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**Health Literacy:
A Hermeneutic Study of New Zealand Baby Boomers**

A thesis
submitted in fulfilment
of the requirements for the degree
of
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Abstract

Health literacy has traditionally been conceptualised as individual skills in a health context. Although there is growing consensus that health literacy is a multidimensional construct, interacting with socio-cultural contextual influences, such aspects are under-researched. In particular, there is limited research regarding the interrelationships between individuals' and primary healthcare professionals' (PHCPs) health literacy beliefs and experiences. Despite the predicted impact of the ageing population on healthcare costs and services, little empirical research has been conducted in New Zealand (NZ) on the health-related behaviour of the influential baby boomer cohort. The purpose of this thesis is to explore the phenomenon of health literacy among NZ baby boomers and PHCPs.

Using hermeneutics as both the theoretical lens and the research method, this research draws on in-depth interviews to understand the participants' constructions of health literacy and how their constructions influence healthcare goals and service encounters. The research takes a broad perspective of health literacy to answer the overarching research question, *How are the roles and practices of health literacy perceived/constructed and performed in primary healthcare?*

This thesis makes an original contribution to knowledge as the first empirical investigation of health literacy of NZ baby boomers (46 participants) and NZ primary healthcare professionals (11 participants). Specifically, this research contributes to health literacy knowledge in a geographic area (NZ) and among individuals within a generational cohort not defined by health condition or health risk.

NZ baby boomers construct health literacy as a highly contextualised social practice linked to [a]symmetries in health-related information, power, autonomy, and patient-practitioner roles. These participants stress the importance of an individual's personal health context, capabilities, relational processes, and networks in health literacy. Interpreting these baby boomers' health literacy behaviours leads to five categories of description - seeker, decider, networker, sensemaker, and manager, which are appropriately framed within two horizons of self and interactivity, providing conceptual space within which individuals move and adapt their health literacy roles, responsibilities, and behaviours.

In the PHCPs' experiences regarding baby boomers' health literacy there are underlying power and information imbalances, conflicting authority concerns, and [de-]professionalisation issues. Using categories of description, the PHCPs' health literacy behaviours are described as – knowledge broker, ethical agent, and

enabler. Iteratively drawing on pre-understandings, these meanings are theorised in a collective notion of managed empowerment that implies a negotiated balance between PHCP expert control and professional expertise, and patient-consumer autonomy and expertise.

This study extends the understanding of health literacy by presenting an empirically-based conceptual framework, depicting health literacy operating across multiple levels, relationships, and networks, variably influenced by contextual factors of the postmodern health context; the communication and information revolution; and neo-liberalism and consumerism. The thesis contributes to health literacy knowledge by illustrating the fundamental role of relational processes in co-producing individuals' health literacy and in subsequently reaching individuals' health goals. Primary healthcare service providers, policy makers, and health promotion advocates can benefit from this study as it reveals particular health literacy roles and behaviours likely to be influential in encouraging individuals' authentic involvement in their healthcare.

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Chapter 1

Introduction

Will you still need me, will you still feed me, When I'm sixty-four?

Lennon-McCartney, 1967

1.1 From curiosity to a thesis

We live in an era of significant population ageing. Whether one subscribes to the view that this ageing population will bring a wave of negative effects or an opportunity to be harnessed, there will be impacts on society, financially, socially, and politically. There are already changing healthcare roles and responsibilities between state and citizen, unrelated to the ageing demographic, but which are likely to be exacerbated with increasing proportions of individuals aged over 65. It is the baby boomers, the generation that grew up with the Beatles' music, who will make the over-65 year olds such a significant population cohort. Therefore, Lennon-McCartney's lyric is today increasingly more real than rhetorical – who will feed, nourish, and maintain the health of these individuals who are predicted to live longer than, live healthier than, and age differently to the generation before them?

Individuals are exhorted, and indeed expected, to take responsibility for their health as an individual right but also as their moral obligation as citizens to minimise the burden on others in society. In New Zealand, the Health Funds Association¹ warns that individuals should be prepared to make a larger financial contribution to their own healthcare as the public health system comes under increasing monetary constraints. Altered professional roles and accountabilities are also shifting the answer to Lennon-McCartney's question in favour of empowered and responsible citizens.

¹ R. Styles, Health Funds Association, New Zealand, NZHerald Feb 13, 2013.

Complex and diverse forms of health information, alternative treatment options, and increasing variety of non-traditional healthcare professionals present individuals with considerable choice. Enter health literacy. Once considered as literacy in a health context, health literacy is evolving to include the diverse capabilities and social processes that enable individuals to participate in their health and health decisions, beyond the setting of a health encounter. Recently a NZ women's health advocacy group "urged women to read their medical files and *use them to help them make the best decisions*" (emphasis added).²

These, then, are the pre-understandings that both stimulated and sustained the researcher's interest in how individuals and primary healthcare professionals understand health literacy, and how they experience health literacy in these changing times.

1.2 Health - a significant issue

The term 'health' almost defies definition. The Ottawa Charter describes health as "...a resource for living, not the objective of living - the goal of health promotion activity is...to help people to be as healthy as they wish to be" (Wills, 2010, p. 64). However, health is an unobservable, highly personal construct that is more often defined by what it is not. The definition that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948³), has been well-cited but has not reduced the controversy over a health definition (Abel & McQueen, 2013). The ancient Greeks considered health to be the ideal of life, a sound mind in a healthy body reflecting a condition of completeness. This research adopts a broad conceptualisation of health as a basic human need fundamental to the functioning of individuals and societies. As a priority of life the perspective of Kantian ethics argues that there is a moral duty to address health disparities and, importantly, Kant's requirement of autonomy requires individuals to be fully informed about health and health decisions in

² NZHerald, August 27, 2014.

³ <https://apps.who.int/aboutwho/en/definition.html>

order to make rational decisions (Beach et al., 2005; Sugarman & Sulmasy, 2010).⁴

The significance of health socially and politically is immense. Health is “...no longer seen simply as a consequence of economic growth, but as one of its engines” (Labonté, 2008, p. 471). Health is often linked to the economic strength of a country as a marker of a government’s success; there is an “enduring association between national wealth and national health...” (Jones & Earle, 2010, p. 6). While the challenge for all industrialised countries is to provide their populations with quality, accessible, and efficient healthcare there are complex and varied determinants of health (see the work of Fuchs, 1982, and Grossman, 1972). Accompanying these aspects, healthcare today is characterised by change, complexity, and escalating costs (Kickbusch & Seck, 2010; Lee, 2003; Schoen et al., 2007). A further challenge is the new consumerism in health that “locates responsibility [for health] with both individuals and the providers of public and private organisations serving the public” (French, 2010, p. 248).⁵ Action for improving health and wellbeing is becoming “...‘everybody’s business’ in the challenge to create healthier societies” (Jones, 2010, p. 2). The responsible, neoliberal subject who actively and capably regulates his or her health is part of an important social process influencing health and health research (see Section 1.3.1).

Among the many social determinants of health is an individual’s active participation in his/her own health (e.g., Protheroe, Nutbeam, & Rowlands, 2009). Moreover, socio-demographic factors are producing a variety of stresses and opportunities for healthcare systems and services; the “ageing populations and medical science advances will likely require...system innovations to improve health and meet population needs” (Schoen et al., 2007, p. 733). The traditional

⁴ Kant treats all individuals as rational and his account of autonomy relies on rational choice, not for choices arrived at by non-rational or idiosyncratic means. Hinkley (2012) suggests that paternalism is therefore justified based on the presumption of a potential non-rational response. It is beyond the present scope to debate the link (or otherwise) between being informed and acting rationally.

⁵ The philosophy of consumerism, neoliberal perspectives, and consumer choice are likely to differ significantly between countries and healthcare systems. The discussion in this chapter focusses on the New Zealand healthcare system, unless otherwise specified.

authoritative view of healthcare is focussed on experts defining the desired behaviour outcome and imparting information to communities and individuals deemed to require interventions. A contemporary perspective, on the other hand, suggests that the notion of healthy public policy needs to be “re-interpreted” in light of changes to governance structures and socio-cultural differences in health characteristics, demands and behaviours (Nutbeam, 2008b, p. 437). Within this latter perspective, health literacy proponents suggest that health promotion should enable individuals to make their own assessments of advice, understand conditions, and choose healthcare services to allow them to be healthy.

Achieving health and the freedom to achieve health are cornerstones of Sen’s (2002) capability theory, focussing on the ability of individuals to choose health-related behaviours, including the ability to navigate through constraints in their health environments (Ruger, 2010). Health literacy fits into this as being an individual’s capacity to make sound health decisions in the context of everyday life and the capability to participate in such decisions, including individuals’ engagement in their healthcare. Although a health literate person does not have the expertise of a health professional nor does she or he replace medical knowledge with personal preferences, health literacy plays a fundamental role in the social processes of an individual reaching his or her health goals. Therefore, health literacy plays an important part as a social determinant of health (Schulz & Nakamoto, 2012a).

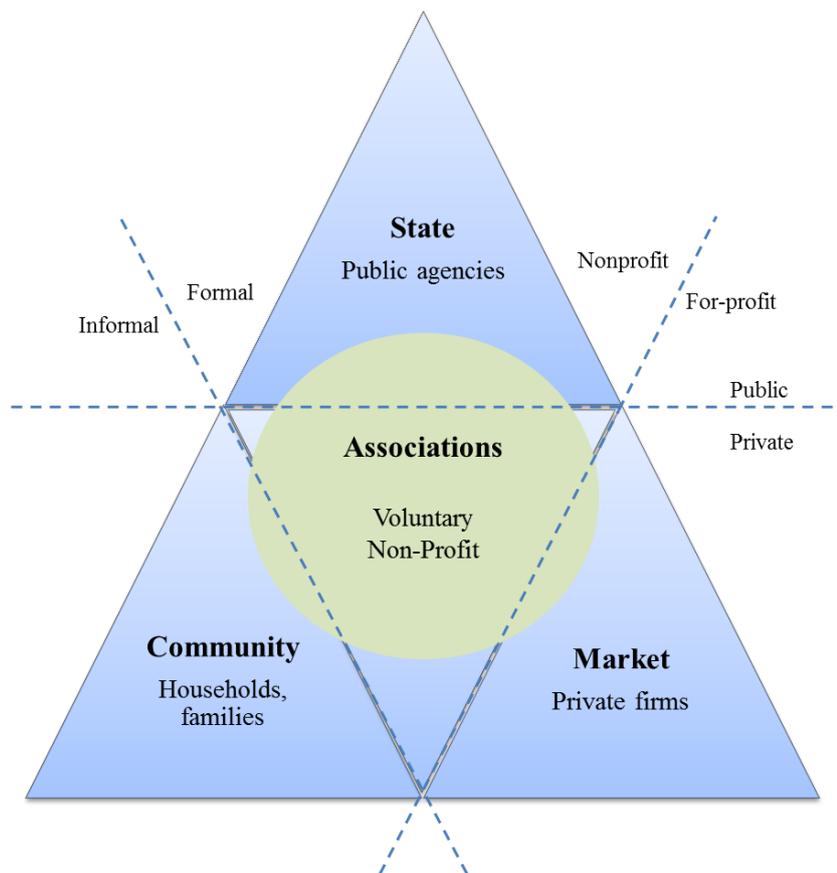
This chapter presents an overview of the thesis providing initial insights into the researcher’s pre-understandings, which are integral to the hermeneutic interpretive process adopted in this research. Pestoff’s (1998, 2009) welfare triangle and neoliberal approaches to healthcare policy and systems provide the broad domain within which this research is positioned. These pave the way for introducing the research focus on health literacy and New Zealand baby boomers. Section 1.5 outlines the research problem, which is developed later through the literature review in Chapter 3. The intended contribution and research boundaries are set out and Chapter 1 ends by outlining the structure for the remaining thesis.

1.3 Health, health literacy, and the regulatory social order

Health is variously influenced by social and environmental factors, including ethnicity, socio-economic status, gender, housing, and community participation, making it inherently political (Hodgetts & Chamberlain, 2006). Consequently, research focussing on the social determinants of health benefits from a consideration of how healthcare fits within social and political institutions and societal order. Societal governance systems typically identify three pillars or institutional bases of social order - the community, the market, and the state. One framework for explaining the characteristic elements and processes within these three pillars is provided by Streeck and Schmitter (1985, adapted in Figure 1.1). The community, the market, and the state are guided (respectively) by principles of spontaneous solidarity, dispersed competition, and hierarchical control based on the central institutions in each that embody these principles.

Figure 1.1 The three pillars of social order

(Adapted from Pestoff, 1998 and Streeck & Schmitter, 1985)



Public interest theory views the state as identifying the public interest, intervening to improve social welfare and order. From this perspective, state intervention corrects inadequacies in the market that may reduce societal welfare/benefit. Private interest theories hold that private interest groups and industry groups work to use political processes to obtain higher prices. Private interest groups will lobby the state for measures to maximise their wealth. Corporatist theory, including elements of private interest theory, refers to the management of social order through private groups or organisations having a direct role in the creation and implementation of state policy along with certain constraints on their operation (Schmitter, 1974). The corporatist model of social order integrates diverse interest groups into state planning and policy making. Such arrangements can maintain discipline among the private interest groups since the concession(s) granted by the state are given in return for compliance.

In addition to the three pillars of social order Streeck and Schmitter (1985) suggest a distinctive fourth institutional basis of social order, termed ‘associations’ - functionally defined associations such as school parent associations or neighbourhood watch groups. Associations are a coherent social form that overlap inside the governance triangle (refer Figure 1.1). Associations, defined by the principle of organisational concertation, are more than just an expedient mix of the other three dimensions and they provide important opportunities for public policy. Although each of the three pillars of social order “have dysfunctions for each other” there are “specific problems of order that each of them is better equipped to resolve than the others. The same...can be said of associations” (Streeck & Schmitter, 1985, p. 121). Indeed, associations often mediate the tensions between the other three dimensions.

The associations dimension parallels the Third Sector (Defourney & Pestoff, 2008; Pestoff, 2009) overlapping public and private, profit and not-for-profit, and formal and informal institutions. It is important to note that much of the restructuring of public services (including healthcare systems) has resulted in mixed economies of service provision, involving central and local government partnering with private and third sector organisations.

In New Zealand, within the healthcare sector the medical profession is a deeply entrenched interest group, mirroring a corporatist model that typically exhibits a high degree of “private interest government” (Greer & Rauscher, 2011, p. 802). This means that the state in New Zealand works with these influential private interest groups (the market) to decide policy and deliver healthcare services, incorporating organised interest groups into the state’s own system of control and using them to implement its policies. Unlike either the community order where actor choices are interdependent based on shared norms, the market order where competitors’ actions are assumed to be independent, or the state order where actors are dependent on hierarchical coordination, the corporatist-associative social order is based on “mutual recognition of status and entitlements” (Streeck & Schmitter, 1985, p. 126) where the actors are strategically interdependent. However, this corporatist model often reinforces the status quo since these interest groups generally resist change (Barnett, 2005).

Pestoff (2009) maintains that “neither the state nor market allows for much more than marginal or ad hoc [citizen] participation” (p. 214) in the provision of social services, resulting in little citizen influence. Therefore, “...citizens of democratic welfare states...want to (re-) claim their influence and control over the services that they both support politically and pay for with their taxes, regardless of who provides them” (Pestoff, 2009, p. 202). Fotaki (2011) discusses this as the demand for greater choice and participation to both empower individuals and place more responsibility on users of public services, noting that “provision of welfare services through social enterprises facilitating co-production will alter the relationship between the state and citizens in a fundamental way, prompting users to become active participants...” (Fotaki, 2011, p. 938).

This thesis adopts the welfare triangle as a backdrop to position health literacy within the predominant New Zealand social institutions of power and knowledge. Health sector reforms in New Zealand have typically moved between state and market with limited authentic involvement of the community pillar (discussed further in Chapter 2). The corporatist framework in New Zealand has been dominated by the medical profession who have fought for independence from the state at the same time as being highly influential in making policy. Consequently,

“On the few occasions that governments have sought to impose an alternative approach, excluding the [medical] profession from the development of policy or making decisions counter to its interests, there has been sharp resistance and government goals have not been successfully achieved” (Barnett, 2005, p. 314). Although the New Zealand healthcare system remains in a state of flux (Gauld, 2009a, 2009b) there has been a strong neoliberal influence on policy particularly evident in the 1980s to 1990s with a more recent emphasis on social democratic goals (Cumming & Mays, 2009; Tenbensen, Mays, & Cumming, 2011; and refer Section 2.3).

1.3.1 Neoliberal consumerism

Neoliberalism, “the (re)privileging of liberal principles” (Savard, 2013, p. 201) popular in some circles in the nineteenth century, refers to individuals as rational agents with rights to knowledge who are capable of exercising regulated freedom (Petersen & Lupton, 1996). This ideology also means that the healthcare consumer has considerable responsibility, since the “choice of options for action is, or so the neo-liberal notion of rationality would have it, the expression of free will...the consequences of the action are borne by the subject alone, who is also solely responsible for them” (Lemke, 2001, p. 201). The era of neoliberalism and the trend towards greater patient responsibility and autonomy intersected with pressures, worldwide as well as in New Zealand, to contain costs and increase efficiency in healthcare systems.

This trend towards requiring individuals to act responsibly, make informed choices, and take appropriate preventive action regarding health and healthcare has been criticised for allowing governments to “...offload[ing of] informing and care work...onto the shoulder of ordinary citizens...” (Harris, Wathen, & Wyatt, 2010, p. 221). In this mode of governance, that functions by individuals regulating their own actions rather than due to imposed external constraints, individual duties and responsibilities take precedence over the welfare state and the role of government in healthcare (Petersen, Davis, Fraser, & Lindsay, 2010; Petersen & Lupton, 1996); government institutions traditionally mandated to protect citizens

are part of a “market of authorities” (Shamir, 2008, p. 6) to facilitate shared responsibility. The subsequent managerial discourse allows the state to reposition itself and as a result of the emphasis on active citizenship the patient has become the healthcare consumer, largely recast from a passive, sick role to an informed and empowered individual.

The neoliberal view of the healthcare consumer, for example in Australia, brought about shifts in healthcare professionals’ responsibility and regulation, between lay and expert knowledge, as well as shifts in power (Irvine, 2002). The healthcare consumer can challenge physicians’ status as professionals, adding another (in addition to state, institutional, and/or the profession itself) regulatory layer to professionalism (Hartley, 2002; Madison, 2010); consequently, consumerism has been associated with a shift from autonomy-based professionalism to accountability-based professionalism requiring ‘justified trust’ (Light, 2010; Timmermans & Oh, 2010). In general, the neoliberal view of shared responsibility and empowerment means that medical professionalism is being re-defined (Light, 2010; Light & Levine, 1988; Mechanic, 1996, 2000; Stevens, 2001).

Consumerism and the loss of trust in health professionals have changed individuals’ health-related behaviours, their health information-seeking, their use of complementary and alternative medicines, self-diagnosis, and care. Consequently, the individual as a neoliberal subject and subsequent challenges to health professionalism are important contextual influences for understanding health literacy.

1.4 Significance of this research

Health literacy advocates have traditionally focussed on marginalised and at-risk groups in recognition of health-denying circumstances in people’s lives. More recently, the health literacy view is widening to include those skills, capabilities, and relationships that enable individuals to make their own assessments of advice, understand conditions, and choose healthcare services to allow them to be healthy. While health promotion achievements can be evidenced targeting specific segments of an often at-risk population (e.g., Raphael, 2008; Ziglio, Hagard, &

Griffiths, 2000) there is little evidence of research targeting a non-risk population defined according to socio-cultural dimensions. One such socio-culturally defined population is Baby Boomers.

In New Zealand, along with most western developed countries, the complexity of healthcare is now facing the extra pressures of population ageing. In particular, New Zealand analysts are concerned at the potential impacts on healthcare resources caused by the influential Baby Boomer segment born between 1946 and 1965,⁶ the first of whom reached the official retirement age of 65 in 2011 (Ministry of Health, 2004a; Stephenson, 2006; Teasdale, 1999). There are varying estimates of the impact of this cohort on health expenditures; most recently it has been forecast that by 2028 nearly 50% of healthcare expenditure will be required for the care of those aged 65 and over compared with 37% in 2006 (Ministry of Health, 2010c), rising to 63% of the total Government health expenditure by the year 2051 (New Zealand Treasury, 2004). Policy strategists recommend that current funding will need to increase or to be redistributed between appropriate service areas if these levels are to be met (e.g., Ministry of Health, 2004b; Ministry of Health, 2010c; The Treasury, 2010).

Moreover, baby boomers are expected to be a consumer segment of considerable power and influence (Spinks, 2010) with characteristic needs, wants and expectations; baby boomers' attitudes, values and lifestyles are seen as being shaped by a particular combination of political, social, technological and economic events - the social ambience of the time. In NZ this social ambience included the 'Golden Age' of "easier access to housing, a universalistic social security system, a more equal spread of incomes, a value system which may have been paternalistic and patriarchal..." (Pool, 2007, p. 158).

⁶ Definition of the baby boom varies between sources and between countries. Statistics New Zealand (1995) defines baby boomers as New Zealanders born between 1 January 1946 and 31 December 1965. The period 1946-1965 was associated with high fertility rates and high number of births.

1.5 The research problem

Contemporary perspectives on health literacy recognise its complexity and its significance as a social determinant of health. This research seeks to understand the phenomenon of health literacy as experienced and constructed by both baby boomer patient-consumers and primary healthcare providers. Better understanding of the negotiated dimensions and practices of health literacy can provide a framework for improved healthcare communication, interaction, service type and timing, health decision-making, and health engagement.

The thesis of this study is that by considering the understandings and responsibilities of health literacy in the recurring primary healthcare practices of individuals, health literacy can be more effectively negotiated. From a deeper understanding of health literacy and how it is ‘practised’, divergent health literacy expectations, roles, and behaviours among primary healthcare professionals and patient-consumers can be addressed. This thesis also answers the call for more research into the “collective nature of healthcare decision making” (Dew, Chamberlain, et al., 2014, p. 41). Not only could this research help address new ways for improved healthcare communication and interaction facilitating patient engagement, that is, more involvement of the community pillar (Figure 1.1), but it could also be used to enhance health literacy awareness and training for primary healthcare professionals.

Despite the impacts their ageing is predicted to have on NZ healthcare, little empirical research has been conducted on the healthcare implications of the baby boomer population segment. In addition, there has been limited research on NZ patient-consumers’ perspectives of health literacy. A recent interpretive study (Honey, Roy, Bycroft, & Boyd, 2014) investigated health information needs of 30 New Zealanders most of whom were managing a long term condition; as indicated in the research title this study only considered health literacy in terms of health information. A third research gap concerns sustained qualitative research on individuals’ health literacy experiences and understandings among non-patient populations (outside of a formal patient-practitioner relationship) or those who do not suffer (or are not at-risk of suffering) chronic disease. These research gaps

regarding health literacy and the ageing population provided the motivation for developing this research study and the research purpose described below.

1.5.1 Research question

The purpose of this study is to elucidate/understand the dimensions of health literacy within the context of New Zealand baby boomers. This purpose can be stated in the form of the following research question:

How are the roles and practices of health literacy perceived/constructed and performed in primary healthcare?

To examine this research question the following more specific questions are used:

1. How do New Zealand Baby Boomers experience and practice health literacy? Specifically,
 - how do Baby Boomers as primary healthcare patients perceive their behaviours, roles, and relationships regarding health literacy?

2. How do primary healthcare professionals (PHCPs) practice health literacy? Specifically,
 - how do PHCPs perceive their behaviours in relation to health literacy and baby boomers?

The thesis uses hermeneutics as both the theoretical lens for guiding the research and the specific method of analysis (Bleicher, 1980). Hermeneutics provides for an historical and contextual interpretation of human action as communicated in text, along with pre-understandings and interpretive processes brought to the research data by the researcher (Ricoeur, 1974a, 1981c, 1990). Ricoeur's iterative circle of interpretation between pre-understandings, empirical data, and the fusion of horizons (between the researchers' understandings and emerging meanings from the textual data) provides an appropriate process for new meanings leading to an extended conceptualisation of health literacy.

The decision to choose hermeneutics as the philosophical lens and the methodological basis for the thesis is based on the following aspects. Firstly, hermeneutics is about understanding a phenomenon through recognition of its meaning which makes it appropriate and useful for research into health literacy as a phenomenon. Secondly, lived experience is expressed through language, which is then transcribed into text and interpreted. In this way “interpretation is at the hinge between...language and lived experience (of whatever kind)” (Ricoeur, 1974c, p. 66) making hermeneutics particularly appropriate for in-depth research interviews. The third aspect relates to hermeneutics acknowledging contextual and historical dimensions of the participants’ experiences which fitted well with the specificity of the New Zealand healthcare context and the baby boomer population segment of research interest. Finally, hermeneutics acknowledges that the researcher brings his/her pre-understandings to the interpretive process.

1.6 Intended contribution

As mentioned above, health literacy studies have mainly focussed on health literacy among at-risk individuals. There has been limited empirical investigation of health literacy among research participants who are not defined according to a health risk or condition. In addition, there is limited empirical research in New Zealand on the healthcare behaviours and health literacy of the baby boomer cohort. Hence, by focusing on the health literacy of New Zealand baby boomers this study contributes to our understanding of the phenomenon of health literacy. By also including the perspectives of primary healthcare professionals, this research aims to highlight and extend the conceptualisation of health literacy as a social practice.

This study will be valuable for individuals in their healthcare encounters, network relationship, and health decisions. By considering network and interactional dimensions of health literacy, primary healthcare professionals can usefully reflect on their patient interactions and changing professional roles. Educators and trainers of primary healthcare professionals will benefit from this study as it highlights areas where health literacy expectations, roles, and practices can be improved. Finally, the research can provide valuable insights for primary

healthcare policy, drawing on health literacy as an influential aspect in developing authentic involvement of citizens in healthcare according to Streeck and Schmitter's (1985) community pillar.

1.7 Research parameters

The research question explicitly situates this research in the primary healthcare domain with a specific population of interest. Primary healthcare professionals (PHCPs) are those healthcare professionals who provide the first level of services or point of consultation for patients within the healthcare system (King, 2001). In New Zealand, a patient can make contact with primary healthcare professionals without needing a referral from another healthcare practitioner, although not all of the services offered by these professionals are funded by the government. In New Zealand, the Ministry of Health emphasises a broad scope of primary healthcare professionals with the term PHCPs including: general practitioners, dentists, pharmacists, nurses, occupational therapists, physiotherapists, and audiologists (refer <http://www.health.govt.nz>).

The participant population is New Zealand baby boomers. Health is the number one concern of NZ baby boomers (Buckland, 2009). Research has suggested that baby boomers want autonomy around their life decisions and want to stay healthier than generations before them (e.g., Arsenault, 2004; Biggs, Phillipson, Leach, & Money, 2007; Bradley, 2012; Buckland, 2009; Coleman, Hladikova, & Savelyeva, 2006; Ozanne, 2009; Westerman & Yamamura, 2007). The participant group is not defined by any health risk factors, that is, the participants are not recruited because they are either ill, disease prone, or considered at-risk of disease. The conceptualisation of health literacy adopted in this research is health literacy as a social phenomenon; the research does not adopt the skills deficit perspective of health literacy.

This research does not claim to be a study of generational differences even though individuals from a particular generational cohort were invited to be research participants. The research does not investigate health literacy interventions and

does not relate health literacy to health outcomes among the participants. However, the research contributes to researchers' growing knowledge of both individuals and healthcare professionals' everyday experiences and understandings of health literacy regarding primary healthcare.

1.8 Thesis structure

In order to answer the research questions this thesis is structured according to seven inter-related chapters. The following is a summary of the content of each chapter.

1.8.1 Chapter 1: Introduction

The chapter provides an overview of the thesis. It introduces health literacy and argues that it has significance as a social determinant of health. Chapter 1 frames health, healthcare, and health literacy by making reference to the welfare triangle and neoliberalism. Hermeneutics is presented as the theoretical lens for guiding the research questions and this chapter begins contextualising health literacy as a social phenomenon among the population of baby boomers and primary healthcare professionals within New Zealand.

1.8.2 Chapter 2: Research Context

Chapter 2 situates the research within the two broad contexts of: firstly health, the New Zealand healthcare system, and reforms; and second, New Zealand baby boomers as a generational cohort. This chapter elaborates the pre-understandings regarding these New Zealand contexts, a fundamental part of hermeneutic interpretation. The purpose of the chapter is to describe the complex and changing nature of the NZ healthcare system for studying health literacy and to explain the socio-cultural characteristics attributed to the baby boomer cohort.

1.8.3 Chapter 3: Health Literacy

The main objective of this chapter is to elaborate the pre-understandings of health literacy, how it is conceptualised, and the changing scope of health literacy dimensions. Much of the early scholarship in the health literacy field, aimed at improving patient behaviour, framed health literacy as a deficit that limited optimal health outcomes. This chapter traces the developments in health literacy research from this perspective to the current view of health literacy as an asset, and finally, to the contemporary health literacy model of Sørensen et al. (2012) that incorporates the health system, healthcare professionals, and individuals as health experts within a socio-political environment. Finally, in Chapter 3, the researcher proposes a revised conceptual framework as a vantage point from which the hermeneutic interpretation of the participants' interview texts can reveal dimensions and characteristics of health literacy.

1.8.4 Chapter 4: Research Methodology and Method

Chapter 4 addresses the methodological foundations of the research and the research design for the empirical research process. The theoretical lens for the thesis is the theory of hermeneutics. The chapter explains the iterative process of pre-understandings, empirical data, and the fusion of horizons leading to new understandings of a phenomenon. This chapter also describes the sample design, data collection techniques, and the method of data analysis. Data collection uses in-depth structured interviews with a convenience sample of 46 New Zealand baby boomers stratified according to gender and ethnicity, and 11 primary healthcare professionals.

1.8.5 Chapter 5: NZ Baby Boomers' Constructions of Health Literacy

This chapter interprets the empirical data in relation to the first research question - how the NZ baby boomers construct health literacy. This chapter balances description of the textual data with interpretation using the pre-understandings from Chapters 1, 2, and 3 in the hermeneutic circle of interpretation. Using

categories of description from phenomenographic methodology, Chapter 5 interprets baby boomers' experiences of health literacy according to five key categories of seeker, decider, networker, sensemaker, and manager. Progressing through further iterations of the hermeneutic circle, the chapter concludes by framing these categories of description along two dimensions, horizons of self and interactivity.

1.8.6 Chapter 6: Primary Healthcare Professionals' Experiences and Practices in Baby Boomers' Health Literacy

Interpreting the construction of health literacy from the perspective of primary healthcare professionals (PHCPs) is the main objective of this chapter, addressing the second research question. Through the hermeneutic process, Chapter 6 interprets the textual data according to three categories of description for PHCPs' experiences and behaviours of knowledge broker, ethical agent, and enabler. The chapter highlights related issues of competing forms of [health] knowledge, de-professionalisation, and professional identity amid changing contexts of health decision making. Finally, the PHCPs' construction of health literacy is collectively interpreted as managed empowerment.

