Pt 1, 2 & 9	CNS

Written Texts, Pamphlets and Leaflets				
What's in a label Cardiac Rehabilitation Exercise Diary Cardiac Support Groups affiliated to the Heart Foundation Healthy eating for your heart Evaluation questionnaire		DHB		
Acute Coronary Information Pack Healthy Eating for your Heart What's in a label? Heparin / Clexane Risk Factor action sheet Are you feeding your heart a healthy diet? Take control of your cholesterol 8 week plan after going home	Folder with leaflets in it	DHB	Pt 2 (given whole folder)	CNS

1b) Data summary

<i>Pseudonym</i>	<i>Audio recorded</i>	<i>Visuals</i>	<i>Follow-up</i>	<i>Time span</i>
Mr Cox	193min of 9 different interactions	Photos, result sheets, researcher notes, log, and transcripts, HeLMS.	5 in-patient hospital visits, 2 out-patient cardiac classes, exit specialist visit, mobile phone texts, CNS conversations and follow-up emails	4.5 weeks
Mr Ray	70 mins of 6 different interactions	Researcher notes & log Unfortunately there was a problem with my recording equipment for the post cardiac class conversation which was held at a remote clinical venue away from the main hospital, HeLMS	5 in-patient hospital, post cardiac class visit, telephone follow-up with CNS	7.5 weeks
Mrs Roberts	36 mins	Researcher notes and log, selective transcripts	A day in-patient & 2 telephone calls follow-up	11 days
Mr Dan	140 mins	Researcher notes and log, transcripts, HeLMS	3 days in-patient, follow-up telephone call Follow-up hospital visit	5 weeks
Mrs Trent	116 mins	Researcher notes and log, transcripts, HeLMS	Out-patient appointment, Follow-up phone call and follow-up home visit	3 weeks

<i>Pseudonym</i>	<i>Audio recorded</i>	<i>Visuals</i>	<i>Follow-up</i>	<i>Time span</i>
Mrs Lewis	91 mins	Researcher notes, log, transcripts, photographs, discharge letter, HeLMS	In-patient visits over seven days	4 weeks
Mrs Newton	90 mins	Researchers notes, log, photographs, transcripts, HeLMS	In-patient visits, telephone calls and home visit, mobile phone texts	4 weeks
Mr Shaw	62mins	Researcher notes and log, transcripts, HeLMS	In-patient visits, telephone follow-up and cardiac class	
Mrs Burns	140mins	Researcher notes, log, transcripts, HeLMS	In-patient visits, telephone call follow-up . (Patient withdrew from study)	2 days with follow up call three weeks later
Mrs Hunt	65 min	Research notes, log, transcripts, HeLMS	In-patient all day, telephone follow-up,	
Receptionists, Director of and Māori Health, Cardiac nurse specialists		Research notes, log, selective transcripts, photographs		

Appendix 2: Overview of approach to text analysis

	Description	Analysis	Questions
Social	Social events Social practices	Accessibility Users Mediators Intertextuality and co-textuality Hegemonies	What social event, and what chain of events is the text part of? What social practice? Is the text part of a chain of texts? Is it publicly accessible or only available through a health professional? Is there a case for seeing any social events or practices as having hegemonic implications?
CONSTITUENT			
Overall structure of text	Constituents/ Moves Understanding condition Understanding care	Definition Demographics of condition Causes Symptoms Effects Responses/interventions Statues /safety of proposed responses/interventions When to seek medical advice Summary of use How to take and store medication Side effects & benefits of medication Monitoring of symptoms and condition Sources for further advice	What sections of text (moves) are present? Are all these moves included? What is the sequence of moves and is this appropriate?
DISCOURSE			
Visual Features	Signposts in text for the reader	Pictures /illustrations Placement of information Font size/ colour White space Headings/subheadings/layout Organisational markers of longer texts	Present? Appropriate? Consistent? Picture/illustration-reality/representations/bias, Inclusion/exclusion of reader - assumptions Illustration alignment with text?