1.8.7 Chapter 7: Conclusion - Extending the Conceptualisation of Health Literacy

Chapter 7 concludes this thesis, linking together the baby boomer participants' and PHCPs' constructions to extend the understanding and conceptualisation of health literacy. The chapter provides a definition of health literacy based on the study findings. In this chapter research limitations are identified along with areas for future research. The contributions of the study to health literacy are discussed and the practical implications of the research are considered. At a societal level, the chapter concludes that empowering primary healthcare users through health literacy can broaden the conception of health services beyond a provider-centric model.

1.9 Summary

This chapter provides an overview of the thesis. The purpose of the research is to explore and extend the understanding of health literacy through a hermeneutic investigation of New Zealand baby boomers' and primary healthcare professionals' experiences, roles and behaviours of health literacy. Insights from this research can be applied to promoting improved primary healthcare relationships, redressing inequalities in health relationships, and improved communication about health and healthcare services.

The structure of the thesis is explained and a summary of the seven chapters provided. The hermeneutic methodology guides this structure throughout the thesis, firstly describing the New Zealand health and baby boomer contexts in Chapter 2, followed by the pre-understandings of health literacy in Chapter 3, research methodology and method in Chapter 4, and the interpretive analysis of the empirical data in Chapters 5 and 6. Chapter 7 concludes the thesis.

Chapter 2

Research Context

2.1 Introduction

The contemporary perspective on health literacy views it as a broad concept that encompasses individual skills and competences, healthcare interaction characteristics, situated within diverse contextual factors. From this perspective, understanding the phenomenon of health literacy warrants an appreciation of contextual aspects – namely, health beliefs and the New Zealand healthcare system and baby boomers as a generational cohort. This chapter is integral to the hermeneutic research methodology adopted in this thesis.

Two important concepts in hermeneutics are historicity and context for understanding the textual data relating to the phenomenon of study. Historicity means that the texts are understood by relating them to the historical setting - including cultural, political, economic, social contexts – from which they emerge. Therefore, it is important that the researcher is familiar with these historical contexts. Understanding these contexts enables the researcher to bridge the horizons of the text and the researcher's own pre-understandings and historic-cultural environment, leading to a fusion of horizons, or understanding. However, these contexts are not simply a given but need to be identified by the researcher and can be defined on varying levels according to the research purpose and questions (Prasad, 2002). It is clear then that the definition of contexts is subjective and will also influence the interpretation of the texts.

The two main research contexts identified in this thesis are: health and the New Zealand healthcare system; and baby boomers as an influential generational cohort. This chapter begins by outlining the philosophical context of health beliefs and the models of health - biomedical, biopsychosocial, and the patient-centred clinical approach - since beliefs and values about health and healthcare underpin

health policies and institutional norms. In New Zealand (NZ), Gauld (2009b) argues that the healthcare system is moving from a neoliberal position to a more social-democratic era. Following these social-democratic goals, patients are provided with better information, more choice, and improved access to healthcare services, and there is increased alertness to patient-centred care. The manner in which healthcare systems are institutionalised affects the patient-consumers in multiple ways including their access to healthcare, their perceptions of healthcare, and the relational processes that can influence health literacy. Therefore, this chapter introduces the socio-political context of health, reviewing the complex and changing arena of the NZ healthcare system. The second part of the chapter introduces the other significant context of this research, the baby boomers and how they can be understood according to socio-cultural attributes, not simply a classification according to age.

2.2 Health beliefs and models of health

Among the many definitions of health, this thesis defines health as a resource for living, representing a condition of completeness. As well as the academic definitions of health there also exist several common-sense understandings of health (e.g., Blaxter, 1990; Blaxter & Paterson, 1982; D'Houtard & Field, 1986; Herzlich, 1973; Williams, 1990). Many of these reiterate three explicit representations of health found by Herzlich (1973). Herzlich's three representations, which could co-exist in the same person, include: health as the absence of illness that is only recognised when one becomes ill; health as a strength ("health as a reserve") to resist illness; and health as well-being and balance.

The traditional view of health and one which is still considered to be the most prevalent notion of health in Western societies is the biomedical model of health (Douglas et al., 2010; Samson, 1999; Wade & Halligan, 2004). This model explains health, viewed as the absence of disease, in terms of biology concentrating on the physical body and its physiology. The body is separate from the mind. As well as this principle of mind-body dualism, the bio-medical reductionist view understands the body as an organism by considering its

elements with each having a normal way of functioning (Samson, 1999). Underpinning the biomedical model are scientific method assumptions for understanding, treating and preventing disease or sickness. Disease is a malfunction of a part of the complex organism that is the human body as a result of specific pathogens according to the theory of specific disease aetiology (Samson, 1999). The task of medical treatment therefore is to deal with this diseased part since "...a cause and therefore a treatment can be found for all disorders, whether physical or mental" (Douglas et al., 2010, p. 28).

There is no denying the record of substantial achievements of medical science under the biomedical approach. However, while the biomedical model is relevant for many disease-based illnesses, it says little about psychological, emotional, and environmental influences on health. Inherent in the biomedical model is the pathogenic paradigm which categorises people dichotomously as either healthy (normal) or dis-eased. Specific diseases are identified and by removing the specific causes and eliminating disease individuals will become healthy. This contrasts with the salutogenic paradigm whereby no individual is either healthy or diseased, but that an individual can locate along a continuum of health-ease versus dis-ease (Antonovsky, 1996). Patient-centred care gained support in the late 1970s, "The present upsurge of interest in primary care and family medicine clearly reflects disenchantment among some physicians with an approach to disease that neglects the patient" (Engel, 1977, p. 134).

Developing out of the humanistic psychology tradition (from theorists such as Carl Rogers and Abraham Maslow) there is now growing support for expanded models of health, the most popular being the biopsychosocial model (e.g., Borrell-Carrió, Suchman, & Epstein, 2004; Engel, 1977; Schwartz, 1982). This model recognises the whole person as well as the influence of the physical and social environment in determining health, thus lessening the emphasis on disease of the organism. George Engel (1977) formulated this model as an alternative ideology to increase patient empowerment and empathy in understanding health. Under a biopsychosocial model health is understood as being influenced by multiple factors, biological, psychological, social, and environmental. Hence health is much more than illness prevention.

The patient-centred approach, developed as the process for operationalizing the biopsychosocial model of health, now plays a central role in healthcare (Epstein, Fiscella, Lesser, & Stange, 2010; Epstein, Franks, Fiscella, et al., 2005; Levenstein, McCracken, McWhinney, Stewart, & Brown, 1986). From this development of patient-centredness, communication and relationships in primary care have grown in importance, including communication based factors of participation in decision making, informed patients, and patient understanding (Heisler, Bouknight, Hayward, Smith, & Kerr, 2002). However, perspectives on whether patient-centred care has occurred may differ between the patients and the providers.

Limitations of the biomedical model, including patients' reduced tolerance of paternalistic patient-practitioner relationships, has influenced the growing use of complementary alternative (CAM) healthcare in Western societies (Ning, 2013). At the same time, changes in information technology (the World Wide Web and social media) offer patients specialised, technical knowledge that once only medical professionals were privy to. Along with changes in medical models of health, patients have become more informed and self-conscious about their healthcare. Patients increasingly expect an approach where healthcare professionals and healthcare systems are responsive to their needs, in a relationship that understands their experiences and shares the power (Putnam & Lipkin, 1995; Schmid, Cacace, Götze, & Rothgang, 2010; Schulz & Nakamoto, 2012a; Stewart et al., 2003). Consequently, general practitioners' professional identity is also being challenged as their practices respond to government funding targets, becoming increasingly biomedical consultants and less family doctors (Charles-Jones, Latimer, & May, 2003). The notion of the health consumer, which emerged in the 1960s and 1970s, allowed individuals to rethink their roles as patients, emphasising issues of choice and questioning the privilege of professional knowledge over lay knowledge (Irvine, 2002).

2.3 The New Zealand healthcare system

The New Zealand healthcare system is 81% publicly funded, of this approximately 90% comes from general taxes (refer Appendix 1). The private funding comes from “out of pocket co-payments for primary medical care and prescribed pharmaceuticals, from patients who bear the full-cost of privately provided elective and allied services, or from private insurance” (Gauld, 2012, p. 1). In 2011 total expenditure on health was 10.3% of NZ’s GDP compared with the OECD average of 9.3% and between 1999 to 2009, health expenditure grew at 4.9% per annum, above the OECD average of 4% (OECD, 2011a; OECD, 2013). More recently, between 2009 and 2011 the growth rate in per capita health expenditure dropped to 0.8% (OECD, 2013). In 2011/2012 government expenditure on health was \$13.7b. Therefore, on-going health sector reforms have tried to address increasing demands for services while trying to curb expenditure. Despite the growth in healthcare expenditure, the perception has “often been that the [NZ] health system is in decline” (Gauld, 2009a, p. 5) and that fragmentation in funding, planning, and service delivery has led to health inequities and lowered levels of healthcare (Cumming, 2011).

Since history plays an important role in hermeneutic interpretation, this section briefly traces some key historical developments that have led to this current state of healthcare in New Zealand.⁷ The characteristics of the NZ health system, including its current fragmentation, are derived from the developments of the mid to late 1800s. The central governments during the 1800s supported “a mix of central and local government, voluntary, and private financing; and a mix of public, private for-profit, and private not-for-profit provision by many independent providers and provider organisations, to ensure the delivery of services to the growing New Zealand population” (Cumming, 2011, p. 2). In 1938, the Social Security Act was introduced in an effort to create a national health system, fully funded by the state, and offering universal free access to a range of health services regardless of socio-economic status. This legislation introduced by Michael Joseph Savage’s first Labour government proposed health promotion

⁷ Refer to Appendix 2 for a brief summary of the prevailing social policy perspectives accompanying these developments.

programmes as well as curative services, emphasising public health and early intervention. This approach is labelled the ‘cradle to grave’ welfare philosophy, “the explicit aim was a generous, universal system based on citizenship, not need” (Starke, 2010, p. 491).⁸

The developments of the ‘cradle to grave’ welfare system in NZ at the time of the Savage Labour government were paralleled by the growth of a powerful medical profession that has continued to play an influential role in the country’s healthcare system. Moreover, the enactment of the 1938 legislation was compromised in its implementation due to the medical profession’s opposition to the government’s proposal to capitation funding, wanting to retain their right to a fee-for-service from patients. Consequently, Gauld (2009a) maintains that “...a set of less than ideal institutions remained dominant throughout the succeeding decades” (p. 17). This plurality is summarised as “a public hospital sector and ‘private’ primary care sector, a predominance of curative medicine, unwieldy funding arrangements and gaps between levels and locations of care” (Gauld, 2009a, p. 3). The fragmented structure of the NZ healthcare system comprises public hospitals which provide the majority of secondary services, some private hospitals and private specialists providing secondary services to private patients, and primary care that is private yet subsidised (Starke, 2010). In addition, numerous private organisations provide community-based services and long-term residential care.

Despite the aim of widening access to healthcare services, Wendt (2009) identifies New Zealand as a ‘low budget - restricted access type’ in that the ideas of universality and equality of access have been incompletely institutionalised due to financial restrictions.

2.3.1 NZ healthcare sector reforms 1980-2010

The NZ healthcare sector has experienced both ‘big bang’ and incremental reforms, under different political parties in government, and with varying economic conditions. This discussion is not intended as an elaboration of what has

⁸ Starke (2010, p. 491) also emphasises that this goal of universality was only “realized to a limited degree. Most income transfers remained income tested”.

caused these reforms. It is important in the present research to consider the healthcare reforms insofar as they offer insights into the problem pressures, demands for reform, and policy ideas that have been influential in their implementation.

The New Zealand healthcare sector has been characterised by “incessant reforms” over the last 20 years (Gauld, 2009a, p. 1) aimed at containing costs, reducing fragmentation, and achieving more integrated care. These changes have resulted in radical changes at both the structural and service delivery levels of the health sector. Consequently the NZ health sector has been the subject of extensive reviews, evaluations, analyses, and commentaries by health professionals, health researchers, political scientists, and policy analysts (Devlin, Maynard, & Mays, 2001; Dew & Davis, 2005; Gauld, 2009a, 2009b, 2012; Mays, Cumming, & Tenbenschel, 2007; Ministerial Task Group on Clinical Leadership, 2009; Ministry of Health, 2012a; Starke, 2010; Tenbenschel, Cumming, Ashton, & Barnett, 2008).

Although the wide-ranging and regular reforms of the health system followed the political ideologies of the government in power, NZ’s healthcare reforms have also paralleled some distinct phases of health reforms internationally. Over the last 20 years the reforms focussed on restructuring the processes for planning and funding health services while the way services are provided has remained largely unchanged (Cumming, 2011). The healthcare reforms contextualise the area of inquiry of this thesis and, for the current purpose, are discussed in three categories (further details are noted in Appendix 3):

(a) Category 1: 1980s to early 1990s

Developing from the New Public Management perspective, the reforms of the 1980s and the early 1990s focussed on cost containment at the macro level. The reforms sought to increase patient choice by stimulating competition at both the healthcare purchasing and provider levels. These neo-liberal reforms sought to roll back state intervention from traditional areas and replace with market relationships and systems (Prince, Kearns, & Craig, 2006).

The reforms of this period aimed to improve quality and efficiency by “subsuming health professionals under ‘managerialist’ structures and creating internal markets amongst providers of public health care services...” (Gauld, 2012, p. 2). Public hospitals were intended to function like private businesses, elected area health boards were abolished, competitive contracting was introduced,⁹ clinicians were largely removed from management, and a single purchasing agency was established (the Health Funding Authority). Gauld (2000) termed these the ‘big bang’ reforms of the NZ healthcare system, which engendered profound opposition from health professionals and the public alike (Gauld, 2009a, Tenbensen et al., 2008). The separation of purchasing from provision, one of the radical reforms of this period, was intended to encourage competition between government-owned, private for-profit, and not-for-profit providers of healthcare services. Provider-based and community accountability did not feature in the health policy discourse of the early to mid-1990s in NZ (Tenbensen, Mays, & Cumming, 2011); there was also little evidence of the expected technical efficiency gains that had provided the reasoning for the reforms (Ashton, Mays, & Devlin, 2005). The overall conclusion was that the level of performance of the healthcare system had declined.

Despite the separation of purchasing and provision, by the late 1990s the centre-right government focussed its health policies more on national consistency and integration, and prioritising services to be purchased (Shipley, 1995). Furthermore, the terms associated with a market model such as competition, for-profit, and commercial practices largely disappeared, being replaced with the traditional principles of a public service.

The quasi-market model of these reforms did not lead to more competition among GPs but rather increased collaboration in terms of Independent Practitioner Associations (IPAs). These collaborations led to some important but unintended consequences, such as integrating primary care information systems, and quality assurance mechanisms (Ashton et al., 2005).

⁹ Crown Health Enterprises (the reconfigured Area Health Boards) were structured as for-profit organisations. The Regional Health Authorities negotiated contracts with both public and private providers for the provision of personal health services.

From the mid-1990s there was a move away from market principles to more centralised state control following traditional principles of public service (Starke, 2010). While some reforms were reversed crucial design elements of the 1993 reforms such as the purchaser-provider split were not reversed.

(b) Category 2: Late 1990s to early 2000s

The centre-left government elected in 1999 saw a return to healthcare policies that emphasised community involvement in governance, local decision making, public health strategies and reducing inequalities. A list of population health priorities became the foundation for the New Zealand Health Strategy (NZHS) (King, 2001),¹⁰ identifying a specific Primary Health Care Strategy. A fundamental reform was in the subsidy regime for primary healthcare. In particular, this strategy addressed the barriers to primary healthcare faced by low socio-economic status (SES) groups, Māori and Pacific Islanders, through capitation based on population characteristics¹¹ and resulted in significant extra funding to improve low-cost access to primary healthcare, namely general practitioner services (Cumming & Mays, 2009). Reports suggest that the use of primary healthcare services increased (Starke, 2010).

The second element of these reforms was to restore the community's 'voice' by returning to previous models of elected member health sector governance and to emphasise outcomes in which communities could be seen as having a role in co-producing such outcomes (Tenbensen et al., 2011, p. 243-244). These reforms saw a move to localised health governance with 21 District Health Boards (DHBs) replacing the Health Funding Authority (HFA) "designed to

¹⁰ Population health generally refers to policy and services aimed at improving equity, universal service access, community involvement in services, social justice and the health of the whole population in an area, community or country (Gauld, 2009a).

¹¹ Ethnicity proportions of the total NZ population are difficult to define as the NZ Census allows people to identify with more than one ethnic group. "Ethnicity is self-perceived and people can belong to more than one ethnic group. People can identify with an ethnicity even though they may not be descended from ancestors with that ethnicity. Conversely, people may choose to not identify with an ethnicity even though they are descended from ancestors with that ethnicity".

http://www.stats.govt.nz/browse_for_stats/population/Migration/internalmigration/appendixes.aspx

democratize and decentralize planning and decision making, as well as run public hospitals and fund other public health services for their regional populations” (Gauld, 2012, p. 1). The DHBs were required by legislation to be accountable by providing the opportunity for public participation in board deliberations, strategic planning, and service provision. However, several factors constrained the extent of community voice (Ashton et al., 2005): DHBs were required to work within the framework of objectives and funding priorities set by the national strategies; DHBs were therefore accountable to central government for the public resources they expended; and tight budgetary constraints meant that service priority decisions were more often disinvestment decisions, than decisions to expand services. While the legislation appeared to decentralise control in these reforms, the predominantly tax-based financing of the healthcare system meant that tight government control continued with upward accountability to the centre. Tenbensen et al. (2011) talk of this as key organisations in the healthcare sector being “simultaneously accountable to central government on the one hand, and local stakeholders and communities on the other” (p. 239). Recent management literature now acknowledges the multiple accountabilities for public sector organisations to what may be conflicting constituencies (e.g., Behn, 2001; Considine, 2002).

Among the measures in this period of reforms was a move to a population-based funding formula for the DHBs (as opposed to an allocation based on the services actually delivered). Strategic planning was part of the NZ Public Health and Disability Act (NZPHDA) which required 5-yearly plans along with annual plans. DHBs were also required to conduct Health Needs Assessments (HNAs) every three years which were “the assessment of the population’s capacity to benefit from healthcare services prioritised according to effectiveness, including cost-effectiveness, and funded within available resources” (Coster, Mays, Scott, & Cumming, 2009, p. 277). Despite such requirements HNAs were found to have little direct influence on planning and purchasing and that prioritisation by DHBs was difficult given the reality of continuing tight levels of central control (Coster, 2000; Coster et al., 2009).

(c) Category 3: Post 2008

In general, questions were being raised about the performance of the healthcare sector such that the centre-right government that won the 2008 general election was concerned principally with fully engaged health professionals, improved productivity, quality improvement in health service delivery and access - especially to electives and cancer treatments (Ryall, 2008). The nature of the reforms that followed also re-centralised the healthcare organisational systems and relationships. The incoming government set up a Ministerial Review Group (2009) for the healthcare system that concluded:

Bureaucracy, waste, and inefficiencies must be reduced and resources moved to the front-line as spending growth slows. We must focus on quality which will deliver better patient outcomes and on ensuring better access to health services through smarter planning and resource utilisation, at regional and national levels (p. 6).

Measures to achieve this included “Shifting resources to the front-line by reducing the cost of ‘back office’ shared services for DHBs and reducing the duplication of functions carried out across the country” (Ministerial Review Group, 2009, p. 4) and strengthening clinical leadership and the role of doctors, nurses allied and other health workers in decision-making...[so that they]...share responsibility and accountability for improved system performance, in terms of efficiency, quality, and cost” (Ministerial Review Group, 2009, p. 7).

The international financial crisis impacted on the already-existing issues, compounding the need to keep healthcare provision within existing funding allocations. Reducing the bureaucracy was central to these reforms including a nationalisation of various functions (e.g., IT planning). The National Health Board had operational jurisdiction, while the Ministry of Health continued its policy and ministerial advice functions. Legislation changes now require DHBs to collaborate and plan regionally. National agencies have been created for specific functions (e.g., National Health IT Board, Health Workforce New

Zealand) although these have complex administrative structures and often vague jurisdictional boundaries (Gauld, 2012). The policy of ‘better, sooner, more convenient’ healthcare services also resulted in funding for Integrated Family Health Centres, intended to improve access and efficiency of primary care practitioners.

These 2008 reforms were done under the government’s election promise *not* to restructure the health system. The return to centralised control aimed to provide a national health system that was committed to clinical governance. However, many of the arrangements affecting the organisational systems and front-line service delivery remained unchanged; some patients may even be unaware that changes occurred.

In summary, the NZ healthcare system now demonstrates strategies to reduce inequalities in service access and health outcomes, adherence to principles of population health, and primary care improvement. Although change will continue it is unlikely that the radical restructuring of the last three decades will reoccur (Ashton, 2005; Ashton et al., 2005; Gauld, 2009a).

2.3.2 Current New Zealand healthcare governance

The new organisational arrangements following the Ministerial Review Report in 2009 represent a move to centralised governance but with more specific targets than the population based goals of the health policies of the early 2000s (Gauld, 2012). Such specific goals are used to benchmark DHBs’ performance and while stimulating improvement these have also led to “resourcing targeted areas to the detriment of others” (Gauld, 2012, p. 3). The present governance structures recognise health professionals as being critical to effective healthcare policy and management of service delivery by placing them in key positions (Ministerial Task Group on Clinical Leadership, 2009). Gauld (2009b) interprets many of the recent changes to the NZ healthcare system as a social democratic response to the earlier neoliberal perspective, citing improved patient information and involvement, and greater attention to coordinated and patient-centred care.

Despite the moves to centralised organisational arrangements, Tenbenschel et al. (2011) conclude that the NZ healthcare system demonstrates a mix of hierarchical, market and collaborative forms of governance. This mixed regime of accountability follows international developments in public management that followed the New Public Management perspective of the 1980s (e.g., Behn, 2001; Considine, 2002). The mix of governance in the NZ health system recognises that the public sector now embodies:

- a. more diverse goals of governance, including goals relating to functional outcomes plus structures and processes that enable accountability to a wider range of stakeholders; and
- b. more complex modes of governance, including networks and hierarchies of governance relationships (Andresani & Ferlie, 2006; Barnett et al., 2009; Ranade & Hudson, 2003).

Yet these governance characteristics also heighten the potential for accountability conflicts between the various groups who are deemed ‘account holders’ and those who determine what ‘doing well’ means. The 2008 reforms focus on “greater clinician involvement in the running of hospitals, greater diffusion and take-up of local innovation between DHBs and greater networking of service provision across regions...[and] greater emphasis on policy targets” (Tenbenschel et al., 2011, p. 253). As such these reforms are a mix of hierarchical and heterarchical accountability.¹² With stringent financial constraints in the health sector the potential for tensions is further increased. However, the NZ system retains a strong level of accountability to the centre with “ministerial appointment of the chair and the statutory accountability of the elected local board to the minister” (Barnett et al., 2009, p. 126). The interest group system is also an important part of the NZ institutional system; medical interest groups have had an important influence on healthcare policy (Starke, 2010).

¹² Heterarchical accountability refers to “...answerability to one’s ‘colleagues in practice’...organisations, providers and professionals are accountable to *each other* for what they do and how they do it. These heterarchical frameworks of accountability share a reduced emphasis on formal hierarchical relationships and a corresponding emphasis on trust-based relationships (Tenbenschel et al., 2011, p. 241).

2.3.3 *Current issues in NZ healthcare planning*

Healthcare planning as part of the health system governance has often received less importance, in favour of market and policy approaches for organising the supply of healthcare services to achieve particular goals (e.g., Ettelt, Fazekas, Mays, & Nolte, 2011; Oliver, 2007). One of the few systematic evaluations of the NZ healthcare planning process uses three criteria - vision, governance, and intelligence (Ettelt et al., 2011). The findings according to these three criteria are briefly discussed below as they add further contextual dimensions to the area of inquiry.

- i. Vision, that is, the “goals and objectives of health care planning, which should be aligned with the overall goals of the health system, be reflected in all areas of the health care system and take a long-term perspective” (Ettelt et al., 2011, p. 2).

Goal setting is a centralised function by the Ministry of Health with the National Health Board (NHB) overseeing regional and district planning. The approach as outlined in 2010 (Ministry of Health, 2010c) emphasises comprehensive planning across the various healthcare sectors (primary, secondary, tertiary and community care) as well as integrated planning around issues of information technology and workforce. The time horizon for strategic planning at regional and national levels has shifted out to 20 years, while annual district plans and capacity for medium term planning remain.

- ii. Governance, that is, “the role of decision-makers and implementers to whom clear responsibilities should be assigned, the alignment of planning with sanctions and incentives that support implementation, the involvement of stakeholders and the consistency of the approach at different levels of planning” (Ettelt et al., 2011, p. 2).

Lines of accountability are predominantly hierarchical (although some commentators have discussed heterarchical accountability relationships,

see earlier), and while sanctions can be imposed from the centre (Ministry of Health) these are rarely used. Clinicians are now involved at various levels of healthcare planning and are expected to play an increasing role. There is a stated link between central vision and regional and local implementation, although the degree of effectiveness of this in practice appears to be questionable (Ettelt et al., 2011, p. 7).

- iii. Intelligence, that which “highlights the availability and appropriate analysis of relevant data, the existence of sufficient analytical and administrative capacity, and the need for continuous monitoring of progress against objectives” (Ettelt et al., 2011, p. 2).

DHBs are required to collect data and provide Health Needs Assessments (HNAs) although these HNAs have been underused to “inform the organisation of health care provision” (Ettelt et al., 2011, p. 8). Coster et al. (2009) suggested that health needs assessments were poorly linked to prioritisation and planning of healthcare services, possibly due to the amount of central control over DHB activities. DHB planning in the past was often criticised for being overly based on diagnosis-related groups and secondary and tertiary services. Monitoring of DHBs and evaluation of implementation of DHB plans is now the mandate of the NHB.

While the governance of the NZ healthcare system is coherent and promotes a long-term view of future health needs, there is still concern over local-level planning with tensions around central accountability and funding. Moreover, planning in NZ relies on routinely collected healthcare utilisation data which tends to bias provision “towards existing levels of supply... [and] “limits the ability of planning to alter the inherited pattern of health care capacity” (Ettelt et al., 2011, p. 8, 9). The Health Needs Assessments did not include the views of consumers as to their requirements for services; “...DHB HNAs were mainly based on data from existing sources (for example, hospital discharge data), which reflect current use of services rather than need. This is an important point because

it means that no new data were collected regarding actual and current health needs of the communities” (Coster et al., 2009, p. 280).

Many policy tools help shape healthcare systems. Ultimately “...political institutions and embedded stakeholder interests...[and] the governance arrangements that underpin the process of planning...” (Coster et al., p. 9) shape the involvement of stakeholders and shape the ‘intelligence’ gathering and/or interpretation undertaken by policy makers.

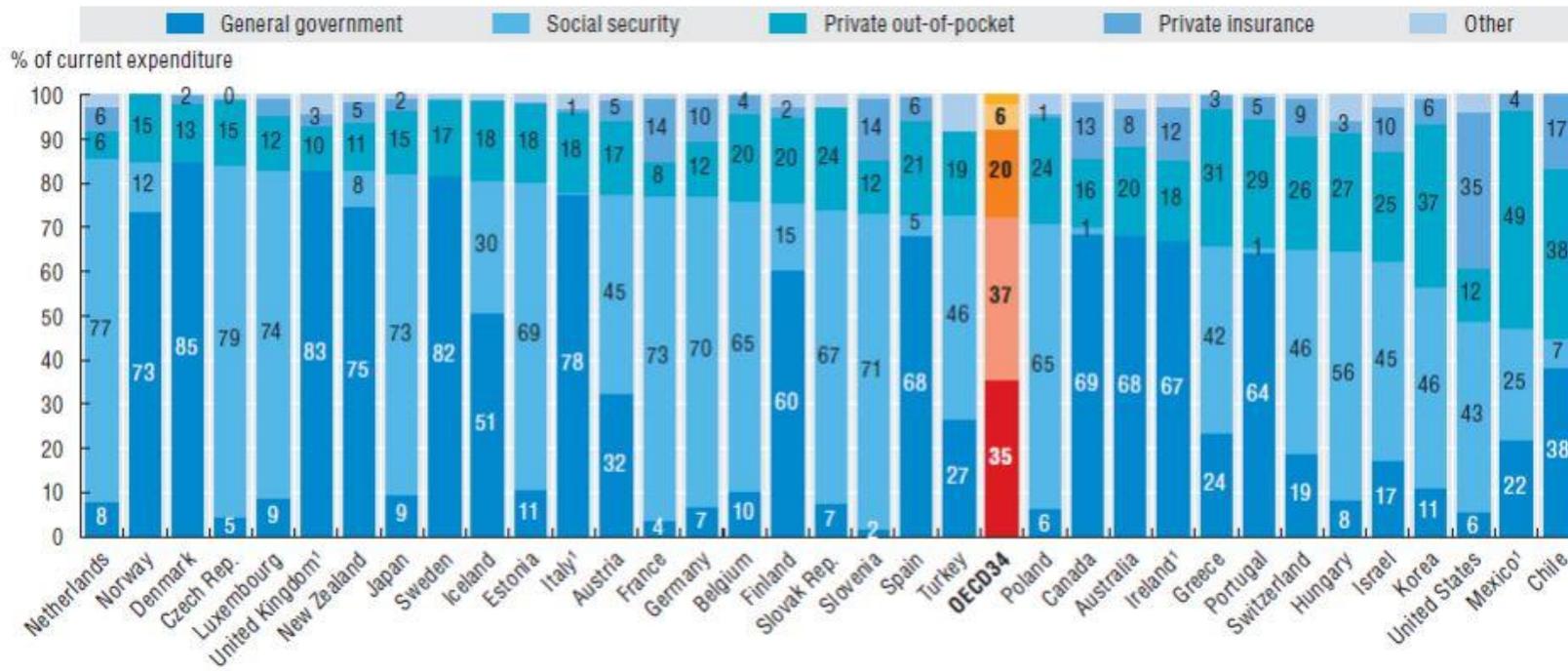
2.3.4 Comparative health funding models

Health systems in industrialised countries are facing similar challenges. On-going pressure to improve cost effectiveness and improve access to healthcare for all citizens has led to changes in governance, financing and delivery of healthcare. Therefore, a brief overview of comparative healthcare funding models is provided as further context for understanding the New Zealand system.

Public sector financing is the main source of health financing in all OECD countries, generally accounting for approximately 80% of all health expenditure (OECD, 2013). The proportions of public and private funding for health in New Zealand (Appendix 1) are similar to other OECD countries and payments for health made by individuals (out-of-pocket payments) have decreased in New Zealand by 4.4% between 2000 and 2011 (OECD, 2013). Expenditure on health in New Zealand is financed by general government financing (75%), social security (8%), and 11% from private out-of-pocket financing. Private health insurance represents a small proportion (5%) of total health financing in New Zealand (Figure 2.1).

Figure 2.1 OECD countries' expenditure on health by type of financing

(Source: OECD, 2013)



Private health insurance in healthcare financing as a means to bridge the gap between what is currently spent and what is needed to be spent on healthcare remains controversial (e.g., Basu, Andrews, Kishore, Panjabi, & Stuckler, 2012; Bramley-Harker, Booer, Ridge, & Bell, 2006; Rae, 2005; Thomson, Foubister, & Mossialos, 2009). While there is a common trend for the state to reduce its involvement in service delivery and or financing, this is often compensated by an increasing state role in regulation (Schmid et al., 2010). Along with privatisation trends, convergence among systems is evident; for example, “public elements grow in the private U.S. healthcare system, while market competition is considerably enhanced in the state-led U.K. system and in Germany’s social insurance scheme” (Cacace, Gotze, Schmid, & Rothgang, 2008, p. 7).

A recent analysis of 21 OECD countries’ funding models (Gotze & Schmid, 2012) used a tripartite division of healthcare funding, namely taxes, contributions and private sources. This analysis developed a “hybridity index which measures the distance of a country’s funding mix to a hypothetical mix that builds on equal levels of taxes, contributions and private spending” (Gotze & Schmid, 2012, p. 1); the closer to 1, the more the financing is equally spread between the three elements. Re-weighting the balance more evenly between public, private and contributions is often sought-after as a means to primarily manage costs and capacity demands. In this analysis the US, Austria, Belgium, and Switzerland have the highest hybrid indices; New Zealand, UK, and Denmark have the lowest. The question however remains as to which institutional arrangements are associated with higher efficiency (Wranik, 2012, provides a comprehensive review of the literature). Changes to cost-sharing schemes, insurance cover, and physician payment arrangements are suggested as important contributors to healthcare efficiency. Equally important is the translation of healthcare resources into health status, typically measured according to mortality and longevity (Joumard, André, Nicq, & Chatal, 2010b). However, little or no relation has been found between relative efficiency and the level of health spending (Anderson & Frogner, 2008; Joumard et al., 2010b); the best performing countries are both the high-spending and low-spending countries and high-performing and low-performing countries are not differentiated by differences in the mix of public and private spending.

A 2014 comparison of eleven countries on five measures of healthcare system performance - quality, efficiency, access to care, equity and the ability to lead long, healthy, productive lives - ranks the UK first with Switzerland second. This evaluation uses physician and patient surveys on care experiences, incorporating information from Commonwealth Fund international surveys of patients' and primary care physicians' views about medical practices and their countries' health systems (2011-2013). According to this analysis, NZ ranks second on effective care and coordinated care, and third on efficiency. The latest data on health expenditures per capita (2011) indicates New Zealand had the lowest per capita expenditure on health among these eleven countries (refer Table 2.1).

Given the complexity of arrangements and the blend of dimensions in complex healthcare systems, analysts recommend care when comparing healthcare systems on binary classifications and simplified typologies. Researchers are now calling for differentiated analyses of health systems as they offer better insights into the complexity of the organisations and contextual factors that influence health policies and systems (Burau, 2012; Burau & Blank, 2006). Market-based and regulatory approaches are more often combined than used separately (Joumard et al., 2010a) and different features of the system evolve over time. Too often, comparisons of health system performance have focussed on one institutional feature, namely, the financing of healthcare such as the public/private mix or the insurance model (Wagstaff, 2009; Wendt, 2009). Moreover, specific institutional features or arrangements are "not good or bad...but should be assessed within a broader institutional context" (Joumard et al., 2010a, p. 42).

Table 2.1 Health system performance - eleven nation summary scores
 (Source: Davis, Stremikis, Schoen, & Squires, 2014)

2013	AUS	CAN	FRA	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
Overall ranking	4	10	9	5	5	7	7	3	2	1	11
Quality Care	2	9	8	7	5	4	11	10	3	1	5
Effective care	4	7	9	6	5	2	11	10	8	1	3
Safe care	3	10	2	6	7	9	11	5	4	1	7
Coordinated care	4	8	9	10	5	2	7	11	3	1	6
Patient-centred care	5	8	10	7	3	6	11	9	2	1	4
Access	8	9	11	2	4	7	6	4	2	1	9
Cost-related problems	9	5	10	4	8	6	3	1	7	1	11
Timeliness of Care	6	11	10	4	2	7	8	9	1	3	5
Efficiency	4	10	8	9	7	3	4	2	6	1	11
Equity	5	9	7	4	8	10	6	1	2	2	11
Healthy lives	4	8	1	7	5	9	6	2	3	10	11
Health expenditure/ capita 2011 (US\$)	3,800	4,522	4,118	4,495	5,099	3,182	5,669	3,925	5,643	3,405	8,508

2.3.5 *Current issues in the NZ healthcare system*

Healthcare spending is a critical issue for the NZ healthcare system as evidenced in the priorities and goals underlying the various reforms. Population growth, inflation, and the economic slowdown mean that it is unlikely that the rate of growth in annual health spending experienced in the early 2000s will continue (Ministerial Review Group, 2009; Ministry of Health, 2010c; The Treasury, 2010). This lower rate has been clearly signalled, “The health and disability system has already adapted to a lower rate of annual increases in spending over the last three years...Changes at a national level are helping the system adjust to a lower growth path” (Ministry of Health, 2012a, p. vi). Uncomfortable questions will inevitably relate to issues such as health rationing, labour force participation rates to support the ageing population, disparities in access to healthcare services as public health providers increasingly tighten their belts to increase efficiencies, and disparities in patient-practitioner health literacy impacting patient satisfaction. At the same time there are rising expectations of health treatments and service alternatives, as summarised by the Ministerial Review Group in 2009:

The growth in health spending is forecast to continue to exceed income growth as, amongst other things, the population ages and as more of us live longer with chronic long-term conditions. Population ageing also means that the ratio of the working to the retired population will shrink significantly, concentrating this heavier spending burden on a relatively smaller group of workers and taxpayers. At the same time, there are increasing expectations on the health system to do more to prevent illness and improve the quality of life, especially as improvements in health technology make more interventions possible (Ministerial Review Group, 2009, p. 12).

Although health expenditure has continued to grow, the NZ health system is perceived to be in decline. Furthermore, “Statistics show that New Zealanders are seeking increasingly personalised healthcare services and increased access to healthcare services. Between 1998 and 2007, over 50% of all New Zealanders consistently considered fundamental changes were needed to improve the New

Zealand health system...” (Ministry of Health, 2010c, p. 17). The traditional configuration of the primary healthcare sector is therefore under pressure to shift the emphasis to community partnerships and integrated models of care that place “the patient rather than the institution as the centre of service delivery and which aim to promote a more seamless patient journey across community, primary, and hospital sectors, greater use of primary and community care, and the shifting of care ‘closer to home’ (Cumming, 2011, p. 6). These integrated family health centres seek to “improve patient access, support improved health outcomes, make the best use of the available workforce, make use of multidisciplinary teamwork to co-ordinate care delivery, improve access to specialist diagnostic testing, and to deliver some traditionally based secondary services” (Ministry of Health, 2010c, p. 20). These new services will require investment in infrastructure and access to improved technologies by clinicians and patients - access to new technologies is typically cost-increasing (Ministry of Health, 2010c).

Several issues surround the decades of on-going structural change in NZ healthcare, including the undermining of relationships within healthcare institutions, the costliness of the changes, and the continuing fragmentation of organisational and funding structures. While there is strategic planning to (re)build healthcare there is not the same translation to lower levels of implementation (Gauld, 2009). At the same time, pressure on the health workforce is signalled with demand for labour in the health and disability services by 2021 forecast to grow in excess of population growth (New Zealand Institute of Economic Research, 2004). The global competition for health workers will exacerbate this factor increasing pressure on competitive wages.

The stresses faced by the NZ healthcare system, reflective of international pressures, include “demographic change, medical progress and individualisation which tend to increase demand for scarce resources” (Schmid et al., 2010, p. 462). Individualisation refers to the changing life patterns of populations as well as the increasingly informed patients who demand responsive and appropriate healthcare services. The on-going perception of health as a right of citizenship will mean that health will remain an important political item in any political ideology. Given the trends of individuals seeking more responsibility for their own healthcare and

adopting new technology in healthcare (for example, e-health and e-contact with their healthcare provider), investment in technology is likely to be required as a priority.

This section has traced some of the major developments in the NZ health system reforms recognising the historicity and contextual underpinnings of the hermeneutic methodology. With the following section discussing baby boomers as a generational cohort, this chapter outlines the contexts that pave the way for the subsequent interpretation of the participants' texts and understanding of health literacy.

2.4 Baby Boomers - a generation

One major healthcare concern in New Zealand is the impact of the ageing population on the demand for and provision of healthcare services (Ministry of Health, 2002). New Zealand already has a demographically old age structure, which will age further (termed "momentum ageing" by Pool, 2007, p. 158) as the large numbers of baby boomers reach retirement age (Uhlenberg, 2009).

Definition of the post-WWII baby boom varies between sources and between countries with much debate about how to define this cohort (e.g., Snoke, Kendig, & O'Loughlin, 2011). In its broader sense, a baby boom has been defined as "a large increase in the number of births relative to some previous year or average (i.e., an increase in birth cohort size)" (Morgan, 2003, p. 73). More specifically, the term 'baby boom' is used to refer to the increase in the birth rate in industrialised countries from post-World War II through to the mid-1960s; these baby boomers now account for a significant portion of the total population in OECD countries and in New Zealand (Glass, 2007; Mitchell, 1995; Roberts & Manolis, 2000).

The first of the New Zealand baby boomer cohort turned 65 in 2011 and by 2036 all NZ baby boomers will be 65 years and older. At that stage these over-65 year

olds are forecast to total 1.2 million people¹³ and to account for 23% of the total projected 2036 NZ population of 5.4 million. By comparison, in 2012, the over 65 year olds comprised 14% of the population or 600,000 people. Moreover, when all the baby boomers are aged over 65 years, they will represent the largest elderly population in New Zealand's history (Ministry of Social Development, 2011a; Statistics New Zealand, 2007; Statistics New Zealand, 2012). The financial and social implications of meeting the healthcare needs of this significant cohort of baby boomers is already being signalled in New Zealand (Ministry of Health, 2004a; Stephenson, 2006; Teasdale, 1999);¹⁴ for example, by the year 2051, NZ baby boomers are projected to account for 63% of the total Government health expenditure (New Zealand Treasury, 2004). Due to the sheer size and ageing of the baby boomer cohort it is both timely and compelling to consider its characteristics with particular relevance to health literacy.

2.4.1 The post-war baby boom

Defining the generational cohort of baby boomers based on birth year and the relative numbers born in any one year leads to national variations that “result in some countries having quite different groups of people labelled as baby boomers, with some countries having no baby boom cohorts at all” (Gilleard & Higgs, 2007, p. 20). Despite these variations the baby boom is found to have been especially strong in non-European countries, particularly Australia, New Zealand, US, and Canada (Pool, 2007; Van Bavel & Reher, 2013). The size of the baby boom cohort as it reaches various life-cycle stages can be particularly significant and, in many countries such as the US, UK, Australia, and New Zealand, additional significance of the baby boom lies in the societal recognition of the characteristics of this cohort.

¹³ The projected NZ population of over-65 year olds by 2036 is 1.18-1.25 million.

¹⁴ The context for this concern arises from the fact that the majority of older New Zealanders are solely dependent on the New Zealand Superannuation (NZS) (Ministry of Social Development, 2011b). NZS, a state-funded package, ensuring access to a basic minimum income and under which many healthcare costs are met by the Government, is currently eligible to all those aged 65 and over.

In response to the variability of the post-WWII baby boom, 1960 is sometimes taken as an internationally representative year of the boom (Lanzieri, 2011). Specifically, the New Zealand baby boom is defined by Statistics New Zealand (1995) as occurring between 1 January 1946 and 31 December 1965. This period was associated with high fertility rates and high numbers of births for 18 consecutive years. This particularly high birth rate post-war peaked at 27.1 births per 1000 in 1961, with a total fertility rate of 4.3 births per woman across all ethnic groups (Van Bavel & Reher, 2013; Pool, 2007).

2.4.2 New Zealand baby boomers as a population segment

During the New Zealand baby boom, from 1946 to 1965, 1.125 million babies were born almost doubling the population, since this occurred at a time when the total New Zealand population increased from 1.7 million in 1946 to 2.6 million by 1965 (Statistics New Zealand, 1995). Pool notes that “for New Zealand, although the Baby Boom occurred at the same time as heavy migration inflows, natural increase, driven by births, was by far the more important determinant of overall growth” (2007, p. 147).

New Zealand baby boomers grew up accustomed to the provision of universal healthcare and social welfare in what is termed the ‘golden age of welfare’ (Esping-Anderson, 1995). However, the view of privilege enjoyed by NZ baby boomers as they were growing up - full employment, free tertiary education, and strong economic growth - needs to be considered alongside research that presents some of the difficulties experienced by these baby boomers later in their lives. For example, many of these individuals experienced redundancies as widespread restructuring took place in the 1980s and 1990s (McLennon, McManus, & Spoonley, 2010), reduced entitlements to welfare, and increased income inequalities (Callister, 2006).

Furthermore, what it means to be a New Zealander has changed dramatically from when the first NZ baby boomers were born to now. One example is ethnic diversity. In 1946, New Zealand was a predominantly European society (more than 90% of the population was European) with only 6.5% of the population being

of Māori ethnicity and less than 1% being of Asian or Pacific origin. By 2013, those claiming Māori ethnicity comprised 14.9% of the population, those of Asian ethnicity comprised 11.8%, and those identifying themselves as Pacific Peoples comprised 7.4% of the population (www.stats.govt.nz).¹⁵ Similarly, when the baby boomers were born their life expectancy was 69.6 years. By 2030, when the last baby boomers turn 65, life expectancy at birth is forecast to be 83.6 years (Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat, 2007). New Zealand baby boomers are therefore likely to follow the international trend of having a longer, healthier old age (Bloom, Canning, & Fink, 2011).

Therefore, research on New Zealand baby boomers needs to acknowledge the political, social, technological, and economic events that have helped shape their values, lifestyles, and preferences. While the term baby boomer does not confer explanatory power, it is necessary to explore how these individuals are represented in general and with regard to the influence of generational values on healthcare preferences and decisions (Berkowitz & Schewe, 2011; Noble, Schewe, & Kuhr, 2004).

2.4.3 Profiles of Baby Boomers

Baby boomers are particularly interesting as they have both experienced and contributed to considerable social change; “...over the course of their life [they] have passed through a number of political, social, cultural, and economic milestones” (Leach, Phillipson, Biggs, & Money, 2013, p. 105). They are generally considered to be a highly influential consumer segment (Spinks & Lawley, 2005) and, with specific reference to healthcare, they are likely to be “equipped, enabled, empowered, and engaged in their health and healthcare decisions” (Lober & Flowers, 2011, p. 178).

¹⁵ Refer to footnote 11 regarding Census ethnicity classifications. By 2026, it is anticipated that the proportion of the population of Asian ethnicity will equal the proportion of the population of Maori ethnicity at approximately 16% (www.stats.govt.nz).

There are differing and sometimes contradictory characterisations of baby boomers in the literature. Many of these characteristics have assumed ‘urban myth’-like status and many have mixed empirical support. Moreover, much of the baby boomer research is based around the American experience that may have limited applicability to NZ baby boomers. Since the sociologically framed definition of generations depends on shared historical and cultural events; generalising across culture should be treated with caution.¹⁶ A range of characteristics attributed to baby boomers is summarised in Appendix 4. This summary uses both scholarly and popular works to identify some of the variety of behaviours, expectations, and traits used to describe baby boomers across multiple contexts (Davey & FitzPatrick, 2013).

Appendix 4 summarises baby boomer characteristics according to psychological values, social values, work values, and environmental values, noting brief details of the research and the research context. A brief list of characteristics from non-empirical sources is also identified (refer Appendix Table 4.2, Appendix 4). Although it is important to avoid stereotyping baby boomers as a homogeneous stand-out group, this summary supports the interpretation that baby boomers “appear to be actively resisting societal expectations of ‘old age’-appropriate behaviour” (FitzPatrick, Davey, Hewinson, & King, 2011, p. 1). Baby boomers do not consider themselves as old and many are unwilling to stop work when they turn 65 (Buckland, 2009; Glasgow, 2013; Kohlbacher, Sudbury-Riley, & Hofmeister, 2011; Quine & Carter, 2006), redefining retirement and old age (Ferguson & Brohaugh, 2010; Huber & Skidmore, 2003; Hudson, 2010).

Baby boomers are often represented as being questioning and sceptical consumers, social activists, and individualists, who value freedom, relationships, achievement, and personal growth. As consumers of healthcare, it is suggested that baby boomers are likely to be more demanding and use more healthcare services than earlier generations (Cox & Hope, 2006; Quine & Carter, 2006), be active in their health decision-making by seeking additional information, and likely to try alternative treatments (Noble et al., 2004).

¹⁶ There is a growing number of recent studies in the UK and Australia (refer Appendix 4).

A common characteristic of the baby boomer cohort is its diversity (Appendix 4) causing some researchers to argue for the 19-year baby boomer group to be further segmented in order to better describe and understand baby boomers' behavioural and attitudinal characteristics (Berkowitz & Schewe, 2011; Green, 2005; Schewe, Meredith, & Noble, 2000). These researchers divide the cohort into leading-edge boomers (1946-1955) and trailing edge boomers (1956-1965) since the entire cohort includes individuals whose experiences will differ quite substantively. For example, leading-edge baby boomers are thought to: particularly value a sense of accomplishment and self-respect (Arsenault & Patrick, 2008); seek youthfulness via exercise, cosmetic surgery, and living a healthy life (Coleman, Hladikova, & Savelyeva, 2006; Green, 2005); be receptive to a pharmacological approach to ageing problems (Berkowitz & Schewe, 2011); and question everything (Noble et al., 2004). Trailing-edge boomers have been found to particularly distrust authority (Berkowitz & Schewe, 2011) and feel less secure financially (Moschis & Friend, 2008). In contrast, however, Reisenwitz & Iyer (2007) maintain that there are no significant differences between younger and older baby boomers on a raft of behavioural variables.

Two recent studies have specifically investigated NZ baby boomers' characteristics. Buckland (2009) found a distinctive Antipodean baby boomer character. This quantitative study of 1162 NZ baby boomers revealed them to be generally 'younger' in spirit, more physically vital, more adventurous, emotionally energetic and fiercely self-determined compared with the findings of the US Boomer Dreams Study (Smith & Clurman, 2007). In addition, NZ baby boomers exhibited greater ingenuity and a more resilient optimism than American baby boomers (Smith & Clurman, 2007). Buckland's study identified health to be the single most significant concern of NZ baby boomers, most of whom were not confident that the NZ health system will be able to support them as they age. More recently, Glasgow's (2013) qualitative study of 70 participants confirmed NZ boomers' "...self-reliance, their entrepreneurial character and belief in their organising abilities" (p. 268), and preference for policy options that suited their individuality and independence. They valued community responsibility and many were confident that collectively they could effect social change. Echoing

Buckland's earlier findings these participants were also concerned about their future health needs questioning if health services would be adequate for their needs. NZ baby boomers demonstrated a generational identity that "is rooted in notions of flexibility and choice" (Glasgow, 2013, p. 289).

Therefore NZ baby boomers are of significance due to their sheer numbers, but also it is anticipated that their characteristic values and behaviours will make them unique as healthcare consumers. Health is one of the top concerns of baby boomers with many deeply concerned about ageing, and losing their vitality and mental acuity (Buckland, 2009; Schultz, 2010), considering youthfulness to be one of their most powerful characteristics (Smith & Clurman, 2007). Furthermore, NZ baby boomers grew up accustomed to the provision of universal healthcare and social welfare which is likely to influence their healthcare demands and expectations. There are many indications that baby boomers are determined to maintain their health and wellbeing for as long as possible, making it even more important that healthcare service organisations understand and are responsive to this cohort's particular characteristics in order to develop appropriate services and products (Gombeski et al., 2010; Pettigrew, 2011; Positive Aging Foundation of Australia, 2002).

Despite the significant impact their ageing is predicted to have on NZ healthcare expenditure and on-going, international debate as to the nature and scale of baby boomers' impacts on healthcare costs¹⁷ (Humpel, O'Loughlin, Wells, & Kendig, 2010; Ministry of Health, 2004b; OECD, 1998), there are convincing arguments that baby boomers will reshape future healthcare services demanding different types and levels of services and utilising more advanced medical care interventions (Uhlenberg, 2009; World Demographic and Ageing Forum, 2010).

¹⁷ The Australian Bureau of Statistics estimates that per person health expenditure is four times greater among those aged 65 years and over than in younger age groups (Australian Bureau of Statistics, 2002).

2.5 Implications of the research context

The health services sector is a complex, interconnected and evolving system within a broad socio-political cultural context (Ettelt et al., 2011; Lloyd-Sherlock, 2000; Moore & Showstack, 2003; Sox, 2003). Health policy and systems research is concerned with “the production of new knowledge to improve how societies organize themselves to achieve health goals” (Mills, 2012, p. 1). Pressure to evaluate healthcare systems and appropriate and efficient service provision has grown with rising healthcare costs and tightening fiscal budgets.

One of the foremost challenges for the healthcare sector in NZ is population ageing. Existing models of healthcare planning may not be sufficient for the trends and pressures that are already being evidenced and are likely to increase, requiring a major change in social policy (Butler, 2008). Despite conflicting views on whether older adults are going to be living healthier even as they live longer, it is generally considered that their longevity will require institutional adjustments (Jay Olshansky et al., 2011) and that they will be more ‘health conscious’ than earlier generations (Macias & McMillan, 2008).

This chapter has highlighted the goals of public sector governance in the 2000s as being more diverse, serving a wider range of stakeholders, with modes of governance that are more complex and networked (Barnett et al., 2009). Furthermore, as recognised in the briefing to the incoming NZ government in 2012, healthcare policy and planning needs to “respond to demographic change, particularly the ageing and increasingly diverse population...with more complex needs” (Ministry of Health, 2012a, p. vii, viii).

The trend towards individualisation also requires a shift in healthcare planning and policy setting. Although the term ‘consumer’ appears peripherally in NZ health planning documents (e.g., Minister of Health, 2001; Ministry of Health, 2010c), one of the seven principles in the Primary Health Care Strategy was the “Active involvement of consumers and communities at all levels” (Minister of Health, 2001, p. 2). The increasing international emphasis on patient-centred care and building customer-centric health solutions will require a “shift from strictly

professional control to active citizen control” (French, 2010, p. 248) with “Future public health strategies...recognis[ing] that people are powerful agents of their own health...” (French, 2010, p. 249). In the NZ context, the Health Needs Assessments (HNAs) did not include the views of consumers regarding their requirements for services, and separation between the Health Needs assessor and the planners and policy makers prevented the HNAs from being a conduit for customer-centric health solutions to be translated into policy (Coster et al., 2009).

Healthcare systems are grounded in a set of values and beliefs about health and about the practitioner-patient relationship (Schmid et al., 2010). At the same time, as healthcare systems face increasing pressure there is a demand for new ideas and policies for coping with relevant social needs. Therefore reconfiguring healthcare services and practitioner-patient encounters presents multiple challenges. Without understanding the characteristics of the individuals who are the service users nor without appreciating how that understanding is communicated within the network of healthcare stakeholders, healthcare providers risk delivering inefficient health services that do not align with individuals’ expectations and health literacy.

The values and attitudes that are characteristic of different generational groups have gained considerable attention, particularly in the United States. In particular, ageing baby boomers may behave differently to previous generations and while international literature proposes certain characteristics about baby boomers, there is little NZ-based empirical evidence. In particular, little empirical research has been conducted on the health-related behaviour of baby boomers, despite the significant impact their ageing is predicted to have on healthcare costs and healthcare systems.

2.6 Summary

In order to gain an understanding of a phenomenon, the hermeneutic researcher situates texts in the horizon of related historical events and situations. Thus, this chapter has examined the two broad, high-level contexts in which New Zealanders’ health literacy is situated and from which the participants’ texts originate. Health beliefs and health models provided a platform for appreciating the NZ healthcare

system, which was described as fragmented, with limited universality and equality of access. The characteristics of baby boomers and implications for healthcare were then discussed. These all contributed to the researcher's pre-understandings. In the following chapter, Chapter 3, further pre-understandings arise from the classic and contemporary literature on health literacy, its origins, developments, and limitations. Chapter 3 concludes with the researcher proposing a conceptual framework and research questions that are used to guide this research investigation.

Chapter 3

Health Literacy

3.1 Introduction

The previous chapter introduced the context for studying the phenomenon of health literacy, namely, the New Zealand (NZ) health system and New Zealand baby boomers. It concluded that a critical challenge for the NZ healthcare system is population ageing. Earlier, Chapter 1 presented some implications of the socio-cultural context of health for health policies and services, suggesting that healthcare service providers must pay increasing attention to the need for customer-centric health solutions as individuals engage in diverse and changing patient roles. Furthermore, the generation of NZ baby boomers identify health as their key concern. After identifying the implications of these contexts for the empirical research, Chapter 3 now elaborates the literature on health literacy, how health literacy is conceptualised, and the changing scope of health literacy dimensions.

Health is defined in this thesis as “entailing physical, mental, and social wellbeing and not merely the absence of disease or infirmity” (World Health Organisation, 1986); it is therefore an unobservable, highly personal construct. Among the many social determinants of health is an individual’s active engagement in his/her own health. Health literacy, in its broadest sense, is an individual’s capacity to make sound health decisions in the context of everyday life which is critical in individuals participating in the management of their own health (Andrus & Roth, 2002; Nutbeam & Kickbusch, 2000; Schloman 2004). Since the aim of health literacy is to promote the individuals’ engagement in their healthcare, there is growing appreciation of health literacy as an important social determinant of health (Schulz & Nakamoto, 2012a). This thesis focuses on exploring the experiences and understanding of health literacy of patient-consumers and primary healthcare professionals.

Health literacy was traditionally framed as patient literacy skills in a health context. Growing out of a clinical perspective, health literacy was seen as an important contributing factor in levels of compliance with medical recommendations and avoidance of risky behaviours. This perspective, that these issues could be explained by a deficit in health literacy and which then limited optimal health outcomes, has spawned considerable research. After reviewing early perspectives of health literacy, this chapter presents the emerging view of health literacy as being relational, approached from a “whole-of-society” perspective (Kickbusch, Pelikan, Apfel, & Tsouros, 2013, p. 9), and involving many dimensions, where patient skills or abilities interact with education, health, social, and cultural influences.

This chapter traces the large body of research in the health literacy field from origins and definitions of health literacy, through prevailing conceptual frameworks, to contemporary views of health literacy. The definition and application of health literacy within the New Zealand context is then reviewed. Observations regarding predominant research trends and issues in the field are presented as they prompted and guided the present research. The chapter then outlines a proposed conceptual framework highlighting the relational, network, and social domains for extending the understanding of health literacy. Finally, the chapter outlines the research questions that are the basis for the research. This serves to establish the relevant concepts and frameworks from which the research data can be interpreted and new meanings understood through the hermeneutic research process (Chapter 4).

3.2 Origins and development of health literacy

Health literacy is increasingly considered essential in everyday living - “health literacy is one of the most critical capabilities in modern society” (Kickbusch, 2009, p. 132). Not only is health literacy an important element in illness prevention and health maintenance, but it is of relevance in multiple contexts of health, education, economics, and healthcare policy (An & Muturi, 2011; Begoray, Gillis, & Rowlands, 2012). If health literacy, as a social determinant of health, can

improve individuals' health outcomes then decision makers, as well as individuals, will be keen to support and engage with health literacy interventions that take advantage of its considerable potential. Not only is health literacy a compelling initiative for health and wellbeing on moral grounds but also timely given the unsustainable costs predicted to face the healthcare sector (refer Chapter 2).

Health literacy has been appearing in health literature since the 1970s. The term health literacy was initially used to describe and explain an individual's ability to apply literacy skills to health related materials; the investigation of health literacy, or more correctly health illiteracy, emerged primarily to help reduce health disparities. From this perspective, low rates of health literacy have been linked to a raft of health outcomes both individual and societal. This research linking health literacy to health outcomes has been predominantly US based with several reviews supporting consistent conclusions about the impact of health literacy on health outcomes, healthcare services, and health knowledge (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, AMA 1999; DeWalt et al., 2004; Institute of Medicine, 2004; Rootman & Ronson, 2005). However, in an updated systematic review of health literacy and health outcomes commissioned by the United States' Agency for Healthcare Research and Quality (AHRQ), the researchers found insufficient strength of evidence of links between many health outcomes that had in the past typically been associated with low health literacy, such as adherence, self-efficacy, healthy lifestyle, chronic disease prevalence, asthma, and diabetes control (Berkman et al., 2011).¹⁸

In contrast to the abundance of US-based research, there have been few UK studies linking health literacy with health outcomes (Jochelson, 2008). Despite research in the field being considered "in its infancy" (Sørensen & Brand, 2013, p. 640) in Europe, recent attention by European researchers has gathered considerable momentum culminating with the European Health Literacy Study (HLS-EU Consortium, 2012; Sørensen et al., 2012). This study surveyed 8000 EU individuals over 15 years of age across eight European countries. It used a

¹⁸ This review synthesised the data qualitatively from numerous studies and graded the overall body of literature according to the strength of evidence - high, moderate or low - "...after considering the domains of risk of bias, consistency, directness, and precision" (Berkman et al., 2011, p. ES-4).

measure of health literacy (47 items) based on self-reported health literacy incorporating measures of “interactions between individual competences and situational complexities or demands” (HLS-EU Consortium, 2012, p. 1). The conceptual model and definition that formed the basis for this research (Sørensen et al., 2012) are discussed later in this chapter. Importantly, policy initiatives regarding health literacy are now apparent at a national level in Europe. The European Commission’s Health Strategy 2008-2013 makes explicit mention of health literacy as a priority area for action and the European health policy framework - Health 2020 - recently adopted by EU member states, includes health literacy as a key dimension (European Commission, 2007; Kickbusch et al., 2013).

Closer to New Zealand, there is a robust and growing level of attention to health literacy in Australia at both an academic level (Batterham, Buchbinder, Beauchamp, Dodson, Elsworth, & Osborne, 2014; Jordan et al., 2013; Jordan, Buchbinder, & Osborne, 2010; Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013) and at a national policy level. The Australian Commission on Safety and Quality in Health Care seeks to coordinate the activity around health literacy, particularly stressing the importance of environmental factors (namely, the infrastructure policies and processes of the health system) and the centrality of the individual consumer (ACSQHC, 2012, 2013). More recently, the Australian Research Council in collaboration with universities is undertaking a large-scale health literacy research and intervention project across eight health and community care organisations in Australia, known as the Optimising Health Literacy (Ophelia) process (Batterham, Buchbinder, Beauchamp, Dodson, Elsworth, & Osborne, 2014). From the perspective of health literacy as a multi-dimensional concept, this on-going research has identified the participants’ health literacy needs, including customised intervention options.