	Description	Analysis	Questions
Rhetorical elements	Assumptions inherent in text	<p>Skills for understanding complex sentence structures and specialised or infrequent vocabulary</p> <p>Knowledge of specialised medical terminology</p> <p>Diverse cultural traditions and values</p> <p>Access to health professional support</p> <p>Access to support from friends and family</p> <p>Access to technology for further health resources</p>	<p>What assumptions¹ are made against each of the descriptors? Existential – assumptions about what exists, Propositional – assumptions about what is, can be, or will be. Value – assumptions about what is good or desirable</p> <p>Is there a case for seeing any assumptions as ideological?</p>
Relationship between writer and reader - Tone	<p>Nature of relationship</p> <ul style="list-style-type: none"> ◆ Subjectivity & modality² ◆ Tone ◆ Engagement ◆ Power 	<p>Knowledgeable but not authoritarian</p> <p>Respectful of patient autonomy</p> <p>Clear and consistent</p> <p>Reader friendly</p> <p>Supportive</p> <p>Positive tone</p> <p>Encourage patient engagement</p>	<p>Do headings mirror patient questions</p> <p>Does vocabulary emphasise choice</p> <p>Are record keeping charts included</p> <p>Are there suggestions to consult health professionals</p> <p>Are there suggestions to involve family and friends in care</p> <p>Is it clear who the writer and intended audience is?</p> <p>Is this relationship clear and consistent?</p> <p>Is the person expected to take responsibility for any actions clear?</p> <p>Is the importance and/or urgency of the action made clear?³</p> <p>Are their allowances for patient choice?</p> <p>How is the reader/patient addressed?</p> <p>How does modality reflect the relationship?</p> <p>Is there a case for seeing the writer/readers relationship as ideological?</p>

¹ Fairclough's assumption (2003, p. 41, p. 192) is that assumption "assumes common ground" and therefore "reduces difference."

² Halliday (2002) considers modality to be "the judgement component of the meaning of the clause: the opinions – offered by the speaker, or sought from the listener" (p.245).

³ Questions from (Clerehan, (in-print))

	Description	Analysis	Questions
Semantic (Fairclough, 2003)	Relations between sentences and clauses	Semantic relations between sentences and across the text	What are the predominant semantic relations between sentences?(causal-reason, consequences, purpose, conditional etc) Are there higher-level semantic relations over larger stretches of text– e.g. problem solution?
LINGUISTIC			
Linguistic complexity	Sentence structures	Simple/compound/complex sentence Subordination, gerunds, conditional clauses, Numeracy especially related to risk Directives Reformulation/redundancy Active/passive verbs Modality	How simple are sentences? How are sentence variations used to assist understanding?
Lexical choice	Ratio of common words to words that are less frequent or specialised Frequency of specialised words Words and concepts are clearly defined Visuals are used to explain concepts and words where appropriate	Measurement of lexical items and English language frequency. Specialised words occur frequently in the text and are needed to understand the condition or care Devices used for unfamiliar words or concepts Transitivity of verbs	What is the frequency of common vs specialised? Are devices used for introducing unfamiliar words or concepts (e.g., reformulation or diagrams)? What is the lexical density? Is specialised vocabulary use essential to understanding?
Factual content of text	Facts in the text Intertextuality ⁴	References Current Accurate	Other texts or voices that are included or significantly excluded? ⁵ Are their recent citations or references? What voices are included and are they attributed? Direct or indirect quote/reported? How are other voices textured in relation to the authorial voice, and in relation to each other?

⁴ Fairclough's intertextuality (2003) brings "other 'voices' into a text" and "accentuates the dialogicality of a text, the dialogue between the voice of the author of a text and other voices" (p. 41).

⁵ Questions from Fairclough p. 192).

Appendix 3: Guided conversation questions




Questions used in guided conversations with patients around the texts. Patients did not see these questions. They were mediated and restated to the patient by the researcher.

1. How useful is this text to you? Did you get help from anywhere else to understand your condition or care?
2. What do you understand from the most helpful or useful part?
3. What were your concerns or information needs and did the booklet help you or address them?
4. What information or parts don't you need right now, or are not helpful? If you were to prepare a pamphlet or booklet for yourself, what would you put in or leave out, and when would you want to get that information?
5. Do you think you are the audience for this pamphlet?
6. Your comments on the text, the layout, the headings, the font used, the size of the font, new vocabulary?
7. How easy was it for you to understand?
8. Have you written in the text?