The growth of interest in health literacy is also evidenced by the seemingly exponential expansion of research output. Over recent decades the body of health literacy literature and scholarship, produced across many disciplines, has grown prodigiously (Bankson, 2009). Sørensen et al. (2012, p. 2) cite 5,000 PubMed listed publications up to 2011 with most of these having been published since 2005. Similar figures are cited by Sykes, Wills, Rowlands, and Popple (2013) who

recorded a ten-fold increase in articles on health literacy between 1997 and 2007. Along with this proliferation in research output, numerous health literacy measurement tools have been developed. A recent comprehensive review identifies 51 such instruments, yet despite this proliferation most of these instruments measure limited dimensions of health literacy and lack adequate construct validity (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014).

Research associating health literacy with a range of outcomes has until recently focussed on functional health literacy. Investigations into health literacy and specific health conditions (for example, asthma, diabetes, hypertension, cancer screening) reveal that low functional health literacy is associated with poorer health regardless of the illness (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004), increased rates of hospital admission, and generally increased use of healthcare services (Brown et al., 2011; DeWalt et al., 2004; Mancuso & Rincon, 2006; Powers, Trinh, & Bosworth, 2010; Wolf, Gazmararian, & Baker, 2005.) Other researchers found low literacy to be associated with low medication adherence and less engagement in preventive health activities (deBuono, 2004; Miller, Brownlee, McCoy, & Pignone, 2007). In several studies patients with low health literacy demonstrated a lowered ability to act on health information lowering their ability to manage their condition(s) (Gazmararian, Williams, Peel, & Baker, 2003; Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; Jordan, Buchbinder, & Osborne, 2010; Mancuso, 2008; Paasche-Orlow et al., 2005).

Health literacy has also been linked to social and interactional consequences. For example, health literate people were shown to live longer and be more productive (Ratzan, 2001) and demand fewer health services (Sørensen et al., 2012). People with low health literacy have been found to generate higher health expenditures (e.g., Hardie, Kyanko, Busch, LoSasso, & Levin, 2011; Mancuso & Rincon, 2006) and they are less able to make effective use of healthcare resources (Eichler, Wieser, & Brugger, 2009; Howard, Gazmararian, & Parker, 2005; Ishikawa & Yano, 2008). Low functional health literacy has also been linked to lower participation by patients in their health decision making (DeWalt, Boone, &

Pignone, 2007; McKinstry, 2000) and lowered preference for involvement in healthcare problem-solving (Goggins et al., 2014). Different levels of health literacy are associated with varying conceptualisations of involvement in the patient-practitioner relationship (Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). However, while these studies measure health literacy using different tools and typically measure restricted conceptual dimensions of health literacy, understanding of the phenomenon will be limited and interventions could be misdirected.

Despite the abundance of health literacy research and policy measures, part of the challenge is a lack of agreement over the concept, with multiple definitions and limited operationalisation of the term (Berkman, Davis, & McCormack, 2010; Chinn, 2011; Frisch, Camerini, Diviani, & Schluz, 2012; Sørensen et al., 2012). Advances in theorising have been further hampered by the diverse health contexts in which very different individuals with very different goals exercise a range of knowledge, skills, and judgments, in all of which health literacy may be considered applicable (Pleasant, McKinney, & Rikard, 2011). Therefore, although initially defined as reading, writing, and numeracy skills in a health context, the construct of health literacy is being re-examined and re-constructed as a multi-dimensional construct, including broad notions of health understanding and consumer empowerment. In this evolution of the construct, Chinn (2011) considers that the term ‘literacy’ may even have been stretched to “an indefensible extent” (p. 60) and Tones (2002) that it is little more than “old wine in new bottles” and that the other constructs themselves are often debated and open to misinterpretation.

The next section reviews definitions of health literacy and the conceptual frameworks that have been developed as the construct of health literacy has evolved.

3.3 Definitions of health literacy

The concept of health literacy emerged in the 1970s to refer to health-related literacy skills. As different definitions and research developed, national perspectives became apparent. Much of the health literacy research emerging out of the US focussed on healthcare providers managing and responding to those patients with low literacy, with some suggesting that functional health literacy is a necessary condition for “patient compliance” (Tones, 2002, p. 287). The following sections discuss the diverse and contested nature of health literacy definitions (summarised in Table 3.1).

3.3.1 Definitions of functional health literacy

A large number of definitions focus on functional literacy, that is, the ability to handle words and numbers in a medical and health context (Baker, 2006; Nutbeam, 2009; Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012; Speros, 2005; Zarcadoolas, Pleasant, & Greer, 2005). In this group of definitions, health literacy is largely cognitive and individual. Measures of health literacy adopted by researchers following this perspective typically include the Test of Functional Adult literacy (TOFHLA and the shortened version S-TOHFLA), the Rapid Estimate of Adult Literacy in Medicine (REALM), the Health Activities Literacy Scale (HALS) and the Newest Vital Sign (NVS). These result in health literacy metrics measuring numeracy, reading, and writing in a health context and a clinical approach to developing improved diagnostic tools and literacy interventions.

Research into the relationship between functional health literacy (often reading skills) and healthcare outcomes have received considerable attention in the US, typically among patients in clinical settings. These research findings then focussed on interventions that could improve literacy skills, often advocating education as the key to improved health outcomes. There appears to be little disagreement that low functional health literacy is a powerful influence on personal health (e.g., DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Nutbeam, 2008a, 2009; Schulz & Nakamoto, 2012a; Wolf, Gazmararian, & Baker,

2004) with potential consequences of improved health literacy linked to “improved self-reported health status, lower healthcare costs, increased health knowledge, shorter hospitalisation, and less frequent use of healthcare services” (Sørensen et al., 2012, p. 8). Concomitantly, lower health literacy levels have been linked to higher health expenditures (e.g., Eichler, Wieser, & Brugger, 2009; Parker & Ratzan, 2010).

While indisputably valuable these functional skills have been re-classified as “health-related literacy in clinical settings” (Nutbeam, 2009, p. 305). Estimates of health literacy according to functional skills give the impression that the concept of health literacy can be measured reliably, validly, and comparably yet, in effect, functional literacy measures leave important dimensions un-measured (Pleasant et al., 2011). Being able to read a prescription label is not the same as: being able to navigate the health system; accessing sufficient health information; identifying appropriate healthcare media and messages; understanding health determinants; nor making an informed decision. Literacy (reading and writing) is not equivalent to health literacy since “the acquisition of these skills gives no special insight into the proper and advantageous use of these skills in the field of health” (Schulz & Nakamoto, 2012b, p. 70), just as Pattison (1982) argues that giving man [sic] the skills to read and write does not turn him into a citizen capable of making democratic choices.

Functional health literacy is therefore an important but not sufficient condition for a health literate individual. It is also questionable what the functional measures of health literacy are capturing - they may be measuring disease control or tasks associated with the management of a health condition. Furthermore, Ostini & Kairuz (2014) found an equivocal relationship between health literacy, as defined by disease and medication knowledge, and medication non-adherence. Their conclusion is that these aspects of functional health literacy are not sufficient to explain the relationship of health literacy with health-related outcomes, while from their research self-efficacy is a more useful indicator.

3.3.2 *Extending the definition of health literacy*

The notion of health literacy has expanded as has the complexity of health systems. The Institute of Medicine (Institute of Medicine, 2004, p. 2) acknowledges that health literacy is more than just obtaining information and “...emerges when expectations, preferences, and skills of individuals seeking health information meet the expectations, preferences, and skills of those providing information and services. Health literacy *arises from a convergence of education, health services, and social and cultural factors*” (emphasis added). Although this definition includes other than literacy skills and implies contextual and interaction factors, there is an emphasis on information and on health literacy as an outcome only not a process.

The perspective widely followed in Europe and Australia connects health literacy with education, empowerment, and social marketing of public health interventions, from the perspective of health literacy as an asset (not a risk to be managed). This group of definitions underscores the importance of developing a range of skills and relational attributes that enable effective interaction between all parties involved in the communications and decisions about health (Peerson & Saunders, 2009; Zarcadoolas, Pleasant, & Greer, 2003). This perspective parallels the interactive and critical health literacy in Nutbeam’s typology and signals an emphasis on health literacy as a process not just an outcome. In this way, health literacy is considered both a resource and a skill that facilitates valuable interactions within an individual’s health contexts and encounters (Dubbin, Chang, & Shim, 2013).

These broadened definitions move health literacy from a strictly functional focus on reading, writing and numeracy to referring to decisions, not only in health-related settings but also about health. Including interactive aspects, these definitions view health literacy as a set of interconnected abilities that include reading literacy but extend to: communicating one’s needs and acting upon information; and a cluster of “individual skills to obtain, process and understand health information and services necessary to make appropriate health decisions” (Sørensen et al., 2012, p. 3). In doing so, such definitions acknowledge the

responsibility of each individual but also that health literacy changes over time, contexts, and according to varying levels of information and resources (not just individual skills).

The individual is therefore an active participant engaged in health decisions in a range of settings and at a range of levels - individual, community and policy. In these definitions, health literacy is accepted as encompassing knowledge acquisition, knowledge application, motivation, communication, and decision making processes. Another major shift apparent in this perspective is the acknowledgement that these competencies and skills need to be considered in a variety of contexts, and therefore that they also apply to the other 'actors' (co-creators of health literacy) in those contexts – including, healthcare providers, the healthcare system, public health message disseminators. In line with the expanded notion of health literacy there has been increasing interest on developing measures that encompass the patient perspective and functional, interactive and critical dimensions of health literacy. Researchers in the UK (Chinn & McCarthy, 2013) have recently developed the All Aspects of Health Literacy Scale (AAHLS) and Australian researchers (Jordan et al., 2013) have constructed the Health Literacy Management Scale (HeLMS) and the Health Literacy Questionnaire (HLQ) (Osborne et al., 2013).

Health literacy definitions continue to evolve with some researchers suggesting that there may never be international consensus on a single definition (Begoray, Gillis, & Rowlands, 2012; Pleasant, 2013). There are diverse and nuanced definitions of the term; Tones (2002) suggests that this supports his contention that health literacy is little more than re-packaged health promotion. Notwithstanding the diversity of definitions and seeking to avoid the broadening of scope of the term until it encompasses everything (e.g., simply health), a recent systematic review of definitions identified 17 explicit definitions and 12 conceptual frameworks (Sørensen et al., 2012). Table 3.1 summarises the health literacy definitions from that review adding unique definitions published since 2009, the date of the data collection by Sørensen et al. (2012). The updating process (refer Appendix 5) followed the Sørensen et al. approach, searching the

Web of Science and PubMed (including Medline) databases and, in addition, searching the Scopus and PsycINFO databases, for additional unique definitions.

The far right-hand column of Table 3.1 identifies the key perspective of each definition. All these definitions have been important in the researcher's pre-understandings, however the orange-shaded cells are those definitions that have been particularly instrumental in guiding the research process and in the hermeneutic processes of data interpretation.

Table 3.1 Definitions of health literacy
(chronological order)

		Definition	Comments / Emphasis
1998	WHO (cited in Nutbeam, 1998) <i>Most cited</i>	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health...Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions.	Individual skills, including motivation and social skills. Health promoting behaviours.
1999	American Medical Association. <i>Most cited</i>	The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment.	Individual skills.
2000, 2008	Nutbeam	The personal, cognitive, and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information to promote and maintain good health.	Motivation, interaction, engagement, & application of information. Not simply a derivative of literacy & numeracy skills.
2001	Selden, Zorn, Ratzan, et al.	The currency patients need to negotiate a complex healthcare system.	Includes healthcare context.

2004	Sihota & Lennard	The capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health-enhancing.	Individual skills.
2004	Institute of Medicine (also refer Healthy People, 2010; Ratzan & Parker, 2000) <i>Most cited</i>	The individuals' capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.	Individual capabilities. Cognitive skills. Health literacy as a risk factor to be managed.
2006	Baker	The ability to function in the healthcare environment and depends on characteristics of both the individual and the healthcare system. An individual's health literacy is context specific (dynamic) and may vary depending upon the medical problem being treated, the healthcare provider, and the system providing care.	Context-specific. Includes health knowledge.
2006	Kwan, Frankish, & Rootman	People's ability to find, understand, appraise and communicate information to engage with the demands of different health contexts to promote health across the life course.	Cognitive & social skills. Health promoting behaviours.
2006	Paasche-Orlow & Wolf	An individual's possession of requisite skills for making health-related decisions, which means that health literacy must always be examined in the context of the specific tasks that need to be accomplished.	Individual skills according to context.
2006	Zarcadoolas, Pleasant, & Greer	The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life. A health literate person is able to use health concepts and information generatively - applying information to novel situations.	Individual & social skills. Media literacy skills. Health promoting behaviours.

2007	Abel	Health literacy means to understand the conditions that determine health and to know how to change them.	Includes ability to access information, critical thinking skills, and acting on information.
2007	European Commission	The ability to read, filter, and understand health information in order to form sound judgments.	Includes judgment skills.
2008	Australian Bureau of Statistics	The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.	Health promoting behaviours.
2008	Ishikawa & Yano	The knowledge, skills, and abilities that pertain to interactions with the healthcare system	Individual skills. Healthcare system.
2008	Kickbusch & Maag	Health literacy is the capacity to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the health-care system, in the market place, and in the political arena. It is a critical empowerment strategy to increase people’s control over their health, their ability to seek out information, and their ability to take responsibility	Emphasis on cognitive skills & decision making. Not restricted to healthcare environment. Essential part of social capital.
2008	Mancuso	A process that evolves over one’s lifetime and encompasses the attributes of capacity, comprehension, and communication. The attributes of health literacy are integrated within and preceded by the skills, strategies, and abilities embedded within the competencies needed to attain health literacy.	Personal, social, critical thinking, & problem solving skills

2008	Pavlekovic (cited in Sørensen et al.)	The capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health.	Personal & social skills. Health promoting behaviours.
2008	Rootman & Gordon-El-Bihbety	The ability to access, understand, evaluate, and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.	Personal & social skills. Health promoting behaviours.
2009	Adams et al.	The ability to understand and interpret the meaning of health information in written, spoken or digital form, and how this motivates people to embrace or disregard actions relating to health.	Cognitive & social skills including motivation for health promoting behaviours.
2009	Adkins & Corus	The ability to derive meaning from different forms of communication by using a variety of skills to accomplish health-related objectives. Health literacy is socially constructed between the consumers and the healthcare providers.	Socio-cultural skills.
2009	Freedman et al.	The degree to which individuals and groups can obtain process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.	Health promoting behaviours. Community level.
2009	Peerson & Saunders	Information and decision-making skills occurring in the workplace, in the supermarket, in social and recreational settings, within families and neighbourhoods, and in relation to the various information opportunities and decisions that impact upon health every day.	Broad context and settings for health literacy.
2009	Yost et al.	The degree to which individuals have the capacity to read and comprehend health-related print material, identify and interpret information presented in graphical format	Functional literacy in a health context.

		(charts, graphs and tables), and perform arithmetic operations in order to make appropriate health and care decisions.	
2010	Berkman et al.	The degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions.	Cognitive skills.
2010	Parker & Ratzan	Health literacy occurs when the skills and ability of those requiring health information and services are aligned with the demand and complexity of information and services...how patients access, understand, and use health information provided to them to promote, protect, and manage their health.	Cognitive & social skills for health promoting behaviours. Interaction with healthcare system.
2012	Begoray & Kwan	The degree to which people are able to [1] access, [2] understand, [3] appraise and [4] communicate information to engage with the demands of different health contexts to promote and maintain health across the life-course.	Added dimensions of context and life course.
2012	de Leeuw	The skills, capacities and knowledge required to access, understand, and interact with social and political determinants of health and their social discourse.	Includes social & political dimensions.
2012	Martensson & Hensing	Complex approach to health literacy described in three themes – acknowledging the complexity, the significance of the context, and shared responsibility.	More than an individual skill or responsibility.
2012	Paakkari & Paakkari	Health literacy is a broad range of knowledge and competencies that people seek to encompass, evaluate, construct and use. Health literacy enables people to understand themselves, others and the world in a way that will enable them to make sound health decisions, and to work on and change the factors that constitute their own and others' health chances.	Theoretical knowledge, practical knowledge, critical thinking, self-awareness, & citizenship.

2012a	Schulz & Nakamoto	Health literacy entails patients capitalizing on their domain of unique expertise - the experience of their health condition as a basis for judgments related to health decisions...Health literacy as phronesis becomes the capacity of making health information relevant for action by recognizing personal needs or limitations which may stand in the way of good health decisions.	Literacy distinguished from empowerment. Individual internalised construct. Critical self-examination.
2012	Sørensen et al. and adopted by HLS-EU	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 everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.	Comprehensive definition.
2013	Jordan et al.	An interaction between individual abilities and factors at a personal, healthcare system, and broader community level...an individual's health literacy is not fixed, and is dependent on a combination of circumstances, several of which may be outside the control of the individual.	Multiple dimensions of abilities and contextual influences.
2013	Sykes et al.	Critical health literacy as a distinct concept with...a unique set of characteristics of advanced personal skills, health knowledge, information skills, effective interaction between service providers and users, informed decision making and empowerment including political action.	Based on colloquial and theoretical concept analysis.

These definitions, illustrated in Table 3.1, describe the range of aspects considered to comprise health literacy. Many of these definitions overlap with each other while others use different terms to describe the same phenomena. The following section presents the issues raised over the difficulties of defining health literacy, the challenge to differentiate between aspects considered to comprise health literacy versus outcomes or consequences of health literacy, and the imperative for robust yet relevant measurement of the phenomenon.

3.3.3 Health literacy redefined

Originally health literacy was emphasised as an individual-level outcome construct (an individual is health literate) with associated consequences regarding the health and health behaviours of an individual. More recent definitions are acknowledging the contextual nature of health literacy and the public health dimensions of health literacy. The concept has now been extended to include service users' own understandings of the term, including healthcare providers (e.g., Chinn & McCarthy, 2013; Jordan et al., 2010; Sykes et al., 2013). Another broad definition considers health literacy generally as an inequality of opportunity in health (Rosa Dias, 2010). The construct of health literacy therefore has many nuanced interpretations depending on the goals for which it is being used.

If health advancement is privileged as the goal of health literacy then it takes away from the individual's own freedom in choosing how to live and the health decisions he or she makes. Many theorists and researchers are calling for the subjective, lived experience of health literacy to be fully recognised by “Re-ground[ing] health literacy in the individual's existential experience” (Rubinelli, Schulz, & Nakamoto, 2009, p. 308). Since health and health literacy are both covert constructs there can be “no meaning separate from personal (internal) experience” (Schulz & Nakamoto, 2012b, p. 75) framing health literacy as a socially constructed concept. According to Kickbusch (2009) “Health literacy is about the balance between the power of the providers and the users and patients in the system... about rights, access and transparency. It is about a new form of health citizenship, in which citizens take both personal responsibility for health and become involved as citizens in social and political processes” (p. 132).

The various definitions of health literacy overlap other equally complex and imprecise concepts, for example, motivation, self-efficacy, patient activation, and cultural health capital. This has led some scholars to argue that health literacy is little more than a re-badging of other terms, such as empowerment (Tones, 2002; Wills, 2009). However, there are contradictory perspectives on the relationship between health literacy and empowerment. According to some researchers, health literacy is a pre-condition for empowerment (Kickbusch, 2009; Kwan, Frankish, & Rootman, 2006; Nutbeam, 1998, 2000; 2008). However, Schulz and Nakamoto (2012a) argue that health literacy and empowerment are separate constructs and not simply different terms for the same construct; the two are independent but important determinants of health outcomes and behaviours.

In a similar manner, cultural health capital is used by Dubbin et al. (2013) to refer to resources and skills that share many aspects in common with health literacy, but in addition allow a patient to mobilise their health literacy and self-efficacy resources in healthcare encounters. Frosch and Elwyn (2014) contrast health literacy as a skill with the all-encompassing concept of patient activation that also includes the psychological construct of motivation to take action. Patient activation and health literacy, as measured by functional health literacy (TOFHLA), have been weakly correlated (Hibbard, Peters, Dixon, & Tusler, 2007; Smith, Curtis, Wardle, von Wagner, & Wolf, 2013), yet patient activation (using a Patient Activation Measure, PAM) has been found to have a strong effect on health information seeking behaviours and use of health-related information (Nijman, Hendriks, Brabers, de Jong, & Rademakers, 2014) - both considered indicators of yet another construct, patient engagement. However, these empirical relationships must be considered within the boundaries of health literacy definitions and measurement tools and for measuring the same phenomenon.¹⁹ Nutbeam (2008) and WHO (1998) expand the definition of health literacy beyond skills to include motivation to access, understand and use - all action-oriented behaviours - information to promote and maintain health, indicating that a

¹⁹ Items in the PAM (Smith, S. G. et al., 2013) parallel several of the HLQ items (Osborne et al., 2013) that were developed using a validity-driven approach from a variety of community individuals.

combined approach (functional health literacy and patient activation) is valuable for progressing health literacy research and understanding (Smith S.G. et al., 2013).

Clearly, the term health literacy will continue to evolve with scholars, practitioners, and nationally-based institutional researchers adding aspects (or restricting the definition) to suit their specific settings and goals. Rudd, McCray, and Nutbeam (2012) note the widening scope of health literacy to include engagement and participation in decision making, but they also identify a gap in the definitions so far. Several recent definitions of health literacy (including critical health literacy) represent a shift from a set of individual capabilities to a co-constructed, transactional concept that calls for cooperative/collaborative efforts at an organisational and structural level. Health literacy definitions while recognising the wider determinants of health literacy have paid scant attention to other stakeholders in the health literacy context - many of whom shape the health encounters and health information. These stakeholders - administrators, medical staff, health planners, various professionals - help shape the determinants of an individual's health literacy and the capacity for effective health appraisal, evaluation and individual action.

3.3.4 Definitional complexity

Definitional agreement is not evident in health literacy literature. It is agreed that the complexity of health literacy cannot be captured in one single 'best' definition - "nearly everyone agrees [health literacy] is important...very few seem to agree on what the concept actually represents" (Pleasant, 2013, p. 85). The variety of definitions and constructs enables multiple dimensions of health literacy to be explored in particular contexts to match the aims and perspectives of specific research.

However, many measures of health literacy are too limiting as they do not support contextual variations (health event and life-course) in health literacy, de-emphasise the multi-dimensional nature of the construct, and isolate the engagement of individuals in their health decisions from the functional and

informational aspects of health literacy. These latter dimensions are being increasingly endorsed as fundamental to health literacy, reinforcing the need for “greater sophistication in both the definition and measurement of health literacy...” (Smith, Nutbeam & McCaffery, 2013, p. 1). The range of measures based on diverse definitions challenges scholars and practitioners to clearly understand the conceptual dimensions being measured and to determine the commonality between the measures (and definitions) and the “social construct called health literacy” (Pleasant, McKinney, & Rikard, 2011, p. 11). Following their comprehensive inventory of health literacy measures, Haun et al. (2014) endorse this by concluding that the field currently lacks a validated measure that addresses the complexity of the construct of health literacy.

This thesis uses the extended perspective and definition of health literacy as followed in Europe and Australia, including individual and social skills, motivation to apply and use health-related information, and interactive and communicative aspects of health literacy such that individuals are able “to interact successfully with health information” (Begoray et al., 2012, p. 156).

3.4 Conceptual frameworks for health literacy

A conceptual framework provides a structure of the current thinking on the phenomenon being studied offering “the current version of the researcher’s map of the territory being investigated” (Miles & Huberman, 1994, p. 33). Conceptual frameworks, in graphic and/or narrative formats, are structures for organising and representing ideas to communicate how the researcher perceives, understands, and interprets the phenomenon or topic of study. In health literacy differing definitions of health literacy have resulted in several conceptual models of health literacy. These frameworks, in varying degrees, provide the dimensions and structure for understanding the complex phenomenon of health literacy, linking the concept to the multiple areas of knowledge that are appropriate, and identifying the presumed relationships that influence a phenomenon (Miles & Huberman, 1994).

Nutbeam (2000) describes three typologies of health literacy: functional health literacy, interactive health literacy, and critical health literacy. In his

conceptualisation, the individual progresses from the functional skills level to the interactive and critical levels of health literacy. These latter levels of health literacy incorporate skills and activities that enable the individual to analyse information and derive meaning from that information. With critical health literacy skills an individual can exercise increasing autonomy in their health decision-making.

Nutbeam's (2000) foundational work has been followed by numerous frameworks and models. Zarcadoolas et al. (2005) conceptualised health literacy in four levels – fundamental literacy, science literacy, civic literacy, and cultural literacy. Freedman et al. (2009) suggested three dimensions – conceptual foundations, critical skills, and civic orientation. Mancuso (2008) identifies capacity skills, comprehension, and communication and interestingly adds competencies labeled as: contextual and cultural. A contextual competency seems difficult to translate into behaviour and Mancuso (2008) does not differentiate between those cultural and contextual dimensions that are influencing factors or outcomes in the form of 'competencies'. Schulz and Nakamoto (2005, 2012a) and Rubinelli et al. (2009) suggest a model that overlays functional health literacy elements with: declarative knowledge (explicit knowledge that can be verbalised), procedural knowledge (knowledge of how to do things), and individual judgment skills. Frisch, Camerini, Diviani, and Schulz (2012) add awareness, particularly as this dimension makes explicit the acts of problem-recognition and self-examination in individual health decisions, both of which are closely linked to health knowledge. Jordan et al. (2010, 2013) develop a conceptualisation of health literacy from the patient perspective. Their framework identifies core individual abilities (subsequently refined, refer Table 3.5) and adds to the schematic, extrinsic factors (e.g., healthcare setting, social support, socio-economic) and intrinsic factors (e.g., attitudes towards health, emotional or physical disposition, educational background). Jordan et al. (2013) avoid explicit directional implications in their framework although the core individual abilities are positioned above the extrinsic and intrinsic factors.

These multi-dimensional conceptualisations of health literacy have yet to be fully "translated into [empirical] measures that fully encompass their theoretical

richness” (Frisch et al., 2012, p. 120). Recent work on the Health Literacy Management Scale (HeLMS) and the Health Literacy Questionnaire (HLQ) is seeking to overcome this limitation by using a validity-based approach to instrument development (Jordan et al., 2013; Osborne et al., 2013). The HLQ covers 9 conceptually distinct aspects of health literacy and, although the researchers acknowledge the need for further testing, it has been based on individuals’ experiences of health literacy, albeit individuals recruited from a patient population.

Tables 3.2 and 3.3 summarise narrative health literacy frameworks (adapting Sørensen et al.’s, 2012 review) separating the models according to their emphasis on health literacy as a risk (Table 3.2) versus a personal asset (Table 3.3). The majority of these narrative representations do not address the processual or interactional elements of health literacy. Health literacy may emphasise different facets depending on the context of application, and the society or groups involved (Abel, 2008; Nutbeam, 2009), yet only a few frameworks explicitly account for social, environmental, or interactional dimensions.

Table 3.2 Health literacy conceptual frameworks - Medical literacy models

(Source: Adapted from Sørensen et al., 2012)

Conceptual frameworks based on individual cognitive capabilities, skills & behaviours - Health literacy approached as a clinical risk

	Domains	Comments / Emphasis
2004 Institute of Medicine	<ul style="list-style-type: none"> - Cultural and conceptual knowledge - Listening - Speaking - Arithmetical skills - Writing skills - Reading skills 	Emphasis on improving health literacy among those with inadequate or marginal health literacy skills.
2004 Lee, Arozullah, & Choc	<ul style="list-style-type: none"> - Disease and self-care knowledge - Health risk behaviour - Preventive care and physician visits - Compliance with medications 	Emphasises intermediate factors through which health literacy affects outcomes.
2005 Speros	<ul style="list-style-type: none"> - Reading & numeracy skills - Comprehension - Capacity to use health information in decision making - Successful functioning in a healthcare consumer role 	Identifies attributes, antecedents, and consequences of health literacy.

Table 3.2 ctd.		Domains	Comments / Emphasis
2006	Baker	<ul style="list-style-type: none"> - Health-related print literacy - Health-related oral literacy 	Identifies moderators and mediators of health literacy. Emphasises role of prior learning.
2006	Norman & Skinner	<ul style="list-style-type: none"> - Traditional literacy - Health literacy - Information literacy - Scientific literacy - Media literacy - Computer literacy 	<p>Separate skillset for electronic health literacy.</p> <p>Analytic (traditional, media, information) and context-specific (computer, scientific, health).</p>
2007	Paasche-Orlow & Wolf	<ul style="list-style-type: none"> - Listening - Verbal fluency - Memory span - Navigation 	Identifies causal pathways between health literacy and outcomes.
2009	von Wagner, Steptoe, Wolf, & Wardle	Literacy and numeracy skills for problem-solving	Uses constructs from social cognition to situate health literacy in a framework of health actions.
2014	Ownby, Acevedo, Waldrop-Valverde, Jacobs, & Caballero	<ul style="list-style-type: none"> - General intellectual ability - Academic skills - Health-related knowledge 	Synthesised as the ASK model of health literacy.

Table 3.3 Health literacy conceptual frameworks - Public health literacy models

(Source: Adapted from Sørensen et al., 2012)

Conceptual frameworks that extend beyond individual competences & medical context - Health literacy approached as a personal asset

		Domains	Comments
2000/2008	Nutbeam	- Functional health literacy - Interactive health literacy	Three progressive levels.
2008	Kickbusch & Maag	- Critical health literacy	Refer section 3.4.1
2005	Zarcadoolas, Pleasant, & Greer	- Fundamental literacy - Science literacy - Civic literacy - Cultural literacy	Emphasis on making health communication understandable & appropriate.
2008	Mancuso	- Capacity skills to gather, analyse and evaluate health information - Comprehension within a process of interaction of logic, language and experience to interpret information - Communication, via multiple media, feedback and critical involvement	Interaction between the three attributes.
2008	Manganello	- Functional health literacy - Interactive health literacy - Critical health literacy - Media literacy	Focus on adolescents.

Table 3.3 ctd.		Domains	Comments
2009	Freedman et al.	<ul style="list-style-type: none"> - Conceptual foundations of public health - Critical skills for public health decisions - Civic orientation to address public health concerns 	<p>Public health literacy distinct from individual health literacy.</p> <p>Aim: to engage more stakeholders in public health efforts</p>
2010	Jordan, Buchbinder, & Osborne	<ul style="list-style-type: none"> - Patient health literacy abilities - Patient-Health professional interaction - Broader factors 	Developed from the patient perspective.
2011	Chinn	<p>Adopts Nutbeam's 3-tiered model, subdivides critical health literacy into:</p> <ul style="list-style-type: none"> - Critical analysis of information - Understanding of social determinants of health - Engagement in collective action 	<p>Individual and social asset.</p> <p>Observable outcomes including: questioning health information, personal research, changed behaviour, social action.</p>
2012	Frisch, Camerini, Diviani, & Schulz	<ul style="list-style-type: none"> - Functional literacy - Factual & procedural knowledge - Awareness - Critical dimension with a) meaning matching – comprehension, & b) meaning construction - judgment of relevance 	Motivation implied in dimensions.

Table 3.3 ctd.		Domains	Comments
2012a, b	Schulz & Nakamoto	<ul style="list-style-type: none"> - Declarative - factual knowledge in order to be able to learn how to approach a health condition - Procedural - know how to apply factual knowledge in a specific context - Judgment & practical wisdom - the ability to judge based on a factual knowledge necessary to deal with novel situations 	Refer section 3.4.2
2012	Massey, Prelip, Calimlim, Quiter, & Glik	<ul style="list-style-type: none"> - Navigating the system - Rights & responsibilities - Preventive care - Information seeking - Patient-provider relationship 	<p>Health system context & adolescent population.</p> <p>Relevant practices to operationalise dimensions.</p>
2012	Sørensen et al.	<ul style="list-style-type: none"> - Healthcare - Disease prevention - Health promotion <p>Modes of dealing with health relevant information:</p> <ul style="list-style-type: none"> - access/obtain; understand; appraise/judge/evaluate; apply/use 	Refer section 3.4.3

Three frameworks central to health literacy scholarship are reviewed. First, Nutbeam's (2000) framework is reviewed since it was a transformation in the then-existing concepts of health literacy and has been a foundational framework in health literacy scholarship. Second, the framework from the work of Schulz and Nakamoto (2012b) is presented as these researchers effectively frame health literacy with reference to constructs of judgment and knowledge skills, moving beyond information skills. Finally, Sørensen et al.'s (2012) framework is presented as one of the most recent and comprehensive frameworks integrating contextual, life course, and healthcare setting dimensions into a conceptualisation of health literacy.

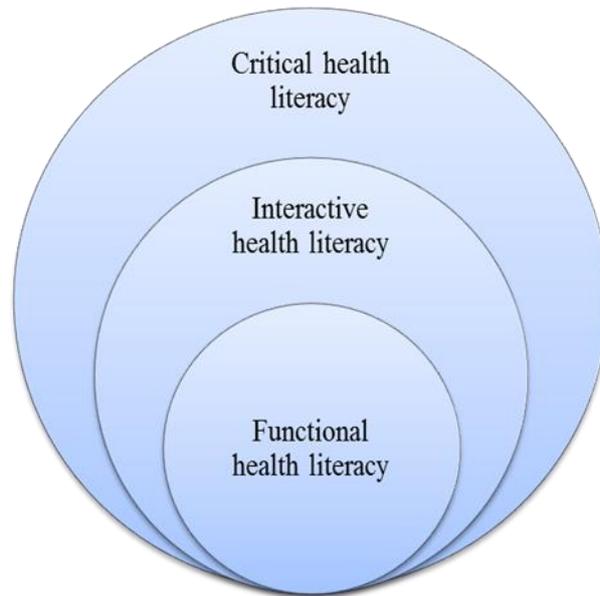
3.4.1 Three-tiered health literacy framework

Nutbeam's (2000, 2008) conceptualisation of health literacy includes three layers, functional skills, extending into the second layer of interactive skills, and then to a critical level (Figure 3.1). Functional health literacy refers to the ability to apply basic literacy and numeracy skills to gather, appraise and understand health materials in order to function in everyday situations. Interactive health literacy refers to more advanced cognitive, literacy, and social skills which an individual can use to actively participate and engage in health and "to apply new information to changing circumstances (interactive)" (Nutbeam, 2008a, p. 2075). The third level is critical health literacy referring to the consumer's/patient's ability to "analyse information and to use this information to exert greater control over life events and situations" (Nutbeam, 2008a, p. 2075). This critical aspect of health literacy also implies an imperative for social change adding a community dimension to this conceptualisation.

Nutbeam presents these levels as having an ascending order of difficulty, progressively supporting the development of greater autonomy and empowerment of individuals and improved involvement in health decisions in "the context of [their] everyday life" (Kickbusch & Maag, 2008, p. 205). Recently, Smith, Nutbeam, and McCaffery (2013) propose that these three levels are not sequential but are related in a continuous iterative process, with patients moving back and forth between them. In this conceptualisation, health literacy is an everyday

process, not a single outcome which extends into multiple behaviours and practices.

Figure 3.1 Nutbeam's (2000, 2008) 3-tiered health literacy framework



Lower functional health literacy does not preclude patients engaging in interactive and critical health literacy activities, nor does a high level of health literacy guarantee that an individual will engage in the other levels (Chinn, 2011; Ishikawa & Yano, 2011; Smith, Nutbeam, & McCaffery, 2013). Nevertheless, this framework considers health literacy as an asset that can enable effective and confident interactions between individuals and healthcare providers, enhance navigation of the health system, raise awareness of public health issues, and help consumers develop skills in collective action.

Sykes et al. (2013) explore the definitions and understandings of critical health literacy identifying dimensions of: advanced personal and social skills; skills that arise from the relationship between services and individuals; understanding of the policy context of health including the opportunities and motivation for challenging these; a learned and movable state depending on context. In Sykes et al. research “the colloquial sample [who] stressed that critical health literacy

would only exist if there was a commitment from health practitioners to provide accessible information and to engage in shared decision making” (Sykes et al., 2103, p. 5). Chinn (2011) has also linked critical health literacy to collective action, incorporating social capital, psychological empowerment, and emancipation. In effect these researchers are endorsing critical health literacy as moving beyond an individual focus - skills and motivation - to a relational concept (paralleling Adkins & Corus’, 2009, co-construction of health literacy) having structural dimensions and responsibilities beyond the individual. Some have called this the health literate system.

The use of the term ‘critical’ in critical health literacy is also understood as “being able to identify bias and credibility of a source, differentiate fact from opinion, determine if a message is unrealistic, understand a message’s purpose, determine [the] truth and applicability [of a message]” (Center for Media Literacy, quoted in Bergsma & Carney, 2008 cited in Chinn, 2011, p. 62). Therefore, while critical health literacy is considered the third wave of health literacy development,²⁰ there is confusion over its scope. Some researchers restrict it to a higher order individual cognitive skill, while others maintain it includes engagement in collective action and is a driver for social and emancipatory change (Chinn, 2011; Sykes et al., 2013).

This framework was one of the first to provide a foundation for understanding health literacy as more than functional skills that reside within an individual. This model has been the stimulus for a wealth of research and interventions in health literacy.

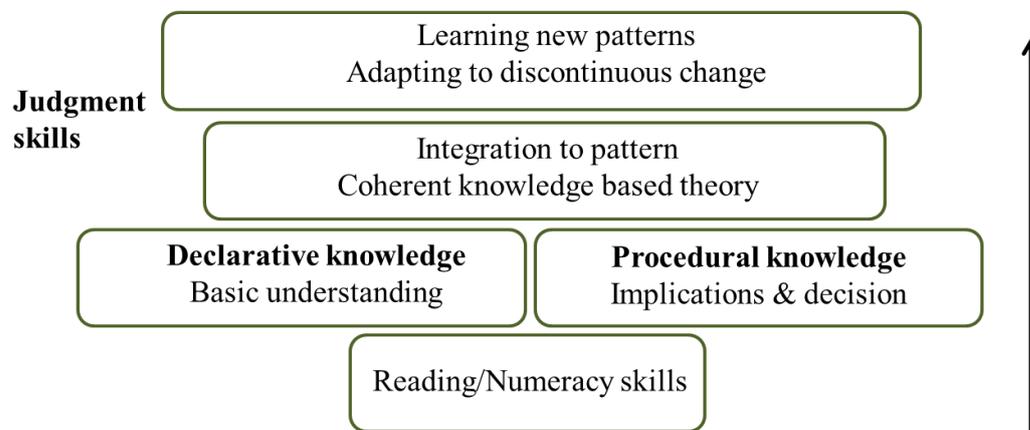
3.4.2 Schulz and Nakamoto (2012a, b) health literacy framework

Schulz and Nakamoto (2012a, b) build their framework (refer Figure 3.2) on declarative knowledge - the ‘knowing that’ information that is explicit and accessible - and procedural knowledge - the tacit or implicit knowledge of ‘knowing how’. At this level in the framework, while an individual shifts his or

²⁰ The “second wave” of health literacy research was one in which multiple literacies are considered relevant (Frisch et al., 2012).

her declarative knowledge into procedural knowledge one is not superior to the other. How this shift occurs is through judgment including motivation and autonomy. Schulz and Nakamoto (2012a, b), in further explaining this process whereby individuals use information and expertise to have control and responsibility for their health, collapse Nutbeam's interactive and critical categories into judgment skills. These are defined in the framework as an individual's ability to integrate knowledge and apply this knowledge in adapting to change. Judgment skills are fundamental to health literacy, since these integrate multiple areas of knowledge involving evaluation and motivation critical to individuals managing their health. Recent studies, using scenario-based measurement scales to evaluate these judgment skills (Londono & Schulz, 2014), are substantive additions to understanding the complexity of health literacy.

Figure 3.2 Health literacy conceptualised as health empowerment
(Adapted from Schulz & Nakamoto, 2012a, b)



These researchers distinguish health literacy from expert advice, alerting readers first, to the subjectivity involved in health literacy and second, that judgment skills do not disregard medical expertise. The framework emphasises that "...the one domain in which the patient is uniquely expert is the experience of health and illness and his or her health goals" (Schulz & Nakamoto, 2012a, p. 5). Therefore, an important aspect of judgment skills includes when an individual recognises and evaluates when to apply certain knowledge and what they know or do not know. These skills are closely related to the concept of *phronesis*, or practical wisdom

and include individuals' self-examination and reflective capabilities (Rubinelli, Schulz, & Nakamoto, 2009). In health, practical wisdom enables and motivates an individual to behave and make choices in ways that have the end-goal of well-being. For example, according to this framework, health literacy includes "...the individual's capacity to contextualise health knowledge for his or her own good health, to decide on a certain action after a full appraisal of what that specific action means for them 'in their own worlds'." (Rubinelli et al., 2009, p. 309).

Equally, Schulz & Nakamoto (2012a, 2012b) present an argument for empowerment and health literacy to be considered as related but separate constructs. Conceptualising them as interdependent yet separate improves the explanatory power of both concepts. Importantly, for the current researcher's pre-understandings, Schulz and Nakamoto's framework provides key insights into the psychological and lived experience dimensions of health literacy, which had been alluded to in other studies but had not been so clearly enunciated.

3.4.3 Sørensen et al. (2012) integrative framework

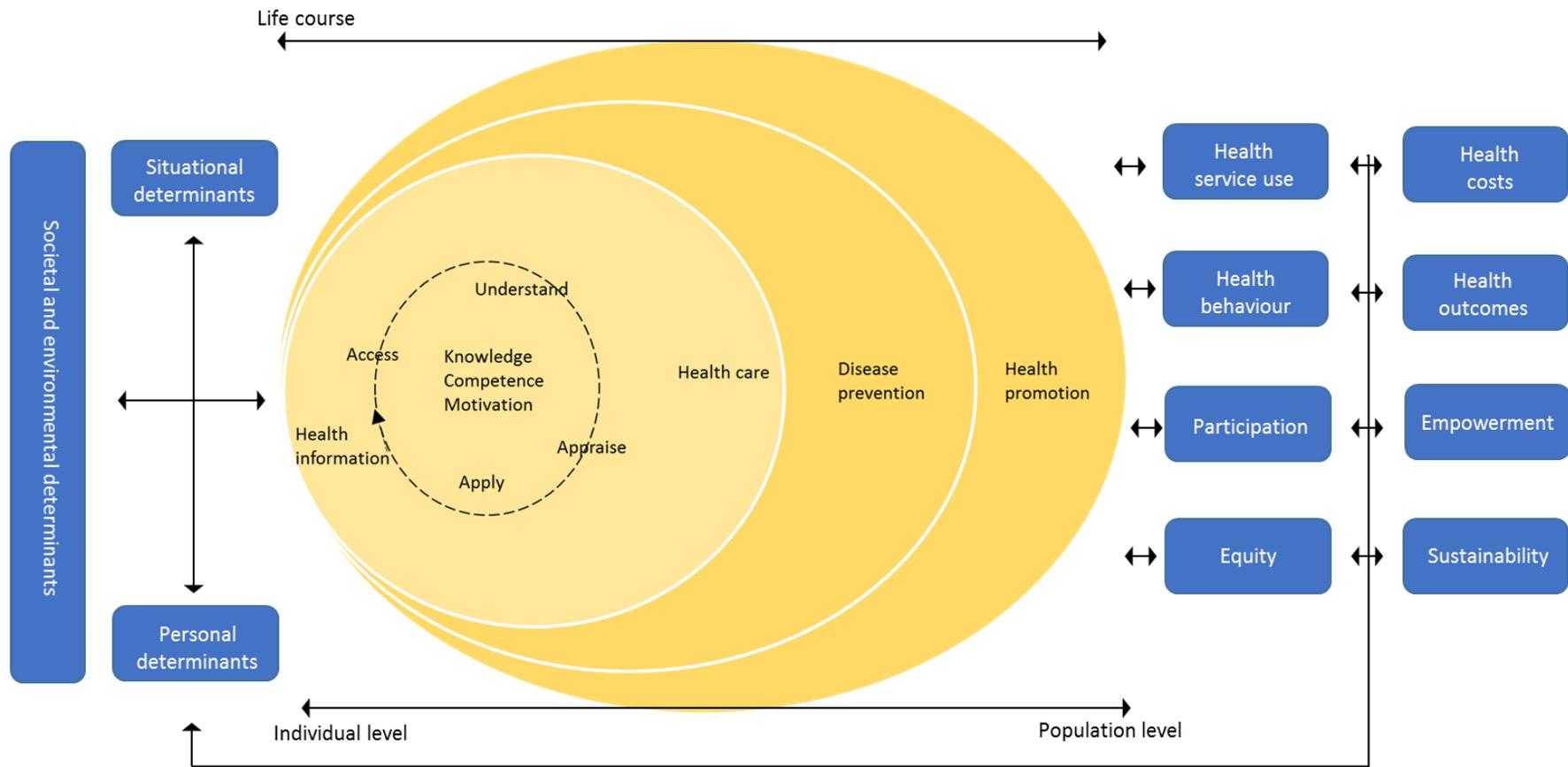
A recent integrative model (Figure 3.3) includes the above dimensions (relabelled) but also includes the varying contexts of health literacy application and the processual nature of health literacy over the life course. This model identifies knowledge and motivation as important elements in health literacy.²¹ In this sense, health literacy is internalised implying critical reflection on contexts, knowledge, and choices, in other words, "the capacity to contextualise health knowledge for his or her own good health, to decide on a certain action after a full appraisal of what that specific action means for them "in their own world" (Rubinelli et al., 2009, p. 309). The labels 'access', 'understand', 'appraise' and 'apply' are noted as incorporating the layers of functional, interactive and critical health literacy as proposed by Nutbeam (2000), while the three domains - healthcare, disease prevention, and health promotion - make explicit both individual and population influences in health literacy.

²¹ The inclusion of motivation as an affective dimension within the health literacy construct is debated by several researchers (Frisch et al., 2012; Peerson & Saunders, 2009).

The three domains are considered the contexts within which cognitive, psychosocial development, as well as previous and current experiences, influence individuals' health literacy. The influences of context and psychosocial development are particularly relevant to this thesis, also echoing the socio-cultural conceptualisations of health literacy (e.g., Adkins & Corus, 2009) and the cultural literacy/world-view dimensions of the conceptualisation proposed by Zarcadoolas et al. (2005). These antecedents of health literacy are 'loosely' divided in the model into personal and situational factors. Sørensen et al. (2012) add other constructs such as empowerment and sustainability as consequences of health literacy (refer Figure 3.3²²).

²² Use of this model is permitted according to the Creative Commons Attribution license that permits unrestricted use, distribution and reproduction in any medium, provided the original work is properly cited.

Figure 3.3 Integrative health literacy model
 (Source: Sørensen et al., 2012, p. 9)



While this model defines health literacy by integrating 12 dimensions²³ based on the literature, some observations are relevant here. First, the authors avoid labelling any of the 12 dimensions as explicitly critical despite many theorists acknowledging the importance of the health consumer being critical and reflexive; that is, an individual who is in “a conscious and rational state, involving continual monitoring and criticism based on a challenging approach that is itself reliant on knowledge” (Lupton, 1997, p. 380). It is worth noting that Chinn and McCarthy (2013) introduce aspects of information appraisal and individual autonomy in their AAHLS scale as additional factors in critical health literacy, emphasising the expansion of this evaluative dimension that is gaining increased research attention (refer Table 3.4). Second, while this model makes explicit that health literacy changes over an individual’s life course and their health contexts, there appears to be little consideration that health literacy may vary within an encounter and/or between encounters in similar contexts and at similar stages of the life course. Third, the emphasis of the model appears to remain on the internalised skills and competencies of the individual. However, literacy of all kinds is considered a social practice (e.g., Barton & Hamilton, 2000; Freire, 1970; Papen, 2009) shaped by power structures and, often, institutionalised systems of authority.

Within the broadened perspective of health literacy several factors - the changing patient-provider roles in healthcare decision-making, increased respect for patient autonomy, and the parallel trend of the democratisation of health (de Leeuw, 2012) - are important foci for deepening an understanding of the health literacy phenomenon. A further dimension Neal (2007) argues for is the inclusion of multiple stakeholders in a definition of health literacy; and, the corollary being to include those relationships and networks within the healthcare system that form part of health literacy will enable a just system shifting the responsibility away from the individual patient. These socially contextualised views of health literacy, paralleling the emergent examination of literacy as a practice embedded in social and cultural dimensions (Street, 2001), are given little exposure in Sørensen et al.’s integrative model.

²³ The 12 dimension have subsequently been reduced to 11 (refer Table 3.5, and refer Haun et al., 2014) as the dimension maintaining and promoting health did not receive sufficient agreement in further development of the taxonomy.

Finally, the integrative model does not address the [mis]-match between empowerment and literacy. Schulz and Nakamoto (2012a) hold that empowerment is the subjective experience that motivates action, while health literacy includes the abilities and skills to use the empowering motivation. They would not agree that high levels of health literacy expertise will lead to empowerment. Health literacy, in their conceptualisation, refers to the individual's capabilities to make health-related decisions and the capability to participate in the decision making; empowerment gives the consumers responsibility for the decisions. With the diverse perspectives and models that have developed health literacy is conceptually problematic.

3.5 Empirical research on the extended dimensions of health literacy

Much of the empirical research has relied on the functional measures of health literacy and their relationship with particular health outcomes. While conceptual frameworks have been developed from extensive and exhaustive reviews of existing definitions and others' conceptualisations, there is limited empirical research of the broadened conceptualisation of health literacy. In order to develop a better understanding of the extended dimensions, the researcher undertook a systematic review to identify only those empirical research studies that have used the expanded definitions of health literacy (that is, since Nutbeam's conceptualisation in 2000) and empirically related these measures to health-related outcomes.

The method involved:

1. Reviewing the definitional and conceptual framework articles cited in Sørensen et al. (2012).
2. Reviewing national commissioned 'state-of-play' reviews of health literacy research (e.g., Jochelson, 2008; scoping report of the Scottish Government, 2009).
3. Searching relevant databases (Web of Science, PubMed and PsycINFO) since 2000 with key words: health literacy, empirical research, health

knowledge, health empowerment, health judgment, and filtering out those studies focussed solely on functional health literacy. Google and Google Scholar were also searched for additional articles meeting the criteria.

Eligible studies: were written in English; involved health literacy empirical research; included the terms interactive or critical health literacy; and/or mentioned domains other than functional competences; and provided findings relevant to an extended conceptualisation of health literacy. Research studies were not included if they used measures that could be deemed to be measuring the extended conceptualisation of health literacy but were described by other terms. For example, Ownby et al. (2014) used a health knowledge scale, S. G. Smith et al. (2013) used a patient activation measure (PAM), and Mbuagbaw, Momnougui, Thabane, and Ongolo-Zogo (2014) used a health competence measurement tool (HCMT). Studies that were validating existing scales but not measuring relationships or associated elements were not included. One study was included that qualitatively evaluated health literacy dimensions and, indirectly, its association with related outcomes (Sykes et al., 2013).

This review found fifteen studies that met the criteria, with only three in the US (refer Table 3.4). The green shaded cells highlight the populations studied – 8 of the 15 studies sampled ill or at-risk (e.g., low socio-economic status) individuals. Six of the studies used qualitative methods. The far-right column (orange-shaded cells) summarises the findings. The majority of these studies found support for a positive relationship between the extended dimensions and social practices aspects of health literacy and individuals' engagement and involvement in their health management and decision making.

Table 3.4 Empirical studies reporting dimensions and relationships regarding extended health literacy

Author; Year; Country	Sample population	Research method	Respondents	Findings
1 Ishikawa, Takeuchi & Yano; 2008; Japan	Diabetes patients	Quantitative Self-report health literacy scale: functional (5 items), communicative (5 items), critical (4 items)	138 outpatients with Type 2 diabetes	Communicative and critical health literacy correlated with self-efficacy scores
2 Adkins & Corus; 2009; US	Low literate consumers Healthcare providers	Phenomenological interviews, observations, & field notes	23 participants: low literate consumers (n=10); free-health clinic staff (n=5); pharmacists (n=8)	Health literacy is socially constructed between consumers & healthcare providers.
3 S. K. Smith et al.; 2009; Australia	General population	Qualitative In-depth interviews, TOFHL & NVS Framework analysis	73 participants: lower education (n=41); University alumni (n=32)	Dimensions: skills and strategies in involvement; role of significant others; interaction with health professionals; & function of health information
4 Jordan et al.; 2010; Australia	Adult patients (over 18 yrs of age) General population	Qualitative Face-to-face & phone interviews Grounded theory analysis	48 participants: chronic disease (n=20); general population (n=14); emergency department patients (n=14).	Seven key abilities: knowing when to seek health information; knowing where to seek health information; verbal communication skills; assertiveness; literacy skills; capacity to process and retain information; & application skills.

Author; Year; Country	Sample population	Research method	Respondents	Findings
5 Rubin, Parmer, Freimuth, Kaley, & Okundaye; 2011; US	Adults (mean age 70.7 yrs)	Telephone conversation S-TOFLA, healthcare satisfaction, & self-efficacy	334 low SES adults in health literacy trial.	Measures interactive health literacy based on oral interaction. Oral-based health literacy affected health outcomes.
6 Camerini, Schulz, & Nakamoto; 2012; Europe	Fibromyalgia (FMS) patients	Quantitative Critical health literacy 10 multiple choice questions related to FMS, adapted empowerment scale, & self-report of self-management. Structural equation modelling	209 patients	Dimension of empowerment had large effect on health outcomes. Some effects of knowledge/health literacy and empowerment on health outcomes.
7 Diviani et al.; 2012; Europe	Parents of adolescents (14-16yr) regarding MMR vaccination decision	Quantitative Functional health literacy (3 questions), objective & perceived knowledge (9 T/F statements), empowerment (12 items across 4 dimensions), & information search behaviour (2 questions) Structural equation modelling	Proposal, no results reported	Proposed extended health empowerment model.

Author; Year; Country	Sample population	Research method	Respondents	Findings
8 Edwards, Wood, Davies, & Edwards, 2012; UK	Adult patients (aged 22-76) with a long term health condition	Qualitative & longitudinal. Three interviews over 9 months Analysis using framework approach	18 participants with long term condition, recruited from patient education programme	Five steps in a pathway model: building health knowledge, developing health literacy skills & practices, displaying health literacy actions, the production of informed options, & making an informed decision. Outcomes include: increased knowledge, active involvement in decision-making.
9 Massey et al.; 2012; US	Adolescents (aged 13-17 yrs)	Qualitative Focus groups & interviews Grounded theory analysis	12 focus groups, publicly insured, low-income adolescents (n=137), & 8 key-informant interviews with physicians	Five dimensions: navigating the system, rights and responsibilities, preventive care, information seeking; & patient-provider relationship.
10 Chinn & McCarthy; 2013; UK	General population	Quantitative 3 factors, 14 item self-report scale AAHLS Mixed administration methods	146 participants, mixed ethnicity	Functional - skills in using written health information; Communicative - skills in communicating with healthcare providers; Critical - skills in health information management and appraisal; - assertion of individual autonomy with regard to health.

Author; Year; Country	Sample population	Research method	Respondents	Findings
11 Jordan et al.; 2013; Australia	Adult patients Emergency & chronic illness	Quantitative HeLMS scale, 8 factors & 29 items	350 respondents: emergency department attendees (n= 238); individuals with a chronic condition (n=112)	Multidimensional understanding of health literacy including abilities and contextual factors.
12 Sykes et al.; 2013; UK	Database search since 1995 Policymakers & practitioners with interest in health literacy.	Literature analysis and in-depth interviews Theoretical & colloquial evolutionary concept analysis	8 practitioners 5 policy makers	Contextual variations in understanding. Critical health literacy: advanced personal skills; health knowledge; information skills; effective interaction between service; providers and users; informed decision making; and empowerment including political action.
13 van der Heide et al.; 2013; Europe	General population	Quantitative Face-to-face Survey (HLS-EU). Competences of accessing (13 items); understanding (11 items); appraising (12 items); applying (11 items).	925 Dutch adults	Domains of healthcare, disease prevention & health promotion. Perceived social status affected all health literacy competences. Mixed results on age and health literacy.

Author; Year; Country	Sample population	Research method	Respondents	Findings
14 Londono & Schulz; 2014; Europe	Asthma patients	Quantitative Self-administered Health literacy questions, scenario-based judgment skill tool, asthma control test, & self-management questions	80 patients (aged over 18) from medical offices Diagnosed with asthma	Judgment skills were related to health information use. Higher judgment skills meant patients: visit doctor more often when they experience problems; were more compliant with their control medicine; & made appointments more regularly with their physicians.
15 Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken; 2015; Europe	Chronic disease patients	Quantitative Dutch Functional Communicative & Critical Health Literacy Scale, Partners in Health scale, & Perceived Efficacy in Patient-Doctor interactions	1,341 Dutch adults on national panel of adults with chronic illness or disability	Communicative and critical health literacy significant in self-management of chronic disease & confidence in medical consultations.

3.5.1 Implications for extended health literacy dimensions

As health literacy definitions evolve to encompass the interactions between individual capabilities and healthcare providers, the healthcare system, and society, the constructs of individual control, empowerment, decision-making are being brought into the ambit of health literacy (Chinn & McCarthy, 2013; Sørensen et al., 2012). Consequently, recent quantitative health literacy measures have sought to develop a better linkage between the items being measured and these wider definitions of health literacy.

The pre-understandings of this thesis come from a broad array of literature. Health literacy is not a simple construct but a complex multi-dimensional phenomenon. Table 3.5 summarises three key categories of health literacy dimensions that have provided critical pre-understandings for this thesis and research direction. Schulz and Nakamoto (2012b) emphasise that while individuals shift between these dimensions this does not necessarily imply a hierarchical or superior relationship between them. Moreover, Schulz and Nakamoto alert researchers to appreciating health literacy as more than knowledge elements by introducing aspects of empowerment and motivation. Thus, these researchers question the assumption that empowerment and health literacy go hand-in-hand, that individuals who are health literate are also (and always) empowered and motivated to act on their knowledge. This notion presents important pre-understandings; first, to consider health literacy as a construct independent, yet connected to empowerment, and second, that a multitude of factors can influence health literacy making it a dynamic and variable phenomenon.

Table 3.5 Comparison of health literacy dimensions

Schulz & Nakamoto, 2012a,b	Sørensen et al., 2012 (11 dimensions)	Osborne et al., 2013 (9 domains)
Declarative knowledge	<p>Able to perform basic reading literacy.</p> <p>Able to derive meaning from information - comprehension.</p> <p>Able to perform basic numerical and arithmetical tasks - numeracy.</p>	<p>Understanding health information well enough to know what to do.</p> <p>Having sufficient information to manage my health.</p>
Procedural knowledge	<p>Able to communicate on health matters - interaction.</p> <p>Able to find health related information - information seeking.</p> <p>Able to use process or act on health information and apply new information to changing circumstances.</p> <p>Skill to navigate in society and in health systems to manage one's health needs.</p>	<p>Feeling understood and supported by healthcare providers.</p> <p>Ability to actively engage with healthcare providers.</p> <p>Navigating the health system.</p> <p>Ability to find good quality health information.</p>
Judgment skills	<p>Able to make sound health-related decisions and informed choices.</p>	<p>Appraisal of health information.</p>
-Integration of knowledge	<p>Able to take responsibility for one's health.</p>	<p>Actively managing my health.</p>
-Adaptation to changes in knowledge	<p>Able to filter, interpret, and evaluate information.</p> <p>Confidence (self-efficacy) to take action to improve personal and community health.</p>	<p>Social support for health.</p>

3.6 Health literacy in New Zealand

Since this hermeneutic research is set in the New Zealand context, it is important to review the national perspectives and scholarship regarding health literacy. At a national governmental level, the New Zealand Ministry of Health defines health literacy “as the ability to obtain, process, and understand basic health information and services in order to make informed and appropriate health decisions” (Ministry of Health, 2010a). Other national bodies, such as the Health Navigator website (healthliteracy.org.nz) and the NZ Tertiary Education Commission, also define health literacy as functional skills needed in a health setting.

A recent international review noted that New Zealand government policy does not expressly use the term health literacy although many of the policies appear to embed aspects of health literacy (Pleasant, 2013). Ministry of Health requests for research proposals are requiring health literacy to be addressed, considered by the review participants as evidence of an increasing awareness of health literacy among people in the New Zealand health sector. A 2010 report on the Adult Literacy and Lifeskills Survey concluded that 80% of Māori males and 75% of Māori females have poor health literacy skills, insufficient to cope with the demands that they face. Although Māori were found to have much poorer health literacy than non-Māori, approximately half of all New Zealand adults are assessed to have low health literacy (Ministry of Health, 2010a).

New Zealand-specific health literacy research to date has focussed on health literacy of at-risk segments of the population - either by virtue of their ethnicity (particularly Māori and other Pacific Peoples) or illness risk. For example, one study is focussing on cardiovascular disease and health literacy regarding appropriate medicine among New Zealand and Canadian indigenous people (Principal investigator, Dr S. Crengle, University of Auckland); and, at least three projects are focussing on the Māori population and health literacy among different at-risk groups/illness categories – namely, gout (older Māori men), skin infections (children under 14 years of age), and diabetes in pregnancy (mothers under 25 years of age) (refer Ministry of Health, 2012b and Pleasant, 2013). Other NZ

initiatives include the Health Navigator and Workbase websites²⁴ (and a health literacy website, www.healthliteracy.org.nz) that emphasise health literacy as an understanding of educational materials related to health.

The concept of health literacy is relatively new to New Zealand (New Zealand Guidelines Group, 2011a). However, health literacy has been the focus of a systematic literature review regarding rheumatic fever. Rheumatic fever rates in NZ are comparable to those of developing countries and there are widening and significant ethnic disparities in the incidence of the disease (NZ Guidelines Group, 2011b). In addition, health literacy has been investigated in relation to medications safety (New Zealand Guidelines Group, 2011a); “Attention to health literacy with respect to medication safety, beyond provision of written resources and dedicated websites, is rare” (p. 5) and this report called for NZ-specific research on effective interventions to improve health literacy. Improvements to knowledge generally comprised written materials.