Appendix 4: Summary of my heart action plan

Summary of my heart failure action plan

The full version of your heart failure action plan is on pages 34/35. Your doctor of nurse will fill in the shaded areas to ensure that your plan is specific to you:

 <p>I feel well</p>	<p>My symptoms:</p> <ul style="list-style-type: none"> Weight is on target Little or no swelling Breathing is easy. 	<p>What to do:</p> <ul style="list-style-type: none"> Keep taking my pills (page 14) Keep eating less salt as part of a healthy, balanced diet (page 21) Keep doing my daily checks – weight, swelling and breathing (page 28) Keep making changes to improve my health (page 36).
 <p>I do not feel well</p>	<p>My symptoms:</p> <ul style="list-style-type: none"> Weight is up by <input type="text"/> kgs over 1–2 days Weight is down by <input type="text"/> kgs over 1–2 days Swelling in ankles, legs or tummy Hard to breath with activity or at night Need to use more pillows at night Constant cough or wheeze Very tired More frequent angina. 	<p>What to do:</p> <p>Call my doctor or nurse on tel:</p> <input type="text"/> <p>Change my pills:</p> <input type="text"/> <p>Other instructions:</p> <input type="text"/>
 <p>I need to get help now</p>	<p>My symptoms:</p> <ul style="list-style-type: none"> Sudden, severe shortness of breath Angina not relieved after following angina action plan Develop new chest pain/ tightness/heaviness Sweating, weakness or fainting 	<p>What to do:</p> <ul style="list-style-type: none"> Get help NOW Call 111 for emergency help.

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Staying well with heart failure

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Constituent: Understanding condition – symptoms & effects of extract above	Understanding care – responses & interventions
Rhetorical Elements:	Symptom recognition strongly tied to reader/patient responsibility & actions. Formatting consistent, headings mirror patient experience, Use of imperative voice for patient action which escalates as the patient’s condition deteriorates and becomes more authoritarian – bigger font, use of capital letters and no modality,
Intertextuality:	Record keeping chart invites participation/dialogue, refers to check lists in other sections of the book
Semantic:	Higher level semantic relation across text is problem-solution,
Visual:	Use of colours – green for go, orange for alert and red for trouble or stop used as signposts, text augmented by visual aids - drawings
Lexical choice:	Vocabulary used has been previously defined in the booklet Lexical density of 0.65 (Discourse data text pg 109), and 70% of words used are in the first 1000 words of the English language with a further 11% off-list (Heatley & Nation, 1994) (Cobb, 2013), for example, wheeze, symptoms, angina.

Appendix 5: Mrs Hunt

CNS: *Oh, I've got it. [Laughs] Ok so did he explain what it was?*

Mrs Hunt: *No*

[The doctor had said earlier: You have a common nuisance value rhythm disturbance by the name of atrial tachycardia, or in your case paracismal. It comes in fits and starts. Or PAT (...). Basically it comes from the top chamber of the heart and it is an extra little heart – extra bit of rapid conduction from the top chamber to the bottom chamber.]

CNS: *A big word. So your heart has top chambers and bottom chambers and the top chamber are called your atria. Normally the heart contracts like this [shows with her fist and hand]. The atria goes first and then the ventricle. And that . . . is normal . . . but sometimes because of electrics being extra excited in our heart, the atria decide they want to race so you get this happening [shows with her hands].*

Mrs Hunt: *Ok, he explained that. What is the difference between that and what they thought I had – atrial fibrillation?*

CNS: *Um atrial tachycardia usually comes from one specific part of the heart and there is one part in the atria that is firing so therefore it can be a little easier to treat perhaps, with some methods of treatment, whereas atrial fibrillation can come from many different points in the atria that all decide to fire so it is quite an irregular – I describe it as happening like this [uses hands] a person's heart is just fibrillating.*

Mrs Hunt and CNS: *Yes [over talk each other]*

CNS: *It is very hard to make a quick diagnosis on one ECG sometimes because it can present in many different ways and AF is the commonist [sic]*

Mrs Hunt: *Oh really?*

CNS: *Yes, very, very common so perhaps that is why they first guessed it, but also they often present with common symptoms, shortness of the breath, tiredness, feeling of racing heart.*