Six health literacy intervention initiatives have been identified within New Zealand (excluding research projects noted above): cultural competence training for healthcare practitioners and health professional bodies (run by Mauri Ora Associates for the Ministry of Health); private pharmacist-led initiatives to address low health literacy in their community; District Health Board funding of pharmacists to train identified at-risk patients in self-management of their condition; a Workbase initiative to establish a website to raise awareness of health literacy among healthcare providers and healthcare organisations; health education for Community/Māori Health Workers; and, a shift away from solely written materials by the New Zealand Heart Foundation.

The Midlands health region of New Zealand has an on-going research project studying health literacy needs among patients with diabetes and cardiovascular disease (Hunter & Franken, 2012). This research diverts from the reading and writing skills focus of other national work, approaching health literacy as a “...complex cognitive, social, cultural and affective challenge[s] for patients at

²⁴ <http://www.healthnavigator.org.nz>; <http://www.workbase.org.nz/>

multiple levels...” (p. 27). Phase 1 of the research reports the analysis of information texts collected from the medical practices in the region and a survey of those practices’ medical staff, recommending the need for improved language and literacy skills among patients and emphasising the complexity of effective health communication. Nevertheless, the “dominant discourse of individual responsibility remains” (Hunter & Franken, 2012, p. 37).

The prevailing health literacy perspective in New Zealand is that health literacy concerns functional skills in a health setting, that health literacy is viewed from a deficit perspective, and that health literacy is an individual responsibility. This perspective results in initiatives focussed on educational processes for individuals as patients in order to encourage improved functional skill levels to be applied in health situations. In parallel, professional development training for health professionals emphasises identifying low levels of functional health literacy. Therefore, there are clear research and intervention efforts in the field occurring in New Zealand but there is little evidence yet of a cohesive group of scholars and policy makers adopting an asset-based perspective that acknowledges the complex social practices as integral to health literacy.

3.7 Emergent health literacy research issues

Existing health literacy measures based on functional health literacy skills (ability to apply basic reading and numeracy skills for a healthcare setting) have been criticised for lacking a sound conceptual base and leaving fundamental elements under-researched (Pleasant et al., 2011). In addition, recent attempts to develop survey scales that capture the multi-dimensional aspects of health literacy beyond functional skills have had limited success (Chinn & McCarthy, 2013; Frisch et al., 2012). As the concept expands beyond just individual skills and competences to include broader notions of, for example, social and political action, a fundamental issue is the problem of bounding such a concept for research purposes given its highly subjective and dynamic nature. Recognising these difficulties, one conclusion is that research is needed on health literacy as a phenomenon encompassing the abilities of individuals, the abilities of multiple actors in an individual’s health context, and their relational and contextual experiences

(Martensson & Hensing, 2012; Pleasant & McKinney, 2011; Pleasant et al., 2011; Rudd et al., 2012).

At the core of health literacy is “patients’ capability of making good health-related decisions, or of participating strongly in this decision making” (Schulz & Nakamoto, 2012a, p. 4) emphasising an active, dynamic, and negotiated component to health literacy that influences an individual’s health and well-being (Kickbusch, Wait, & Maag, 2005). The prevailing emphasis in the health literacy research is on the individual’s capabilities regarding health literacy and, often separately, on the health practitioners’ (or health promotion advocates’) responses regarding these capabilities. Nevertheless, health literacy is situated in a complex and networked environment.

Recent work emphasises health literacy as a shared responsibility between individuals and society where healthcare professionals are significant agents in an individual’s health decisions and where health literacy is a dynamic relational phenomenon within an individuals’ everyday health (Martensson & Hensing, 2012; Neal, 2007). Kelly and Haidet (2007) suggested that discordance in estimation of a patient’s literacy level can lead to disparities in healthcare. This is one of the few empirical works on the relational dimensions of health literacy and there remains a need for research that captures the richness and broadness of skills and their interplay within the health literacy environment. Furthermore, with changing roles and expectations of healthcare consumers, approaches to health literacy must extend beyond an emphasis on individual skills. For example, research on contextual factors conducive to improving health literacy environments across different patient-consumer groups would improve the conceptualisation of the broadened notion of health literacy.

In the health context, authority has traditionally rested with the health practitioners as they have held both the information and the power of information dissemination to patients. Changing patient-provider roles in healthcare decision-making and increased respect for patient autonomy mean healthcare professionals “...serving sophisticated, health-literate communities may have to adjust to a very different relationship...” (Begoray et al., 2012, p. 160). Despite the significance of

healthcare professionals in patient health literacy, the majority of research in this field has focussed on patients' health literacy capabilities within the patient-provider relationship and healthcare communication. Health literacy has typically been conceptualised as an individual level construct, side-lining healthcare system factors and healthcare professionals' roles in health literacy.

The need to incorporate and evaluate the health literacy of health systems and health professionals in health literacy frameworks was an area of strong consensus in the findings of Pleasant and McKinney's (2011) empirical research. However, there remains a gap in the conceptualisation of health literacy regarding the role of healthcare professionals and the health system. Moreover, there is a gap in how health literacy is conceptualised between health practitioners, policy makers and researchers (Sykes et al., 2013). Sørensen (2013, p. 203) notes that although her integrated definition and conceptual framework for health literacy were based on thorough reviews of literature, that research did not involve the active participation of any citizens, patients, or health professionals. This thesis addresses these gaps by including two key stakeholder groups in health literacy - the patient-consumers and primary healthcare professionals - in the one piece of research.

In addition to the limited research incorporating patient-provider roles in health literacy, the phenomenon of health literacy within a community of healthy individuals is under-researched. Furthermore, few studies have investigated healthy populations defined according to socio-cultural characteristics (refer Table 3.4). Earlier, this thesis provided the justification for researching health literacy among New Zealand baby boomers (refer Chapter 2) as a socio-cultural and age-defined segment of the population for whom health is a key concern (Buckland, 2009).

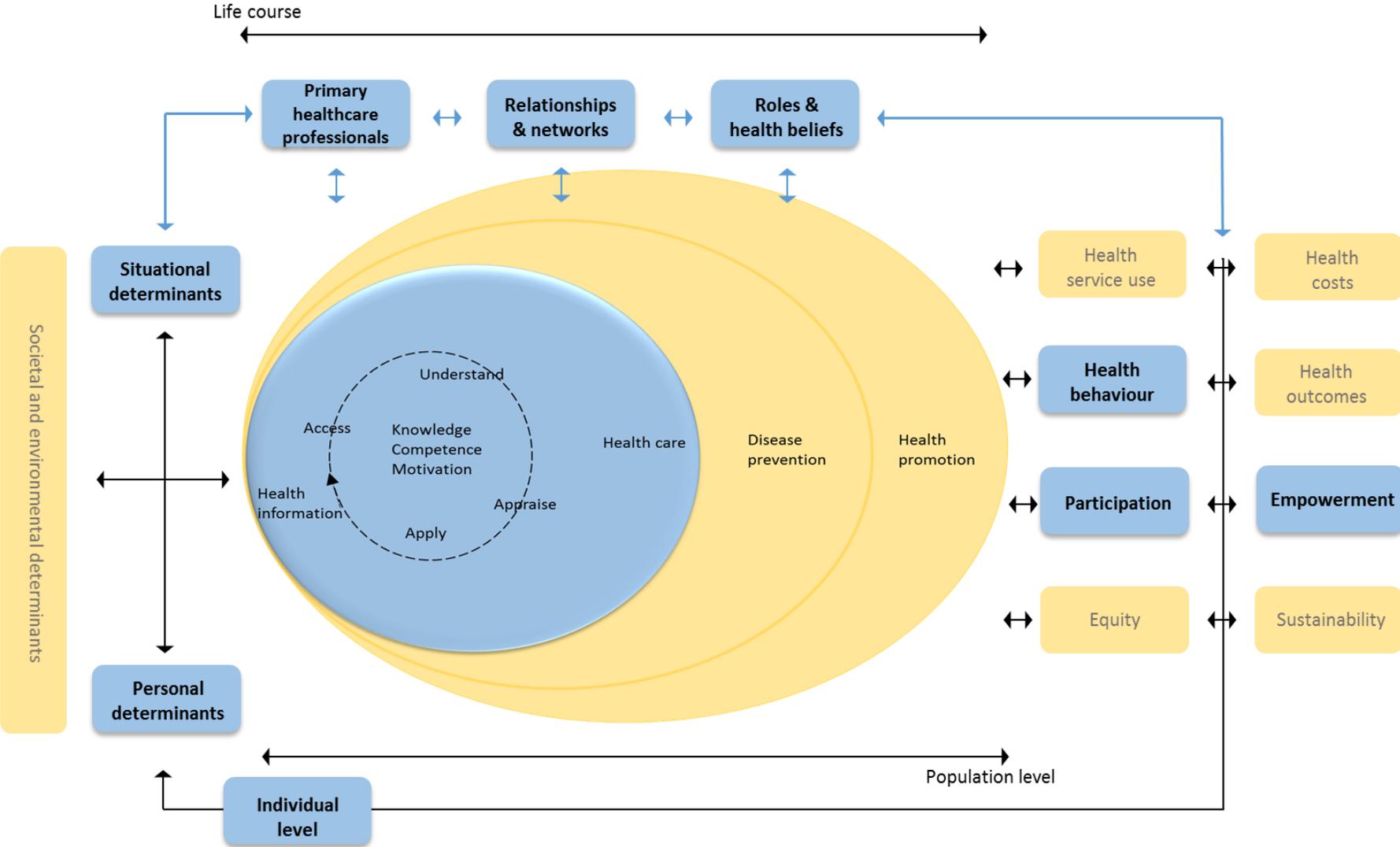
Considerable research has approached health literacy from a perspective of health communication and public health promotion, yet network influences on health literacy and vice versa have been largely unexamined. Theorising on health literacy has paid scant attention to the 'politicisation' of health literacy. Sykes et al. (2013) research on critical health literacy is an initial attempt at considering

health literacy within the institutional structures of health. This thesis seeks to extend the theorising around health literacy into the relationship and network contexts exploring health literacy as a social practice. In doing this, it responds to the call by Chinn and McCarthy (2013) for more qualitative research in the field acknowledging, along with landmark reports and prominent researchers (Institute of Medicine, 2004; Zarcadoolas, Pleasant, & Greer, 2005), that health literacy has “moved from a narrow conceptual focus on patient literacy skills such as reading to being a far more multidimensional construct where patient skills or abilities interact with education, health, social and cultural influences” (Jordan, Buchbinder, & Osborne, 2010, p. 36).

3.7.1 Proposed health literacy framework

The conceptual framework illustrated in Figure 3.4 adapts Sørensen et al.’s (2012) model and identifies key concepts that are central to this research in order to add further understanding of the phenomenon of health literacy. By emphasising these foci (the blue highlighted shapes of Figure 3.4) this schematic combines multiple dimensions of health literacy with multiple, interdependent factors that influence and are influenced by health literacy. This framework provides a key pre-understanding for the thesis, emphasising elements of Sørensen et al.’s model as well as specifying new aspects.

Figure 3.4 Emerging health literacy issues and proposed conceptual framework



An important dimension is how patient-consumers enact health literacy. As well as being recipients of knowledge within the relational context of their personal healthcare context and within the broader social-political context of institutions and systems of social order, the patient-consumer can be an active, dynamic, and engaged participant. This framework highlights these roles and health beliefs at the same time highlighting Sørensen et al.'s (2012) original terms of health behaviour, participation, and empowerment in operationalising this dimension (also refer to Table 3.5).

A skills view of health literacy is too constraining since, *inter alia*, it tends to presuppose that reading and understanding are synonymous. Oral literacy should be included as part of the health literacy experience. In addition, there is a difference between understanding of text or oral communication and the willingness or ability to act on it, although both are within the ambit of health literacy. Therefore, this framework does not include preconditions that health literacy is dependent on functional skills. The patient's active construction of meaning in a health context may not rely on reading skills, nor should their resistance of a particular health view be interpreted as a result of low literacy or poor language skills.

Logical reasoning, critical evaluation, information appraisal, reflective reasoning in a health context, may not be directly related to functional literacy skill levels. For example, people in oral societies have been found to exhibit logical reasoning, historical consciousness, scepticism, differentiation, and complex organisation features often reserved for literate societies (Brandt & Clinton, 2002; Olson & Torrance, 1991). Mbuagbaw et al. (2014) argue for a new health literacy scale (health competence) that moves away from a reliance on reading ability and incorporates oral, auditive, and visual information related to health. This supports the argument against the binary distinction that "literate people were more cognitively advanced than non-literate people" as challenged by Street (1984). In developing the social-practice perspective of literacy, Street argued that social context organises literacy, that literacy is "a delicate interplay of social, cultural, economic, political, and even geographic forces" (Brandt & Clinton, 2002, p. 340). These theorists argue for literacy to be understood as a form of social participation

that is highly contextual; “what literacy does to you depends on what you do with it” (Brandt & Clinton, 2002, p. 340.) The cognitive effects of literacy depend on the settings in which it is learned (Scribner & Cole, 1981) and literacy cannot be extricated from the structures of power within which it operates (Street, 1984).

Although certain health literacy conceptualisations acknowledge that individual health decision-making is significantly influenced by social systems and structures, few models make explicit the behaviours, roles, and values within social structures and institutions of healthcare. Figure 3.4 highlights primary healthcare professionals as a focus in health literacy conceptualisation. In many definitions of health literacy there are underlying issues of influence and compliance and public good. Maintaining healthcare professional expertise and authority is deeply embedded in today’s health and social systems. Therefore, it is important that this is made explicit in any deepening understanding of health literacy. The figure is also explicit in adding relationships, networks, roles, and health beliefs to the integrative conceptual framework of Sørensen et al (2012).

This conceptual framework views health literacy as part of a social practice that is always situated in the context of the individual, the individual’s personal health context, and the social-political context. This model therefore makes explicit the contextual, network, and institutional dimensions of health literacy. A further consideration is that health literacy is continuously variable depending on these factors and the interdependence of the context with individual and relational dimensions – that is health literacy, individual attributes, and contexts are continually shaping, and shaped by, the other factors. Lupton (1997) argues that patients do not always act rationally within the context of a health encounter, “people may pursue both the ideal type consumerist and the passive patient subject position simultaneously or variously depending on the context” (p. 373). At the same time, there may be constraints on the health literate individual from within the healthcare structures, and relationships.

This thesis takes an interpretive approach, using this adapted conceptual framework to further understand health literacy as a phenomenon.

3.7.2 Thesis question

The purpose of this study is to elucidate the dimensions of health literacy within the context of New Zealand baby boomers. This purpose can be stated in the form of the following research question:

How are the roles and practices of health literacy perceived/constructed and performed in primary healthcare?

To examine this research question the following more specific questions are used:

1. How do New Zealand Baby Boomers experience and practice health literacy? Specifically,
 - how do Baby Boomers as primary healthcare patients perceive their behaviours, roles, and relationships regarding health literacy?
2. How do primary healthcare professionals (PHCPs) practice health literacy? Specifically,
 - how do PHCPs perceive their behaviours in relation to health literacy and baby boomers?

In interpretive research enquiries the research questions often remain appropriately at a high level. The development of research questions is however a fundamental step in undertaking research, informed by the relevant literatures and aligning with the methodological foundations and the research methods and procedures selected (Yin, 2003).

3.8 Summary

The Ottawa Charter for Health Promotion (WHO, 1986) describes “Health as a resource for living, not the objective of living – the goal of health promotion activity is not therefore to produce behaviour changes in a particular direction but to help people to be as healthy as they wish to be” (Wills, 2010, p. 64). The traditional authoritative and paternalistic view was of healthcare experts defining

the desired behaviour outcome and imparting information to communities and individuals deemed to require interventions. However, the growing democratisation of health has seen a social construction of health literacy that encompasses multiple, interdependent, and dynamic dimensions. At the same time, the healthcare sector is being challenged to provide more effective and appropriate healthcare.

Having reviewed the literature on health literacy, this chapter describes the polarised views of literacy, between literacy in a health context to health literacy as individual assets and decision making competences. The key pre-understandings taken from this literature review are summarised in Table 3.5 and Figure 3.4. The lack of universal agreement over definitions and conceptual frameworks leads to the conclusion that qualitative research is needed on how individuals experience health literacy. The contextual and dynamic characteristics of health literacy are under-researched. In particular, the literature review concludes that there is a significant gap regarding the interrelationships between individuals' and primary healthcare professionals' health beliefs and expectations regarding health literacy. This chapter locates the research in the area of health literacy, a complex, socially-constructed phenomenon. The following chapter, Chapter 4 Methodology & Method, develops the methodological foundations and the hermeneutic method of this thesis.

Chapter 4

Research Methodology and Method

4.1 Introduction

Based on a review of the literature, the previous chapter proposes a health literacy conceptual framework that combines multiple dimensions of health literacy with multiple, interdependent factors. This framework makes explicit the relational dimensions of health literacy within the larger social order structure and institutional arrangements. From this perspective health literacy is co-created and dynamic. This thesis investigates the phenomenon of health literacy by exploring the negotiated experiences of health literacy between patient-consumers and primary healthcare professionals. Therefore it is appropriate to adopt a qualitative, interpretive methodology.

The ontological and epistemological assumptions of any research and the chosen methodology have a profound influence on the research and its outcomes. Ontology is what (who) is known, what is the form of reality (how do things exist), and what is out there to know (Guba & Lincoln, 1994). Blaikie describes epistemology as “the possible ways of gaining knowledge of social reality, whatever it is understood to be. In short, claims about how what is assumed to exist can be known” (2000, p. 8). When a particular philosophical perspective is declared and understood, the research methods are intelligible and the research interpretations plausible (Gadamer, 1989):

Our constructions of the world, our values, and our ideas about how to inquire into those constructions, are mutually self-reinforcing. We conduct inquiry via a particular paradigm because it embodies assumptions about the world that we believe and values that we hold, and because we hold those assumptions and values we conduct inquiry according to the precepts of that paradigm. (Schwandt, 1989, p. 399)

There is a wide selection of research paradigms and hierarchies that explain and frame the philosophical perspectives that are fundamental to all research. For example, Guba and Lincoln (1994, p. 106) describe the different belief systems under four categories: positivism, post-positivism, critical theory and constructivism; Cavana, Delahaye, and Sekaran (2001) describe three: positivist, interpretivist, and critical; Creswell (2009) describes post-positivism, constructivism, advocacy/participatory and pragmatism; and Burrell and Morgan (1979) specify radical humanism, interpretivism, functionalism and radical structuralism. This latter framework makes explicit one of the underlying contrasts of philosophical perspectives – that of objectivity versus subjectivity that distinguishes (respectively) for example positivists from interpretivists. However, such dichotomous frameworks may be more misleading than helpful (e.g., Deetz, 1996; Reed, 1997; Wilmott, 1993) and exclusivity of these paradigms may hinder creative ways of understanding (Pozzebon, 2004) such that theoretical perspectives are more usefully considered on a continuum (Carson, Gilmore, Perry, & Gronhaug, 2001).

The objectivist approach assumes a realist ontology, in that social reality exists independent of the cognition of the individual. Objectivists adopt a positivist epistemology aiming to uncover universal laws and causal relationships. Using a nomothetic approach to methodology objectivists focus on developing and testing hypotheses concerning causal relationships using quantitative techniques (Burrell & Morgan, 1979; Crotty, 1998).

Subjectivists try to understand the world by an empathic appreciation of those individuals living in the world, assuming that social reality arises out of the interaction of individuals in their situation-specific context(s) (Burrell & Morgan, 1979; Crotty, 1998). Subjectivists adopt a relativist epistemology and an ideographic methodology as they are “concerned with an understanding of the way in which the individual creates, modifies and interprets the world” (Burrell & Morgan, 1979, p. 3).

Theoretical frameworks emerge from these research paradigms according to certain philosophical assumptions. Therefore, this chapter explains and justifies the ontological and epistemological assumptions underpinning this research (an interpretivist ontology and a social constructivist epistemology) and how these support the chosen hermeneutic methodology and the specific research methods. The hermeneutic methodology requires a fore-grounding which prepares the researcher to enter the hermeneutic circle and engage with the text. Part of this preparation involves becoming acquainted with the existing research and literature on the topic (refer Chapters 2 and 3) but also requires the researcher to declare and explain the ontological and epistemological perspectives taken. The first section of this chapter covers these ontological and epistemological assumptions that situate the thesis in interpretivism. As well as a philosophical approach to understanding, hermeneutics is also a method of analysis; the key concepts of hermeneutics as a method - the hermeneutic meaning of text, hermeneutic circle, pre-understandings, and fusion of horizons - are explained. The research method (section 4.6) outlines the detailed processes and techniques of data collection and the method of analysis (section 4.8) describes the process of hermeneutic interpretation used to reach new meanings.

4.2 Ontology

The ontological position in this thesis is that there is no single social reality that can be discovered. Truth is socially and context-sensitive, “a construction that refers to a particular belief system held in a particular context” (Carson et al., 2001, p. 16). Social reality is constructed in social relationships and individuals’ perceptions; the social world cannot exist outside the perceptions and minds of the actors (Burrell & Morgan, 1979) and how meaning is interpreted.

There are many constructed realities (e.g., Guba & Lincoln, 1994; Schwandt, 1994) and although there will be shared realities and “multiple ‘knowledges’” (Guba & Lincoln, 1994, p. 113) among individuals, societies, and cultures, no single reality is right. As humans, our social realities are always changing; we make sense of the world we engage in through interpreting what we find; our interpretations are shaped by our social, cultural, and historical perspectives.

Therefore, this thesis takes an interpretivist ontology where there are no universal truths to be discovered but rather theories and frameworks that can be appropriate to research problems and contexts. Within this perspective a researcher brings his/her prior knowledge and socio-cultural experiences to the enquiry since they cannot be separated from the research endeavour. From this ontological position, research inquiry of the social world is value-laden and interpretation within this paradigm is to understand the subjective meaning of social action, acknowledging that reality is 'always-already-interpreted' (Altheide & Johnson, 2011; Denzin & Lincoln, 2008). Wendt's translation of Hu's statement is that, "The world of human beings is a world of meanings which is always already interpreted" (Wendt, 2002, p. 286).

Interpretivism, according to Hay (2011), is notable for its focus on the inter-subjective nature of meanings and "...the social origins of the beliefs and understandings that inform our actions and the practices to which they give rise" (p. 170). The interpretivist assumption is that these traditions - "...open-ended and dynamic, evolving ..." (p. 170) - are part of individuals' social reality(ies), influencing how they make sense of their experiences (note the parallels to the term 'horizons' in hermeneutics, refer Section 4.5.4). Interpretivist inquiry aims to "capture[s] the actual meanings and interpretations that actors subjectively ascribe to phenomena...through investigating how they experience, sustain, articulate and share with others these socially constituted everyday realities" (Johnson, Cassell, Buehring, & Symon, 2006, p. 132).

This research project explores the negotiated experiences of health literacy and therefore is deliberately placed within this interpretivist ontology. An interpretive research inquiry describes events in real-life contexts through the use of "thick descriptions of members' talk...in specific settings" (Gephart, 2004, p. 457) in order to understand the meanings that those involved ascribe to events and phenomena. An interpretivist ontology also appropriately addresses the requirement to focus on the context and social situations of the actors in this research purpose, since both actors and context are fundamental to the thesis' question. "Ontologically no assumptions are made about what is and is not real - descriptions of phenomena begin with people's experiences of them" (Leitch, Hill,

& Harrison, 2010, p. 73) with the aim to “...develop ‘bottom-up’ interpretive theories...inextricably ‘grounded’ in the lived-world” (Cope, 2005, p. 167).

4.3 Epistemology

A researcher’s predominant ontological position influences ‘how one can know things’ or the epistemology. The interpretivist ontology of this research is supported by a social constructivist epistemology, that things are known by the contextual detail of informants’ construction of their worlds, in particular, that reality is socially constructed (e.g., Berger & Luckmann, 1967; Bruner, 1986; Holstein & Gubrium, 2011; Schwandt, 1994; Vygotsky, 1978). Despite varied interpretations of constructivism (some theorists differentiate collectivism, constructionism, social constructivism/ionism) Guba and Lincoln (2001, p. 1) define it as: “...transactional subjectivism, that is, that assertions about “reality” and “truth” depend solely on the meaning sets (information) and degree of sophistication available to the individuals and audiences engaged in forming those assertions”. Charreire-Petit and Huault (2008, p. 77), citing Gergen (1999) and Schwandt (1994), describe constructivists as maintaining that “what we view as objective knowledge and truth is nothing more than the result of a specific perspective”.

Although a detailed discussion of constructivism versus constructionism (refer Crotty, 1998; Talja, Tuominen, & Savolainen, 2005) is not appropriate here, Schwandt (1994) describes a social constructionism approach as that which looks beyond the meaning-making of an individual to the collective generation of meaning (1994, p. 127). For example, Mir and Watson (2000) argue that the epistemology of constructivism, especially social constructivism, is a useful perspective for understanding the lives of organisation members. Social constructivism or constructionism (for example, Crotty, 1998, labels this *constructionism* as a way of separating this epistemology from the subject-centred *constructivism* associated with Vygotsky) holds that we understand our world through our socially-constructed knowledge. Therefore this epistemology purposefully focusses on those elements that subject-centred constructivists tend to set aside as context and circumstance. Whatever the terms are, the distinction is

an important one having a long history from Hegel and Marx through to Mannheim (1936), and Berger and Luckmann (1967). From this position, “When we describe something we are reporting how something is seen and reacted to, and meaningfully constructed within a given community or set of communities” (Crotty, 1998, p. 64). At the same time, social constructionism does not restrict reality to what is in the mind, acknowledging that there are objects that are real but that are also socially constructed. “Social constructionism is at once realist and relativist” (Crotty, 1998, p. 63). In the present research, the term *social constructivism* will be used to refer to this epistemological position.

The epistemology of social constructivism, and the position taken in this thesis, is that “...the world we live in and our place in it are not simply and evidently ‘there’, but rather variably brought into being” (Holstein & Gubrium, 2011, p. 341). Constructivists hold that social phenomena develop in particular social contexts. Since “...all meaningful reality...is contingent upon human practices, being constructed in and out of interaction between human beings and their world...” (Crotty, 1998, p. 42), the socially constructed reality created by individuals and groups is ever evolving as social interactions occur (these views are associated with Bruner, 1986, Gergen, 1999, and Vygotsky, 1978). This is often termed “the socially constructed character of lived realities” (Holstein & Gubrium, 2011, p. 341) acknowledging the central role of societal conventions, history, and interaction with significant others in the construction of meaning and knowledge. Language and discourse is fundamental to how individuals frame the way they experience the world and to their social constructions. Language continually mediates individuals’ lived experiences and their socialisation with significant others such that, “[this] conversational apparatus...ongoingly maintains, modifies and reconstructs his[sic] subjective reality” (Berger & Luckmann, 1967, p. 172).

This research inquiry appropriately included an examination of the social, cultural, economic, and political contexts (refer Chapter 2). Such contextual, processual, and structural forces are not a limitation to useful theorising (Welch, Piekkari, Plakoyiannaki, & Paavilainen-Mantymaki, 2011). The social constructivist epistemology acknowledges that life is constructed via shared meanings (Hay,

2011; Mir & Watson, 2000), accepting that "...a policy process entails a collective action problem, critically dependent on the relationship between agency and structure, and whereby a variety of actors and a complex structure come together...and, by participating in the socialization process, agency becomes incrementally institutionalized" (Pozzebon, 2004, p. 263).

Epistemologically, constructivism also emphasises the subjective interrelationship between the researcher and participant, and the co-construction of meaning. Researchers, in their "humanness," are part of the research endeavour rather than objective observers, and their values must be acknowledged by themselves and by their readers as an inevitable part of the outcome (Guba & Lincoln, 1989). The researcher is part of the process of 'coming to know' which does not mean forsaking objectivity but that reflection and relationality to the research process allows a researcher to appreciate the limitations of social inquiry (Alvesson & Deetz, 2000; Bradbury & Bergmann-Lichtenstein, 2000; Schon, 1983). Finally then, "epistemological constructivism does not call into question reality as such" (Wendt, 2002, p. 285) but emphasises the social dimension of knowledge.

Consistent with the philosophical and theoretical perspectives of interpretivism and social constructivism, this research enquiry adopts a hermeneutic methodology.

4.4 Hermeneutics theory

Hermeneutics, defined as the theory of interpretation, occupies "both an epistemological and methodological space" (Prasad, 2002, p. 29) as a philosophy and method of interpretation. While originally the rules and principles of hermeneutics were applied particularly to text, they have become used also for interpreting human behaviour, practices, events, and situations (Crotty, 1998; Leonard, 1989). Applying a hermeneutic methodology demands an understanding of the philosophical concepts and then acknowledgement of consequent obligations for the methodology. This section outlines the philosophical concepts of hermeneutics theory and Section 4.5 explains the key elements of hermeneutics as a methodology.

Three main perspectives can be identified within hermeneutics. These are the objectivist approaches following Schleiermacher (2002) and Dilthey (1976), the subjectivist approach following Heidegger (1967) and Gadamer (1989), and critical hermeneutics combining interpretation of text with critical reflection (Ricoeur, 1974a). The following section explains these three different perspectives within hermeneutics and the fundamental elements of philosophical hermeneutics.

4.4.1 Objectivist approach to hermeneutics

Under the objectivist approach hermeneutics seeks to reconstruct the original meaning of a text as intended by the author (Bleicher, 1980; Connolly & Keutner, 1988). Both Dilthey (1976) and Schleiermacher (2002) consider the process of interpretation the inverse of the process of creation as the interpreter systematically brings to consciousness the author's meaning. Understanding therefore is a process of exploring the only meaning of the expression. The objectivists believe that the "meaning of the text is an objective fact, something which in principle could be discovered once and for all" (Connolly & Keutner, 1988, p. 14) in a uniquely correct interpretation corresponding to the unique authorial intention. Schleiermacher considers this to have two aspects - grammatical understanding of the words of the text and the psychological aspect of understanding the author's intention.

Speech and texts, according to Betti (1980), are objectified representations of human intentions which, along with actions, are expressions of meaning (Crotty, 1998). The intentionalism of the text is achieved through a system of interpretative rules, providing for a unity of procedure in bringing to light the meaning of the text (Schleiermacher, 2002). Through reliving the author's experience, objectivists can claim understanding and in this way the meaning of the text is removed from the contemporary world of the interpreter. However, Dilthey also maintained that the interpreter must understand the text in its social and historical context moving back and forth between the author's context and the text (Crotty, 1998; Prasad, 2002). This has connotations of the concept of the

hermeneutic circle, which is that the text can only be understood by the interpreter iteratively moving between the parts and the whole; the understanding of the whole and the parts are mutually interdependent and interpretation is considered as an interminable process never coming to an end (Bleicher, 1980).

The objectivist approach to hermeneutics also assumes that the interpreter can set aside his/her prior knowledge and judgements through the process of bracketing (a term used by Husserl, 1931 as cited in LeVasseur, 2003) so that attention is shifted to the essence of the phenomenon being interpreted (Lavery, 2003; LeVasseur, 2003). Given this subject (interpreter)-object (text) dichotomy, the true character of the phenomenon can be seen.

4.4.2 Subjectivist approach to hermeneutics

Gadamer (1989) and Heidegger (1967) took a subjectivist hermeneutic approach that does not subscribe to the subject-object dichotomy of the objectivists. Gadamer, in expanding Heidegger's views, maintained that there can be no elimination of pre-conceptions or prejudice as the researcher is an involved actor in every research or interpretation process. Understanding is achieved through language and openness to the perspective of others; "knowledge of our everyday existence is inter-subjective, temporal and relational" (Vandermause & Fleming, 2011, p. 369). Subjectivists place pre-understandings as a central element in interpretation in maintaining that all understanding proceeds from what precedes it - including tradition, authority and pre-judgments / *prejudice* (Gadamer, 1989). In understanding a text, the subjectivist acknowledges that the interpreter's own thoughts have gone into that interpretation and, in the process of interpretation, the horizon of the text merges with the horizon of the interpreter. Therefore, interpretation is mediated through "...a subject that is itself located within a context of traditioned meaning" (Bleicher, 1980, p. 216).

Gadamer (1989) points out that there is no final correct interpretation of the text; there can be multiple interpretations of the one text that may go beyond the intended meaning of the author. Understanding and interpretation are always evolving so a definitive interpretation is unlikely to be ever possible. Gadamer

talks of the openness of texts based on the idea that all understanding derives from the interpreter's own pre-judgments and pre-understandings that are embedded in the interpreter's historical and cultural 'situatedness' (Gadamer, 1989; LeVasseur, 2003). Heidegger claimed that nothing can be encountered without reference back to an individual's pre-understandings; a person cannot put aside his/her own consciousness. Similarly, Gadamer does not intend that prejudices are suspended (as do the objectivists) but rather he challenges interpreters to appreciate the presence and complexity of pre-judgments in understanding text. Tradition and pre-judgments play a productive role in the interpretive process. According to this approach, the same text can have different meanings to different interpreters.

According to subjectivists, interpretation comes from involvement with the text. The dialogue between interpreter and the text occurs within the context of the pre-judgments, historical situation and traditions of the interpreter. Gadamer (1989) uses a metaphor of 'horizon' to explain the process whereby the interpreter makes sense of the text against the backdrop of his/her own assumptions, ideas, and experiences. Interpretation and understanding occur through a fusion of the horizons between the text and the interpreter, beginning with a rudimentary understanding of the phenomenon/text. As deeper understanding develops during the process of interpretation, new meanings emerge which are then applied back to the starting point of the text (Crotty, 1998; Geanellos, 2000). This circular process, Gadamer termed a dialogical fusion of horizons, occurs as interpretive understanding moves between the parts and whole of the text in a further hermeneutic circle, likened to the "dialectic between understanding and interpretation" (Geanellos, 2000, p. 114).

4.4.3 Critical hermeneutics

Critical hermeneutics is a more specialised application of hermeneutics that focusses on critiquing dominant ideologies and how these dominant ideologies have shaped and impacted the phenomena being investigated. Critical hermeneutics is often termed emancipatory as it requires the researcher to make known the "...lived experiences and personal voices of persons who are not members of privileged groups..." (Lopez & Willis, 2004, p. 730). The insights

provided allow the researcher to view the world differently helping to enact change; rather than merely interpreting reality, critical hermeneutics is concerned with changing reality through the critique of tradition and authority (Bleicher, 1980).

Habermas, while acknowledging Gadamer's position that interpretation is constituted through an interpreter's prejudices, maintains that all prejudices are not inevitable or legitimate (Prasad, 2002). Through active, critical self-reflection certain prejudices may be confirmed while others are rejected. Similarly, at a linguistic level, Habermas holds that language itself is a vehicle for privileging certain ideologies and power structures. Consequently, interpretation following a critical hermeneutic approach must include a critique of the nature of the language itself for the ideological elements that may be perpetuating particular forms of domination and privilege.

Ricoeur (1973a, 1981, 1990) offers a resolution of the differences between Gadamerian hermeneutics and Habermas' critical position by arguing that both positions are necessary to hermeneutic interpretation. Gadamer calls on interpreters to critically reflect on their pre-understandings to filter out 'unproductive' prejudices (Prasad, 2002) and the ideological critique of Habermas is part of Gadamer's 'traditions' which are re-interpreted in the hermeneutic process of interpretation and understanding.

4.5 Applying hermeneutic theory to this thesis' methodology

Although originally the interpretation of text, Ricoeur's (1971) arguments have expanded the hermeneutic 'text' to human action in general; the term 'text' now covers organisation practices, culture, economic, and social structures. For organisational research this has two important implications "(a) that in any research situation, the context is not a simple given, but needs to be actively defined by the researcher, and (b) that the context can usually be defined at different levels of comprehensiveness" (Prasad, 2002, p. 24). Furthermore, groups of people construct their social reality (Berger & Luckmann, 1967) and these groups may be people working within an organisation or they may be individuals

who are socially and/or culturally connected. Hermeneutics is more contextual than many of the other phenomenological research perspectives and accepts the researcher as a positive influence on the inquiry and on understanding. The subjectivist hermeneutic methodology is therefore appropriate for this enquiry into health literacy as experienced by New Zealand Baby Boomers and primary healthcare professionals.

A working definition of hermeneutics is “...the theory of the operations of understanding in their relation to the interpretation of texts” (Ricoeur, 1981c, p. 43). The fundamental concepts within hermeneutics include: pre-understanding; the hermeneutic circle; the reader-interpreter’s own historic-cultural context and hermeneutic horizon; and understanding as dialogue and fusion of horizons. These are discussed integrating Ricoeur’s key concepts of distanciation, appropriation, explanation, and interpretation (refer Figure 4.1).

4.5.1 Pre-understanding

An important concept within hermeneutics is pre-understanding. These pre-understandings, from which a person can never step aside, always influence an individual’s interpretations; nothing can be encountered without reference to a person’s cultural, social, and historical backgrounds (Gadamer, 1976; Ricoeur, 1981; LeVasseur, 2003). There are therefore multiple, yet still faithful, interpretations of every text since each interpretation is based on the interpreter’s own historico-cultural traditions and horizon from which the text is understood.

The process of interpretation and understanding (refer Figure 4.1) involves the interpreter reflexively moving back and forth from understanding single elements to an understanding of the whole. The cyclical process starts at a point based on insufficient knowledge of the phenomenon but with the interpreter bringing foregrounding or pre-understanding to the hermeneutic interpretation (Gadamer, 1976). Gadamer (1976) terms this pre-understanding, ‘prejudice’, not as an obstacle to understanding but as a necessary pre-condition. While these prejudices determine each interpreter’s horizon of understanding, Gadamer differentiates between productive prejudices that enhance understanding and unproductive

prejudices that do not (Prasad, 2002). A researcher must therefore question his/her pre-understandings making every effort to suspend unproductive prejudices in order to enhance the fusions of horizons between the interpreter and the text. The researcher must also remain critically reflexive concerning the impact of exposure to literature on health literacy on the views and explanations of the participant's texts.

Ricoeur supports this distancing between the interpreter and his/her own pre-understandings, which he calls 'distanciation'. Not only should interpreters distance themselves from their pre-understandings, but Ricoeur identifies four forms of distanciation all of which allow the interpreter to "...approach the text without concern for authorial intent..." (Geneallos, 2002, p. 113). First, the text is distanced from the author as the written word and "...escapes the finite horizon of its author" (Ricoeur, 1973b, p. 95) opening it to unlimited interpretation; second, the text is distanced from the situation of the discourse and "...freed from the context of its creation..." (Geneallos, 2002, p. 113); third, the written word overcomes the limitation of spoken dialogue separating it from the original audience; and finally, the text becomes autonomous since what is said (the meaning) is more important than the act of speaking (the actual words) (Bleicher, 1980; Geneallos, 2002).

It is important to note that Ricoeur's concept of distanciation and objectification of the text is not to be confused with the subject-object split of the objective hermeneuticists. According to Ricoeur meanings can remain implicit and almost go unnoticed and unarticulated by the author(s) themselves (Crotty, 1998, p. 91). Therefore, "interpretation is the work of thought which consists in deciphering the hidden meaning in the apparent meaning, in unfolding the levels of meaning implied in the literal meaning" (Ricoeur, 1974a, p. 13). Fundamental to Ricoeur's theory of interpretation is the distancing of the interpreter from his/her own pre-understandings in order to perceive new meaning - the interpretation of the text is the process that "...gives to the subject [interpreter] a new capacity of knowing himself" (Ricoeur, 1974b, p. 107) - which logically leads to Ricoeur's concept of appropriation.

The hermeneutic researcher brings her experience, worldviews, and foreknowledge to this research. In addition, foreknowledge of the conceptual framework proposed from the review of literature on health literacy (Chapter 3) influenced the researcher in the iterative process between parts of the texts and the whole. The interview documents were read and re-read to accumulate ideas and patterns of expression which were similar and different to pre-understandings. The interaction between the empirical data and these pre-understandings progressively produces the fusion of horizons that inform subsequent interpretations in the hermeneutic circle.

4.5.2 The hermeneutic circle

The concept of the hermeneutic circle is an important part of hermeneutic interpretation referring to how understanding is gained through a circular process of considering a phenomenon/text as a whole and as something composed of parts. This seeming contradiction is that "construing the meaning of the whole meant making sense of the parts and grasping the meaning of the parts depended on having some sense of the whole" (Schwandt, 2001, p. 112). Heidegger (1962) also described the circle of understanding as explaining how pre-understandings are integrated into increased understanding of a phenomenon. This hermeneutic circle is one where,

...a phenomenon first presented in a nebulous unstructured form is combined with past knowledge and experience to create an enlightened understanding of the experience. This enlightenment then enriches understanding of future events and experiences, completing a circle that recurs indefinitely to create increasing knowledge (von Zweck, Paterson & Pentland, 2008, p. 119).

Thus there are two hermeneutic circles during the interpretive process. The first explanation of the hermeneutic circle is the circular movement between the parts of the text and the whole. The second is the layering of new knowledge where the cycling back and forth between fore-understandings and improved conceptualisations/meanings continues. Multiple interpretations of a text can

occur and understanding can change and develop. Therefore understanding and meaning from a hermeneutic perspective permits no final conclusion, only an interpreted, deeper understanding of a phenomenon.

4.5.3 Historicality and context

In the hermeneutic understanding of a text the context of the participants is an important element to be acknowledged. The researcher needs to be familiar with the historical context of the text or phenomenon being investigated. However, the historico-cultural traditions of the interpreter may differ from the context of the text. The researchers themselves are historically situated and shaped by traditions; therefore there is a temporal and historical distance between the researcher and the text. Although a researcher may suspend historically affected understandings in the process of understanding a text, Gadamer maintains that this situated-ness can never totally be explained; interpretation is always contextually situated and therefore partial. Gadamer calls this the ‘historicity of understanding’ (Prasad, 2002, p. 18).

This provides a further dimension to the hermeneutic circle – in that, the researcher’s historico-cultural traditions can be considered ‘the whole’ within which the text (or ‘part’) belongs and is interpreted; every act of understanding occurs within a context. While the historical context of the text or phenomenon can provide meaning, the text is interpreted from the interpreter’s present historic-cultural context. Returning to Ricoeur’s concept of distanciation, “Text converted to writing now has a different audience...the audience is now distanced from the social and psychological context of the original intended audience” (Tan, Grief, Couns, Wilson, & Olver, 2009, p. 7). The contemporary hermeneutic position views the contextual and temporal distances not as something to be overcome, but instead “a condition of understanding” (Prasad, 2002, p. 19).

The significant contexts for this research are the New Zealand healthcare context, the ageing population (in particularly baby boomers), and the neoliberal consumer trends (refer Chapters 1 and 2).

4.5.4 *Dialogue and fusion of horizons*

Closely linked to the historicity of understanding and context dependent interpretation, is the importance of the participation of the interpreter in the circle of understanding. According to Gadamer (1989), this participation between interpreter and text is a dialogue. Through repeated questions and answers the interpreter opens up new possibilities of meaning, can expand his/her own horizons and deeper understanding can occur resulting in a fusion of horizons (Bleicher, 1980; Prasad, 2002).

Ricoeur's concept of distanciation is derived from Gadamer's notion of horizons. The horizons are the "various assumptions, ideas, meanings, and experiences that one has in living. These backgrounds are fluid and open to change, based on world events in time and history when one interacts with another...it is based on a personal horizon of experiences and meanings" (Lopez & Willis, 2004, p. 730). The fusion of horizons that creates new understanding (Gadamer, 1976) refers to interpretation always including the separate but intersecting 'horizons' of the researcher and the participant. The metaphor of horizon is essential, since it connotes a 'gaze' that extends beyond what is close at hand. Without this perspective or horizon, the interpreter will be less effective at the questioning that Gadamer holds is imperative in the interpretive process.

The fusion of horizons may be between the historical horizon of the past and the current horizon of the present, or between the researcher and a research participant. The interpretation gives the researcher a new way of knowing, "bridging the gap between the familiar and the unfamiliar" (Paterson & Higgs, 2005, p. 346). In this way the researcher comes to a deeper understanding of other perspectives, the text, or phenomenon(a), which Ricoeur (1981a, p. 185) calls appropriation - "making one's own what was initially alien". The interpretation of the text represents the intersection of the past horizon of the researcher with the view of the text - the present horizon (Gadamer, 1976) - allowing the researcher to view the world differently. In reading the text, the interpreter must distance him/herself from the text in order to interact with the text, testing out pre-conceptions, suspending unproductive prejudices, ultimately leading to the appropriation of its

meaningfulness. Making sense of the textual data requires more than careful scrutiny of ‘what is said’; it must extend to interpreting ‘what is being talked about’. It is in this process that the structural analysis advocated by Ricoeur (refer Table 4.1) plays an important mediating role between the naïve understanding and disclosing what is implied in the text that people use (Ricoeur, 1973b).

Therefore, the fusion of horizons in this thesis’ hermeneutic analysis took place in several ways (refer Figure 4.1). There was the fusion of the researcher’s horizon with the phenomenon of health literacy. Second, there was the fusion of horizon between the internal world of the text and the participants’ understanding of health literacy, and the world of the researcher. A further fusion of horizons occurred between the conceptual framework and the interview texts; as new meanings were gained through successive interpretations of the textual data these became pre-understandings in subsequent interpretations. This process of interpretation culminates in appropriation which “...does not seek to rejoin the original intention of the author, but expands the conscious horizons of the reader by actualising the meaning of the text” (Thompson, 1981, p. 18), so the interpreter owns what was unfamiliar.

As a research methodology hermeneutics therefore requires: attention to the context and history of the phenomenon under study; self-reflection by the researcher; and, interpretation of the phenomenon in light of previous knowledge and theories. Ricoeur’s theory of the interpretation of texts is illustrated in Figure 4.1 and the methodology is summarised in Table 4.1.

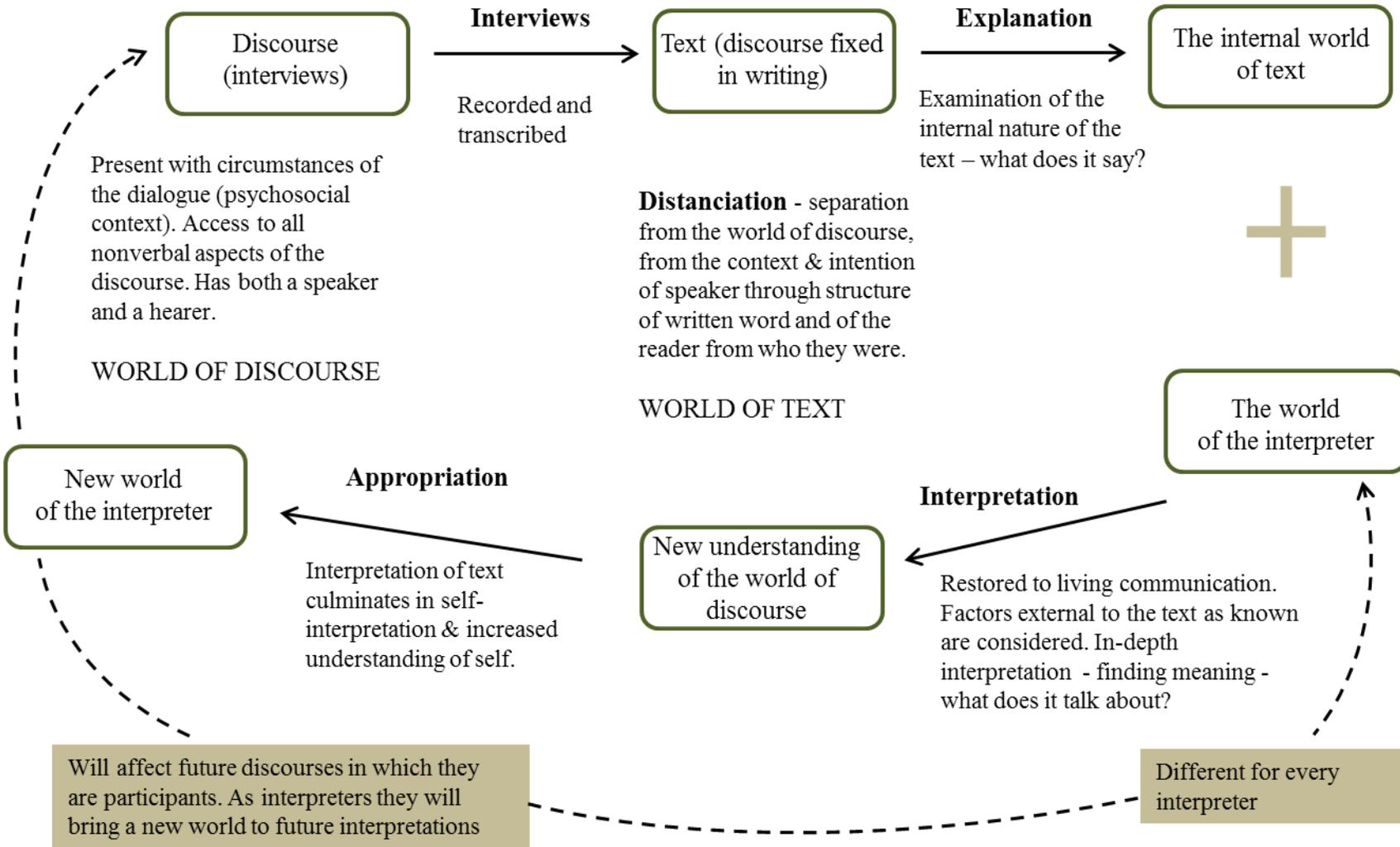


Figure 4.1 Ricoeur's theory of hermeneutic interpretation
 (Source: Tan et al., 2009, p. 6)

Table 4.1 Summary of hermeneutic methodology and this thesis

Philosophy	Understanding is achieved through interpretation of the text as discourse fixed in writing and the context (i.e. objective structures & events) of the phenomenon.
Goal	To generate meaning and deeper understanding of the phenomenon of health literacy.
Method	
Formulating a research question	Theoretical framework made explicit in decisions about: focus of inquiry, sample, subjects, & research questions.
Sampling	Purposeful sampling.
Data collection	Recorded and transcribed in-depth interviews.
Interviewing strategy	After initial question, dialogue agenda set by the participant. Interviewer uses probes and follow-up questions to get clarification and elaboration.
Analysis	
Three phases of analysis of interview transcripts	
Level 1 Naïve understanding	1. Repeated reading of the text to naively understand the text. This is ‘what it says’.
Level 2 Structural analysis	2. Grouping text into units, themes, and sub-themes. These are the meanings the text discloses, ‘what it talks about’.
Level 3 In-depth understanding via the hermeneutic circle	3. Interpretation of factors external to the text; managing ambiguities or contradictions; moving between parts of the text and the whole; contextualised through literature. This interprets the unexpressed within the text.
Outcome	
Categories of description	Interpretive meanings.

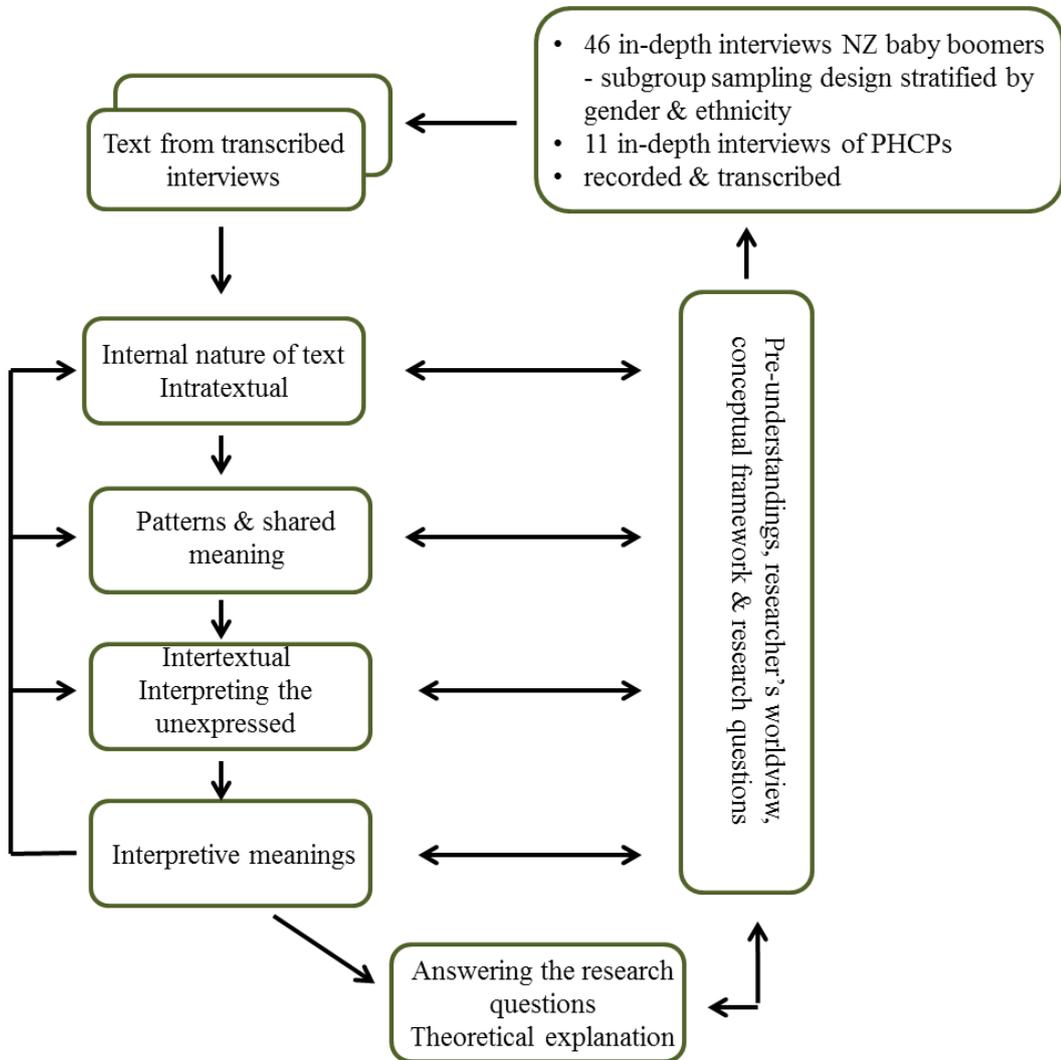
4.6 Research method

Methodology correctly refers to the overall strategy, process or design of the research which then guides the choice and use of particular methods, that is, the techniques and processes used to gather and analyse the empirical information (Chenail, 2009; Crotty, 1998; Hay, 2002). Although there are no set methods tied to particular methodologies, certain methods sit more comfortably with particular philosophical and methodological perspectives. Choosing the method - the particular strategy for collecting and analysing data - that is best suited to the research inquiry is essential to valued outcomes. Furthermore, selection of the most appropriate research method must be driven by the research questions, the current body of knowledge, as well as the accessibility of the data to the researcher by using a particular method.

The purpose of this research is to appreciate how health literacy is experienced and understood among baby boomers and primary healthcare professionals (PHCPs). The inclusion of PHCPs in the research design is justified by the central part that the patient-health professional encounter still plays in the healthcare system and in health information exchange. One of the research objectives is to understand how health literacy is enacted within the health encounter. Consistent with the interpretivist ontology, the epistemology of social constructivism, this research is grounded in a hermeneutic methodology and uses in-depth hermeneutic interview methods. In-depth interviews were selected over focus groups since the area of health and healthcare can engender sensitive issues to surface which could result in unease in a group situation.

The construction of texts arose from in-depth interviews, comprising 46 interviews NZ baby boomers (25 female and 21 male) and 11 interviews with primary healthcare professionals. The research process is illustrated in Figure 4.2.

Figure 4.2 Stages in the research process



4.6.1 Research participants

For qualitative research there are no rules on sample size; the “validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size” (Patton, 1990, p. 185). Purposeful sampling meant that the researcher actively sought out participants who could provide relevant information; ‘good’ informants are those that “have the necessary knowledge and experience of the issue...at their disposal...have the capability to reflect and articulate, should have time to be asked, and should be ready to participate in the study” (Flick, 2009, p. 123).

4.6.2 Recruiting Baby Boomer participants

Recent literature offers detailed guidance and recommendations regarding sample size and sampling schemes (e.g., Curtis, Gesler, Smith, & Washburn, 2000; Onwuegbuzie & Leech, 2007) building on thorough discourses on qualitative sampling strategies (several such strategies are provided in Patton, 2002; Strauss & Corbin, 1998; Miles & Huberman, 1994). Sampling design is extremely important for the credibility of the research and supporting the research conclusions. Therefore, making explicit the decisions over sampling design improves the legitimization of research interpretations, one of the crises qualitative research typically faces (Onwuegbuzie & Leech, 2007).

The sampling frame and the homogeneity/heterogeneity of the participant group first of all need to be decided. The sampling frame for this research adopts a demographic homogeneity - all baby boomer participants were aged between 48 and 67 years of age when they were interviewed (in 2013, being born between 1946 and 1965) - and geographic homogeneity as all participants are resident in New Zealand at the time of the research. This purposeful sampling frame is based on the requirements of the research topic and the research question; the homogeneity contextualises the research within these defined settings. Interpretive understanding, in other words applying the findings to health literacy theorising,

develops on the basis of this contextualisation and the interpreted meanings from the participants' responses.

Next, the sampling design (sample size and sampling scheme) is chosen. Generally, the size of a qualitative research sample should enable thick, rich description that allows interpretive validity; sample size also should ensure data saturation (Flick, 2009; Glaser & Strauss, 1967) or information redundancy (Lincoln & Guba, 1985, p. 204). A sample size that is too large can detract from the ability of the researcher to provide rich and detailed analysis of the phenomenon and too small can limit data saturation (Onwuegbuzie & Leech, 2007). Furthermore, recruiting participants can be unpredictable. Therefore, deciding on the number of participants is not a trivial consideration in order to enable useful understandings from the research findings. For this research, the stated number of participants was initially given as a narrow range to indicate that these were the anticipated sample sizes (refer Table 4.2) however recruiting participants continued until saturation was reached.

Different qualitative sampling schemes - the techniques used to select people or groups - have been classified elsewhere (Miles & Huberman, 1994; Lincoln & Guba, 1985; Onwuegbuzie & Collins, 2007; Patton, 2002). Onwuegbuzie and Collins (2007) identified 24 sampling schemes for qualitative, quantitative, and mixed methods researchers. For interpretive research, where the researcher seeks to gather insights into participants' lived experiences and the meaning of a phenomenon, Onwuegbuzie & Collins stated that "there are currently 19 purposive sampling schemes...the appropriateness of each scheme [is] dependent on the research goal, objective, purpose, and question (2007, p. 287). This research adopts a subgroup sampling design, recognising the potential uniqueness and complexity of each subgroup and then follows the recommendation of a minimum sample size of three cases in each of the subgroup cells (Onwuegbuzie & Leech, 2007, p. 245). The sampling is stratified according to gender and ethnicity (see criteria below, Section 4.6.3) and within this, intensity sampling is adopted (Robinson, 2013; Teddlie & Yu, 2007)²⁵ – that is, individuals will be

²⁵ Robinson (2013) justifies the use of multiple purposeful techniques.

invited to participate based on them being able to offer excellent or rich examples of the phenomenon of interest but not highly unusual cases (Patton, 2002).

The phenomenon of interest in this research is health literacy. The two strata of gender and ethnicity were purposefully chosen to provide understanding of this phenomenon. First, gender differences with regard to health issues are well accepted (e.g., Bertakis, Azari, Helms, Callahan, & Robbins, 2000; Dew & Davis, 2005; Govender & Penn-Kekana, 2010; WHO, 2010). Second, New Zealand demonstrates a similar trend to most developed countries of inequalities in health according to ethnicity. Ethnic inequalities in health in New Zealand are most pronounced when comparing Māori and Pacific Islanders to the majority European population (Blakely, Ajwani, Robson, Tobias, & Bonne, 2004; Harris et al., 2006; Howden-Chapman & Tobias, 2000). For example, Māori life expectancy is 8.3 years lower than non-Māori (Tobias et al., 2009) and the Ministry of Health (2010b) reports differences across several health indicators on both chronic and infectious diseases. Similarly, there is strong evidence that Pacific Islanders have worse health status than the population as a whole (Ministry of Health, 2007). While there is less information on their health, available evidence suggests that Asian New Zealanders have similar health status to European New Zealanders (Ministry of Health, 2004c). Furthermore, stratification by ethnicity is more generally justified “given the racialised nature of access to goods, services, and opportunities within New Zealand society...” (Becares, Cormack, & Harris, 2013, p. 81) and which has added to health and socio-economic inequities.

The stratified sampling design is outlined in Table 4.2 indicating the provisional range of 24 to 40 interviews which falls within the minimum sample sizes suggested for qualitative research. Scholars suggest a minimum of 15 to 20 interviews for grounded theory research (Creswell, 2002); 30 to 50 interviews in ethnographic research (Morse, 1994); and 10 interviews for phenomenological-based research (Creswell, 2009; Guest, Bunce, & Johnson, 2006). This sample size strategy was monitored for data saturation during the fieldwork. As the number of interviews approached five in each of the eight categories, repeated practices and patterns of understanding of health literacy became apparent such

that there was little additional information or new participant meanings being expressed. Therefore, five interviews in each of the cells (Table 4.2) were adjudged sufficient.

Table 4.2 Subgroup sampling design NZ baby boomers by gender and ethnicity

	Male	Female	Sample size
European	3-5	3-5	6-10
Māori	3-5	3-5	6-10
Pacific Peoples	3-5	3-5	6-10
Asian	3-5	3-5	6-10
Total	12-20	12-20	24-40

Note. The 2013 Census data show the following population distribution among the four major ethnic groups: European 74.0% (2,969,391), Māori 14.9% (598,605), Asian 11.8% (471,711), Pacific Peoples 7.4% (295,944), and Other ethnicity 1.2%, (46,953) of the total population of 4.02m (the percentage total adds to greater than 100% because individuals can chose to identify with more than one ethnic group). Source: www.stats.govt.nz.

4.6.3 *Criteria for purposeful sampling of baby boomer participants*

Individuals were invited to participate (further details below and refer Appendix 6 for participant email invitation) and the following criteria were applied. These criteria with explanation are listed below:

1. The participants were aged (in 2013) 48 to 67 years and they had to be usually resident in New Zealand at the time of the research.²⁶

Explanation:

The baby boom in New Zealand is defined as having occurred between 1946 and 1965 (Statistics New Zealand, 1995, and refer Chapter 2). This criterion includes participants of diverse ethnicity, including Māori.