Mrs Hunt: *There is one, like mine that carries on to the next one?*

CNS: *No. They are all electrical problems so that can be more challenging to treat sometimes. There is no fast easy way of altering it. It is not like someone who has got angina which is the arteries so you send the plumber in and fix the blockage there. Whereas electricians we rely on medications to try and ... so, what medications? Well medications to slow the rate down because your heart is working fine, it is just that it is going too fast so therefore we want to slow it down so that is one of the things you want to do which will slow the heart rate down. Do you do much exercise?*

Mrs Hunt: *I walk.*

CNS: *Ok*

Mrs Hunt: *I like to swim.*

CNS: *Because what I was going to say is, if you are a person who likes to go to the gym don't bother taking your heart rate, because your heart rate is not going to go as high as it normally would because we have put a bit of a clamp on it. It means you will still exercise and get fit it's just that you won't see your heart rate go up quite as high which is a problem gym bunnies have sometimes, they want to get their heart rate up. So digoxin is the first thing we use to try and treat it and if that works, good. If you feel that you get the symptoms again, the [inaudible] palpitations. Do you want me to write down digoxin?*

Pt: *Yes, [pause] and that is fox glove?*

CNS: *Yes yes. That's why you don't chew the foxglove plant um medications we'll get you settled on. Hopefully they will control you really well. What happens over time is that our heart changes. We age. I need to get new glasses, my prescription gets stronger, so there might come a day when you feel palpitations again. And so it means that you need to go back to your GP cos the*

dose of your digoxin needs to be altered, might need to be increased a little bit – because of that much aging. Does that all make sense?

Mrs Hunt: Yes mmh, can I exercise through it?

CNS: You can, you can, nothing to stop you going for your brisk walk.

Mrs Hunt: I'm talking about 15 and I've got this rubber band thing that I do this and this [shows her].

CNS: Great great. Exercise is wonderful because if you have a heart arrhythmia you are not going to be as impacted by it if you are fit. You are going to feel better. For heart, the best form of fitness is aerobic, so that is your walking. For women and our flabby arms, a bit of arm exercise helps but that is not going to help your heart. Where the heart actually gets exercise, is your brisk walk. Any aerobic thing.

Mrs Hunt: Yes

CNS: Now did Dr [name] talk about other ways of altering this heart rhythm that they might consider?

Mrs Hunt: Well they didn't want to go to the electric [falters over word] and other drugs

CNS: Um there are other medications we can use if digoxin doesn't suit you and when they see you again in the clinic in six weeks if it wasn't under good control, then that's when they might think about referring you to one of the cardiologist who specializes in arrhythmia and different types of rhythms because there is a way that we can ablate which means to do a radio frequency little cut kind of thing so that it interrupts the electric in your heart going through so it makes only the right ones get through. But we definitely want to go medications first cos that is much easier, and that is usually effective, but if it is not then that is where we can head.

CNS: Now this pamphlet here calls it supraventricular tachacardia which is another name for atrial tachacardia. So atrial and supraventricular are the same

thing. So in here [pointing] it talks about the symptoms, you might notice your heart racing for a minute, [reading from it] you might notice shortness of breath. What causes it mostly they don't know. Mostly we don't know. It can be triggered by exercise and stress but those aren't reasons not to exercise. We all have stress . . . but just to point out we don't know what causes it.

Mrs Hunt: *Is it dangerous?*

CNS: *Is it dangerous? Not usually. That is to say, if you let it carry on and your heart rate is going at 140 beats for a week or so then it could impair your heart a bit because you are making it run a marathon with your feet up, so you don't want to be all the time.*

CNS: *How can you stop it? Did he suggest any way of stopping it?*

Mrs Hunt: *No [inaudible] only medication.*

CNS: *Okay. Something I would suggest that you could try is putting your thumb in your mouth and blowing on it as though it was a balloon.*

Mrs Hunt: *Mmh ok, that's what I/they did down there.*

CNS: *Right and it didn't alter it at that time?*

Mrs Hunt: *I don't know. I was on my back. Couldn't see.*

CNS: *If we do that when the palpitations first start then it can have be quite effective. The longer you leave it the harder it is to revert your heart back to normal rhythm. So if you feel like it is starting to raise, just sit there you can blow for about 10 or 15 seconds while holding your pelvic floor so **that** [her emphasis] actually stimulates the heart to stop impulses.*

Mrs Hunt: *Ok*

CNS: *Mmh, so it works quite well and is very easy to do and other people don't have to know you are doing it. Um and the other thing it says here is to wash the face with very cold water. The text books tell us to immerse the patient's head in a bucket of ice water.*

Mrs Hunt: *Oh really!*

CNS: *So anything that makes you suddenly breathe in can alter that heart rhythm.*

Mrs Hunt: *Oh ok.*

CNS: *So it can be really effective, best as soon as it starts cos once it has been a couple of hours and ... in a cycle, it can be very hard to turn it around (Still in the book). Do that straight away. Um here it should we ever develop chest pain is because it is racing you do need to go and see a doctor. If the palpitations carry on, 15 minutes, you do need to go and see your GP.*

Mrs Hunt: *Ok*

CNS: *How can I prevent it from happening? Well sometimes you can do anything. That's the unfortunate thing. Sometimes you can if you are aware that some things trigger it so for some people it is alcohol some people it is coffee some people it's family hassles. Can be a number of things but often it is nothing. If you find you are stressed and you thought it was stress that was triggering it, um do you have good ways of dealing with stress or has it been getting on top of you?*

[more conversation on stress]

CNS: *So the ongoing thing for you is to take your tablets and if you notice they are no longer controlling you go back to your GP and if you are having palpitations or chest pain then you need to come and see us.*

Mrs Hunt: *That's what, just coming in?*

CNS: *Yeah, cos it means that you are slowing down a bit faster and the other thing to keep yourself well is to be able to cut off from that stress and often. Get someone to share it with. Do you know any relaxation exercises?*

Mrs Hunt: *Ah yes*

CNS: *Good ones?*

Mrs Hunt: *I think so? It relaxes me.*

CNS: *And do you do it?*

Mrs Hunt: *Sometimes [laughs] if I can't sleep I will do it.*

CNS: *Sometimes it is a good thing to practice every day, routinely so that your body remembers what it is like to relax.*

Mrs Hunt: *That's true.*

CNS: *Cos often we don't realize until we are really, really tense and then oh my goodness, look at me.*

CNS: *And as for your echo, I would love to talk about that but I don't know anything about it. I'll put you on the list to follow up. I imagine if it was not a great echo that they would keep you.*

Appendix 6: HeLMS survey



A measure to assess an individual's overall capacity to seek, understand and utilise health information within the healthcare setting

INSTRUCTIONS:

1. Please select the most suitable response to each question
2. There are no right or wrong answers
3. Please answer all questions

Start Here

Please read each question and tick the box most suitable:

A. Are you able to:

	Without any difficulty	With little difficulty	With some difficulty	Very difficult	Unable to do
1 Use information from a doctor to make decisions about your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Make time for things that are good for your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Look for a second opinion about your health from a health professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Ask a doctor questions to help you understand health information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Carry out instructions that a doctor gives you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Change to a different doctor to get better care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Change your lifestyle to improve your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Follow instructions that a doctor gives you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Read health information brochures found in hospitals or at a doctor's clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Know where you can see a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

B. Are you able to:

		Without any difficulty	With little difficulty	With some difficulty	Very difficult	Unable to do
11	Ask someone to go with you to a medical appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Know what to do to get a doctor's appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Pay attention to your health needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14	Fill in medical forms e.g. Medicare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Discuss your health with other people other than a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Afford transport to medical appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Get the information you need when seeing a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Pay to see a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Get the information you need when seeing a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Read written information e.g. leaflets given to you by a doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Take a family member or friend with you to a doctor's appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question 14 was substituted with a New Zealand example rather than Medicare.

C. Are you able to:

	Without any difficulty	With little difficulty	With some difficulty	Very difficult	Unable to do
22 Know how to get a doctor's appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23 Find the energy to manage your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24 Pay for medication you need to manage your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25 Get a second opinion about your health from a health professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26 Use advice from a doctor to make decisions about your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27 Find health information in a language you understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28 Ask family or friends for help to understand health information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29 Know where a doctor can be contacted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>