²⁶ For census purposes, a resident is a person who self-identifies on the census individual form that they usually live in an area (<http://www2.stats.govt.nz>). An overseas resident who has stayed in NZ for less than 12 months is required by the Census to give the address of their home country; by implication usually resident is someone who has lived in NZ for more than 12 months.

Although the Māori birth rate did not experience the boom of the European birth rate during the years 1946-1965, the Māori population did experience the same social and cultural events as the rest of the population born in that period.

This criterion included those individuals born in the baby boom years, not necessarily born in NZ, but who are usually resident in NZ (census data uses this term to denote resident population on census night).²⁷ These participants have experienced worldwide events that are considered to have contributed to the particular attitudes and characteristics of baby boomers. For the purposes of this research, usual place of residence is taken as the criterion. This criterion can be defended on the basis that for this research the significance of the participants is in terms of their experiences regarding healthcare experiences and encounters. New Zealand's diverse ethnicity is likely to impact NZ healthcare services as it ages. Furthermore, purposefully including an ethnically diverse group of research participants recognises that 35% of New Zealand's population identifies with an ethnic group that is non-European.

and

2. The participants were willing to discuss their opinions and experiences regarding their health understanding and how these impact their healthcare decisions and their healthcare encounters. This was explained in the initial introductory conversation and again, prior to the interview, in the Participant Information Sheet (Appendix 7).

Explanation:

This criterion was important since participants' full description of their understandings and experiences of health literacy generated data that gave the researcher genuine insights into the phenomenon according to these individuals' experiences.

and

²⁷ For example, the migration of Pacific peoples to New Zealand occurred predominantly in the 1950s to mid-1970s, driven initially by the employment opportunities (Cook, Didham, & Khawaja, 1999).

3. The participants were willing to participate in an interview likely to last 45 minutes.

Explanation:

Scholars have labelled current society as the interview society where interviews are an increasingly pervasive way of collecting information (Gubrium & Holstein, 2001). Consequently, there is a general familiarity with interview practice and expectations. However, it was important for this research that the interviews went beyond superficial question and answers allowing participants and researcher to explore and discuss experiences that were brought to light. Therefore, participants were forewarned of the likely interview length prior to the interview.

In the initial phase of recruitment the researcher approached colleagues and friends in her own personal networks to develop a list of possible participants, who were then contacted either by phone or email. Subsequently, the researcher contacted key people in specific community groups to invite participants, for example, the Waikato Chinese Association and the Pacific Peoples community (via an academic colleague and a health professional in the Waikato District Health Board). In the latter stages of the data collection phase interview participants were asked to identify others who may be willing participants in the research and who met the selection criteria (Patton, 2002, p. 243).²⁸ Four of the 46 participants were recruited by this method. Although such a process can sometimes result in a restricted sample with participants drawn from similar backgrounds, the profile of participants is evidence that there was considerable heterogeneity across the sample of participants (refer Section 4.6.6).

For some of the participants, the researcher may have been considered an outsider by ethnicity, gender, or social position particularly as health is a very personal construct. Therefore, the researcher was vigilant for aspects of psychosocial distance caused by an insider-outsider distinction (Letherby, 2002; Sixsmith,

²⁸ The terms snowball sampling and respondent-driven sampling have been carefully avoided in describing the recruitment strategies used in this research since the term snowball sampling has been used for different concepts. On the differences between snowball sampling and respondent-driven sampling in hard-to-reach populations, refer Atkinson and Flint (2001), Goodman (2011), and Heckathorn (2011).

Boneham, & Goldring, 2003) that may have impacted on the interview conversations. The researcher's social background and gendered identity sometimes enhanced the empathy between researcher and participant, but also when there was a sense of the researcher as outsider, this sometimes facilitated an open discussion of health literacy experiences, as the participant was assured his/her reflections were not going to be shared with others in the individual's health networks.

4.6.4 Recruiting Primary Healthcare Professional participants

Patton's (2002, p. 243) intensity sampling was used as the strategy for recruiting primary healthcare professionals (PHCPs). It is important to include those PHCPs who have an interest in health literacy since they need to have some awareness of the concept in order to discuss how their understanding of it impacts their interactions with baby boomer patients. This procedure was also used by Sykes, Wills, Rowlands, and Popple (2013, p. 152) who similarly argued that "A general sample of practitioners and policy makers would not have enabled this insight".

The indicative sample size was 10 to 15 participants based on sample size indications for phenomenological interviewing (Guest et al., 2006). The principle for recruiting PHCP participants was to interview those participants who could provide rich information and by selecting information-rich cases, the researcher could "...learn a great deal about issues of central importance to the purpose of the research..." (Patton, 2002, p. 46). Through the researcher's own health network she was able to identify primary healthcare professionals who had an expertise in the field of health literacy. A further PHCP was identified via a search on the Health Quality & Safety Commission New Zealand website. An original list of 14 was compiled making sure that the list incorporated different types of primary healthcare provision. This diversity was deliberately adopted to allow for richer understandings of the PHCPs' construction of health literacy. In addition, people who were interviewed were asked to identify other PHCPs they knew who could be useful interview participants and met the criteria for inclusion (Patton, 2002, p. 243); one further participant was added in this way. All the participants

self-identified as having expertise in the field of health literacy. Eleven of the PHCPs agreed to participate.

4.6.5 *Interview process and topic guide*

The hermeneutic interview is a fluid dialogue between researcher and participant therefore, the researcher aimed to encourage a discussion that flowed as a conversation - the purpose of the interviews was to investigate what individuals experience and understand in terms of health literacy (Vandermause & Fleming, 2011). For all participants the recruitment process was a useful stage in the research design as it allowed time for the participants to think more deeply about their experiences. After an initial question, the researcher used probes and follow-up questions that were focussed on the participant's experiences (Dinkins, 2005; Sayre, 2001). In the interview participants were asked to tell a story that stood out for them regarding health literacy.

The interview topic guide was constructed reflecting the dimensions of Nutbeam's health literacy with an emphasis on communicative and critical health literacy and also the dimensions proposed in the conceptual framework in Chapter 3. The interview topic guide and research purpose did not specifically focus on the details of individual health events, but rather the health literacy surrounding their experiences. Three pilot interviews were conducted comprising two baby boomer interviews (one male and one female) and one PHCP interview. Following the pilot interviews, one addition was made to the baby boomer interview topic guide adding a question on obstacles individuals experienced in accessing primary healthcare. Refer to Appendices 8 and 9 for the two interview topic guides.

For the baby boomer participants, each interview began with the participant answering seven demographic questions (refer Appendix 8), including a question on self-reported health status. Self-reported health is a simple measure which has consistently been shown to be valid indicator of health status (Franks, Gold, & Fiscella, 2003), particularly in population samples similar to this research (Miilunpalo, Vuori, Oja, Pasanen, & Urponen, 1997, p. 517). The answers to these questions provided a demographic profile of the baby boomer participants. Each

participant then answered the Chinn and McCarthy (2013) 13-item All Aspects Health Literacy Scale questions (AAHLS, refer Appendix 8 for the questions, and Appendix 10 for the coding summary).²⁹ This scale was chosen for a number of reasons. It included statements measuring both critical and evaluative aspects of health literacy as well as functional aspects. The parsimony of the questions meant it did not detract from the main purpose of the interview, which was to develop a conversational dialogue between the researcher and the participant; in the majority of the interviews the questions served as useful prompts for discussion around the main interview topics. The demographic information and the AAHLS scores provide participant profile data, summarised in Appendix 11.

Interviews were conducted over five months between August and December 2013. For all participants, the research interviews occurred in four different locations: the participant's workplace, a quiet small room on a university campus, the participant's home, and the home of the researcher. Three interviews were conducted via Skype. Each in-depth interview was recorded using two digital recorders and then transcribed. This resulted in 787 single-spaced pages of transcriptions. After each interview the researcher wrote herself memos, recording reflections regarding the interview data, ideas, or patterns that were revealed by the participants' data. These memos proved useful in the initial iteration of textual interpretation (refer Appendix 12 for examples). The average length of the interviews with baby boomer participants was 43 minutes and 52 minutes for the PHCP participants. The interview details are summarised in Appendix 13.

This research uses verbatim transcripts. The transcription process when "we transform others' words from spoken to written form" (Bucholtz, 2007, p. 802) is part of the research process involving a variety of choices and interpretations that are important to disclose. Transcription has been labelled a socio-political act (Bucholtz, 2007, p. 802) that differs with research perspective and purpose; "...neither transcripts nor electronic recordings should be treated as data that are simply given, in an unmediated fashion..." (Hammersley, 2010, p. 556). Ricoeur similarly notes the problems posed by "the passage from oral to written discourse"

²⁹ Email approval to use the AAHLS survey received from Dr D. Chinn, King's College, London, 19 June, 2013.

(Ricoeur, 1981b, p. 37) and although “the text acquires its semantic autonomy...and is dissociated from the ostensive references peculiar to oral discourse...text implies inscription...of an experience to which it bears testimony” (Ricoeur, 1981b, p. 37). In hermeneutics, the interview text is not the same as already written literary texts: “...a qualitative research interview involves both the generation and interpretation of the text” (Kvale, 1983, p. 187) and the interviewer is often the co-creator of the text that is subsequently interpreted.

For the purpose of the present hermeneutic analysis the interview transcripts are textual representations where the research focus is “less on the mechanics of speech and more on the informational content of the interview and the social or cultural meanings attached to this content” (Hennink & Weber, 2013, p. 700). Therefore, a “naturalized”³⁰ approach (Bucholtz, 2000) is taken to the transcription which detechnologises³¹ the transcribed text so that it conforms to the conventions and practices of written discourse. Despite choosing to create a transcript that is writing-like (as opposed to speech-like) the researcher made no further alterations of the transcripts except to remove filler words (e.g., mm, agh, er). Colloquial dialogue, slang, elisions (including the omission of the end of one word or the beginning of another), non-standard grammar and syntax have not been corrected so retaining some links to the speech-like aspects of the interview dialogues (similar to the protocol recommended by McLellan, MacQueen, & Neidig, 2003, p. 66). Only when the spoken English in the transcript excerpts was considered to prevent a clear understanding for the reader did the researcher construct a meaning of the text by adding words in square brackets. This follows Hammersley’s (2010) call to make changes to transcripts with circumspection since changes can lead to false inferences from the text. While editing the transcripts for slang, nonstandard grammar, and syntax could improve their readability or comprehension, these elements have been kept intact as the researcher preferred to keep the authenticity and variability of the participants’ dialogue for readers to consider.

³⁰ The term retains its American spelling as in the original reference.

³¹ Transcripts produced by linguists and discourse analysts “can technologise a text” (Charteris, 2014, p. 100) by including highly detailed conventions/symbols for example, recording intonation, emphasis, pronunciation, pauses, and overlaps.

Table 4.3 Composition of baby boomer sample - gender, age, and ethnicity

	Male			Female			Total Participants		
	Leading edge	Trailing edge	Total	Leading edge	Trailing edge	Total	Leading edge	Trailing edge	Total
European	4	1	5	4	3	7	8	4	12
Māori	3	3	6	1	5	6	4	8	12
Pacific Peoples	1	4	5	1	5	6	2	9	11
Asian	3	2	5	1	5	6	4	7	11
Total	11	10	21	7	18	25	18	28	46

4.6.6 Profiles of participants

Table 4.3 describes the composition of the baby boomer sample according to age, gender and ethnicity. The age of the participants is subdivided according to the commonly used categories of leading edge and trailing edge baby boomers. The leading edge category, the older baby boomers, includes those baby boomers born between 1946 and 1955, that is, when interviewed these participants were aged 58-67 years. The trailing edge group, younger baby boomers, includes those participants born between 1956 and 1965; when interviewed these participants were aged 48-57 years. The research sample had a slightly higher proportion of these younger baby boomers (61% were trailing edge baby boomers).

The baby boomer profile information demonstrates that the aim of the research to investigate health literacy among a population of baby boomers not defined by illness or health risk has been achieved (Appendix 11). Self-reported health data reveal that 89.13% of the 46 participants rated their health as good, very good, or excellent, and only one participant rated their health as poor.³² Two-thirds of the participants had no disability. According to reported visits to general practitioners the participants were not frequent users of primary healthcare services, only 20% had visited their GP in the month prior to the interview and approximately 20% had not visited their GP during the last 12 months. A similar frequency of visits to other primary healthcare professionals was reported by the participants. These data indicate that the sample of participants was not biased towards those people who were health experts due to specific health conditions or health risk, in line with the research purpose.

In addition, the baby boomer participants had a wide range of educational qualifications and current occupations (Appendix 11). Almost two-thirds of the participants (63.04%) had a tertiary qualification corroborating other research that found volunteer research participants tend to have higher levels of education than

³² These results coincide with the NZ Health Survey (NZHS) 2013/2014 findings that 89.9% of New Zealanders in the age categories 45-54, 55-64, and 65-74 years rate their health as good (that is, 'excellent', 'very good', and 'good') (Ministry of Health, 2014). The NZHS interviews more than 13,000 adults each year. Over all the adult age groups, 91% of the respondents rate their health as good.

the general population (Ownby, Acevedo, Waldrop-Valverde, Jacobs, & Caballero, 2014).

Finally, the baby boomers' AAHLS scores (refer Appendix 11) show scores close to 100% on functional and communicative health literacy (93.48% and 93.96% respectively), with lower scores on critical health literacy and empowerment (79.76% and 67.07% respectively). Chinn and McCarthy (2013) also noted higher scores on communicative literacy than the other three categories. It is noteworthy that participants emphasised the social determinants of health when asked to consider the relative importance of these compared with individual lifestyle choices and behaviours.

Table 4.4 lists the primary healthcare professionals and the years of experience in their respective roles. A diverse range of primary healthcare professionals was purposefully selected to provide a richer understanding of their practices and experiences of baby boomers' health literacy.

Table 4.4 Profile of PHCP participants

Primary healthcare professional	Years practised
Pharmacist	30
Integrative Medicine practitioner (IMP)	28 as GP plus 1 as IMP
Audiologist	11
Regional health network policy and programme adviser	15
Health literacy educator	10
Chiropractor	30
Family General Practitioner	25
Pharmacist	40
Dentist	37
Regional health network medical advisor & General Practitioner	4
Optometrist	40

4.7 Ethical considerations

As this research included human participants, ethics approval was received from the Waikato Management School Ethics committee (Appendix 14). Data were collected in strict adherence to the University of Waikato's policies and protocols on ethics in human subject research. The interviewees were provided with a Participant Information Sheet (Appendix 7) and their written consent to participate and to have the interview audio-recorded was obtained before the interview began (Appendix 15 Consent Form). All interviews were transcribed (refer Appendix 16 for transcription confidentiality statement). The interviewees were guaranteed anonymity and data management maintained anonymity. Transcribed files were numbered and formatted for analysis; one separate word document file contained the numbering in relation to the participant's identity. The transcribed interviews were labelled according to the stratified sampling and filed according to interview number (chronological date). A spreadsheet organised by interview number summarised the participants' demographic information and their survey answers.

The researcher consulted cultural guidelines to ensure the research procedures were culturally sensitive. Key people within the Māori, Asian, and Pacific Peoples' communities provided advice on appropriate and necessary protocols. For these groups, the key contact person reviewed the interview guide and/or completed the interview themselves prior to the researcher inviting individuals to participate.

Furthermore, the researcher adopted what Patton (1990) labels 'empathic neutrality' striving for an attitude of "understanding, interest and caring" but also being "non-judgemental" (p. 55) towards the participant's opinions and disclosure.

4.8 Method of analysis

The data analysis applied Ricoeur's hermeneutic theory of interpretation. In this, the researcher acknowledges her own presuppositions, her pre-understandings of health literacy, and that research contexts are value-laden (Kvale, 1983; Prasad, 2002). The four key concepts - distanciation, appropriation, explanation, and

interpretation (refer Section 4.5 and Figure 4.1) - have been part of the interpretive process. In Ricoeur's theory of interpretation the text is objectified and the intent of the author is removed such that the interpreter searches for the text's meanings not the participant's unique meanings (Simms, 2004); "...multiple interpretations can faithfully represent a text" (Geanellos, 2000, p. 16).

Ricoeur explains interpretation as involving explanation (what the text says) and understanding (what the text talks about), both of which rest on the various dimensions of the hermeneutic circle (Geanellos, 2000). The effective process of interpretation and understanding according to Ricoeur cannot be achieved without "repeated engagement with a text...[in order to forestall] premature interpretive closure" (Geanellos, 2002, p. 114). The narrative text collected during the interviews was read multiple times. The initial reading grasped the whole story; additional readings moved between the parts and the whole, and between the literature and the data. An intra-textual analysis was carried out initially explaining the main details of the text(s) and providing the beginning of an appreciation of the experience of health literacy among baby boomer participants and among primary healthcare professional participants.

The process of interpretation followed the three phases Ricoeur (1976) outlines in his interpretation theory. The first phase was a naïve reading of the text where the researcher became familiar with the texts and made a "guess of the meaning of the text within its context" (Charalambous, Papadopoulos, & Beadsmoore, 2008, p. 437). The next phase built on this surface understanding whereby a structural analysis was undertaken, allowing connections and patterns to be uncovered by dividing the text into units (sentences, paragraphs), themes, and sub themes. During this phase the software programme ATLAS.ti 7.1.6 was used to help sort and reduce the large amount of textual data. The marking, retrieving, and labelling of the textual data meant reading the text numerous times and reworking the coding system. Initially, the marking of the interview data was largely descriptive. The software provided a valuable tool for the subsequent iterative processes of moving between the parts of the text and the whole, and between the marking of the text and assigning codes. By utilising a software programme, the checking and reworking of codes was able to occur without losing any of the detail, allowing

the researcher to focus on remaining immersed in the participants' textual data. The software programme was used to order and organise the textual data into manageable segments. Appendices 17 and 18 are screenshots of first, the Code Manager function of ATLAS.ti and second, a section of coded interview.

During the third phase, the text was reviewed as a whole taking into account the previous phases. The "...new configurations of meaning..." (Ricoeur, 1981b, p. 39) evolved in a dialectic movement between the whole and parts of the text and between pre-understanding and new understandings, whereby these new understandings were contextualised through relevant literature, allowing "...the chosen literature [to] illuminate the interview text and interview text [to] illuminate the chosen literature...Sometimes we need several literature texts to illuminate various aspects or parts of the interview text" (Lindseth & Norberg, 2004, p. 151). Finally, to understand the text as a whole demanded imagination where, "The focus is [was] not on what the text says but on the possibilities of living in the world that the interview text opens up" (Lindseth & Norberg, 2004, p. 151). For Ricoeur (1974, p. 110) imagination is not "...the faculty of deriving 'images' from sensory experiences, but as the capacity to let new worlds build our self-understanding...conveyed by...emerging meanings in our language".

4.8.1 Categories of description

This process was not linear but required recursive loops between all the dimensions of analysis and interpretation as illustrated earlier in Figure 4.1. During this iterative process the interpretive construction resulting from the text was described using labels, often in words that participants themselves used. These interpretive labels were identified to fit with the "concerns, values, and meanings that regularly occur[red] in the dialogue" (Sayre, 2001, p. 97) and was a vital stage in making explicit the researcher's understanding (Polkinghorne, 2000).

In this thesis, categories of description were used to convey Ricoeur's emerging meanings. The process moved from initially using metaphors to phenomenographic categories of description. Ricoeur states that "metaphor relies

on...[the] ‘attribution’ of characters to the ‘principal subject’ of a sentence” (Ricoeur, 1974b, p. 97) and the meaning is carried by this specific structure. Although metaphors were originally conceived as useful interpretations of participants’ understanding/meaning of health literacy, further dialectic interpretation concluded that the attributions were too contrived (Black as cited in Ricoeur, 1974b, p. 102, notes that metaphors are “supported by specially constructed systems of implications...”), often removing the interpretive metaphor far from the world of the participants.

The researcher then developed a word or short phrase to capture the essence of the events, behaviours, or roles described by participants, checking these by moving between the text and literature, between explanation and understanding. The problem between explanation and understanding is that, as Ricoeur notes, “...the capacity to follow a story expresses the irreducible component of understanding in the act of narrating ...” (1981b, p. 38), the backdrop to which is the “formidable question of creativity” (p. 38). Drawing from phenomenographic research, categories of description were chosen as appropriate vehicles for “communicating the ways in which people experience a particular phenomenon” (Marton & Booth, 1997, p. 125).³³ Each category had to reveal something distinct about the phenomenon of health literacy, each category had to relate logically to the others, and the system of categories had to be as parsimonious as feasible for capturing the variation in the phenomenon (Yates, Partridge, & Bruce, 2012). The categories of description are not identical with the ways participants experienced the phenomenon of health literacy but are used to denote them. One aspect whereby Ricoeur grafts hermeneutics to a phenomenological philosophy is in the object of analysis becoming the subject; “the subject becomes, under a hermeneutic analysis, ‘like’ a text” (Ihde, 1974, p. xv). Therefore, the interpretation must decipher the text as well as allowing for an interpretation of the ‘text-self’. In this thesis, the approach to account for these meanings was to label the categories of description as nouns (seeker, enabler, etc, refer Tables 5.1 and 6.1).

³³ Ricoeur encourages different techniques in interpretation and comprehension, “...no noteworthy interpretation has been formulated which does not borrow from the modes of comprehension available [to a given epoch]...” (1974b, p. 4).

The resultant categories of description use everyday language, staying as close as possible to the terms expressed in the participants' textual data, since "[a] researcher who has interpreted players' actions must also... be able to put this within a context and language which is transparent to others..." (Debesay, Naden, & Slettebo, 2008, p. 58-59). For each category of description, verbs were used to communicate the key meanings (e.g., taking responsibility, experimenting, as in Table 5.1 and acting with professionalism, being a partner, as in Table 6.1) since "Verbs are better at revealing lived experience than nouns" (Lindseth & Norberg, 2004, p. 151).

The systematic and formal processes of arriving at these categories of description and the key meanings followed the structural hermeneutic analysis, but there was also a part in the process where "the imagination operates...to produce new configurations of meaning..." and "...the productive imagination assumes the form of a semantic innovation" (Ricoeur, 1981b, p. 39). Although Ricoeur argues (1981c, p. 53) that one can never claim that the interpretation is complete "It is always possible to argue for or against an interpretation, to confront an interpretation to arbitrate between them...", an interpretation must not only be probable but must be considered more probable than others. The interpretations presented by these categories of description are those considered by the researcher to provide a "sensible meaning, a valid unitary meaning, free of inner contradictions" (Kvale, 1983, p. 185) that generate new understandings of the phenomenon. The basis for the resultant interpretation being the most probable derives from the participants' textual data and the integrity of the interpretive processes.

Even though other readers may not arrive at the same meanings as this researcher, it was important that the interpretive decision making was supported and hence interview excerpts are used throughout the analysis and interpretation. The use of participants' quotes provides context and meaning to the particular interpretation chosen by the researcher; "the description must not be so thin as to remove context and meaning" (Patton, 2002, p. 503) and thick enough to elaborate the meaning of the category of description. The interpretation chapters (Chapters 5

and 6) follow a similar procedure to Williams and Irurita (1998), naming the category of description, followed by the researchers' description of the meaning of the category, and then quotations from the interview data illustrating the type of text that describes the category of description.

4.9 Authenticity and rigour considerations

Validity in qualitative research has been defined by Creswell (2009) as being "...findings [that] are accurate from the standpoint of the research, the participant, or the readers of an account" (p. 191). Yet these various considerations of validity are difficult to ensure. Since validity in qualitative research depends on the qualities of the researcher and the research process, the term trustworthiness is becoming increasingly used. There are several elements that contribute to the trustworthiness of this research:

- a. The data collection method is appropriate to the research questions and sufficient data has been gathered to fulfil the research goals;
- b. All the processes have been carefully documented contributing to procedural rigour
- c. The research has faithfully represented the text and documented the progression through multiple stages of understanding as the interpretation cycled between the parts and the whole. This adds interpretive rigour.
- d. This research acknowledges the role of the researcher which provided reflexive rigour. This has been documented appropriately through the thesis.

There are no criteria for deciding among competing interpretations, rather the plurality of interpretations is accepted in hermeneutic analysis. The hermeneutic circle means that the researcher is constantly addressing and re-addressing the phenomenon. Trustworthiness of the research is derived from the research procedures, including documentation and transparency of the research processes (dependability), and sufficient detail to allow other readers to consider the applicability of the findings to other settings (transferability).

4.10 Summary

This chapter describes the hermeneutic methodology and method adopted to understand the meanings individuals bring to the phenomenon of health literacy and to explore the extent to which PHCPs' practices reflect the multiple dimensions of health literacy. Hermeneutics is based on the premise that people undertake their own sense-making to understand what is important in a process or event (Koch, 1996) making it well-suited as a research design for this research purpose. The purpose of this research and hence the choice of methodology and method is not one of generalisation to other subjects or settings but to add to the interpretation and explanation of the phenomenon.

Hermeneutic methodology was chosen as it emphasises the researcher's pre-understandings, at the same time allowing the researcher to explore and extend the meaning of health literacy. This chapter discusses the key concepts of hermeneutic theory namely, the hermeneutic circle, pre-understandings, contextuality, historicity, fusion of horizons, distanciation, and appropriation. The methods of data collection and analysis linked to this hermeneutic theory have been detailed.

This chapter is followed by two chapters that present the results and interpretation of the participants' understanding of health literacy, answering the research questions outlined in Chapter 3. Chapters 5 and 6 present the interpretive conclusions. As described above, a cyclical hermeneutic process was used to reduce and (re)interpret the data, culminating in the new understandings proffered via the categories of description (what Kvale, 1983, p. 185, calls sensible meanings). Given space limitations, these chapters present the results rather than a detailed account of the process.

Chapter 5

New Zealand Baby Boomers' Constructions of Health Literacy

5.1 Introduction

The previous chapter presented the hermeneutic methodology of this thesis and Ricoeur's theory of the interpretation of texts. This chapter is the first of two chapters that presents the researchers' interpretations of the baby boomers' and primary healthcare professionals' (PHCPs) understanding of health literacy. These interpretations are made by proceeding through an iterative hermeneutic circle having regard (primarily) to the context of New Zealand healthcare, baby boomers as a generational cohort, and previous knowledge and theories of health literacy.

In today's health context and healthcare systems, individuals are considered and expected to be active, engaged, and informed consumers (Fox, Ward, & O'Rourke, 2005; Henderson & Petersen, 2002; Hibbert, Bissell, & Ward, 2002; Holmes, 2006; Lupton, 1997; Madison, 2010; Petersen & Lupton, 1996; Rose, 2000; Savard, 2013; Schneider & Hall, 2009; Shaw & Aldridge, 2003; Shaw & Baker, 2004). Individuals hold complex health beliefs and engage in diverse health-seeking behaviours (Germond & Cochrane, 2010). At the same time, being and acting 'health literate' is increasingly demanding in the current context of health with processes emphasising the centrality of self-management of health and illness (e.g., Epstein, Fiscella, Lesser, & Stange, 2010; Fox & Ward, 2006; Petersen, Davis, Fraser, & Lindsay, 2010). Thus, there is an increasing emphasis on an individual's health literacy to enable effective health behaviours and achieve 'good' outcomes. Earlier Chapter 3 highlighted that health literacy research has been predominantly at an aggregate population level, focussing on measurement and intervention with reference to target groups that are at risk or unwell. Similarly, little research has explored how non at-risk individuals experience and understand health literacy. Chapter 3 concluded by proposing a conceptual

framework that health literacy be considered as an interactive, dynamic, and contextual phenomenon.

The term health literacy “...has been stretched, squeezed and reshaped to try to cover all of the factors that affect the way consumers relate to the health system and the resulting outcomes” (Australian Commission on Safety and Quality in Health Care, 2013, p. 11). Given the evolving nature of health literacy definitions and the on-going refinement of health literacy measurement, this research uses qualitative in-depth interviews and hermeneutic analysis to develop a conceptual framework that addresses the call from the World Health Organisation for a “relational whole-of-society approach to health literacy that considers both an individual’s level of health literacy and the complexities of the contexts within which people act” (Kickbusch, Pelikan, Apfel, & Tsouros, 2013, p. ii). Researchers often examine health literacy in the context of specific illnesses, medical conditions or health behaviours. Notably, this research draws on understandings and perceptions of health literacy roles among a population of individuals, selected according to age rather than according to medical condition. Furthermore, this research frames health literacy as a resource, not as a risk/deficit, focussing on the patient as an active consumer (Schulz, 2013, IRiSS).

This thesis explores individuals’ behaviours, roles, and relationships in order to deepen the understanding of health literacy as a dynamic and interactive process (more than just cognitive skills and competences) that is contextually situated. This chapter uses categories of description (Akerlind, 2012; Marton & Pong, 2005) to better understand the complexity of healthcare consumers’ intent (motivation and volition), skills (competencies), and knowledge (bracketed terms taken from Sørensen et al., 2012) in health literacy, without separating the individual from their health context and those contextual processes of communication, relationships, and networks.

This chapter addresses the research question:

How do Baby Boomers experience and practice health literacy? Specifically,

- *How do Baby Boomers as primary healthcare patients perceive their behaviours, roles, and relationships in relation to health literacy?*

Although the 46 New Zealand baby boomer participants were characterised according to gender, ethnicity (European, Asian, Māori, and Pacific Peoples), and age (leading edge baby boomers and trailing edge baby boomers), the study purpose was not primarily to investigate differences between these segments. The aim was to explore diverse responses on the phenomenon of New Zealand baby boomers' health literacy. The research did not seek statistical representation according to gender, ethnicity (although this revealed insights for comparative constructions of health literacy), or baby boomer age sub-group. However, some reflections on these demographic characteristics are offered in developing and interpreting the baby boomers' understanding and experiences of this phenomenon.

Adopting a hermeneutic process, the researcher analysed and interpreted the interview data in an iterative cycle of pre-understandings, the interview text, and new (post) understandings of baby boomers' experiences and perceptions of health literacy. This pull-and-push between text and interpretation, between appropriation and distancing, occurred until the interpretation illuminated the phenomenon. The interview texts were initially organised by applying descriptive codes through the ATLAS.ti software programme (organising codes and an excerpt from a coded interview are attached as Appendices 17 and 18 respectively). Repeated readings of the texts enabled an appreciation of the dimensions of the phenomenon of health literacy and of the phenomenon as a whole. Applying an on-going reflective application of this researcher's pre-understandings to the readings of the texts led to a deeper interpretation and new meanings to be reached; Ricoeur (1974b, 1981a, 1990) refers to this as distancing and appropriation.

Categories of description, adopted from phenomenographic research, are used to denote this interpretation and deeper understanding of the practices and

experiences of the phenomenon of health literacy (Marton & Pong, 2005).³⁴ Such categories, different from the individual's awareness of a phenomenon, present a collective voice of experiencing a phenomenon similar to "any symbol system...by which we organise experience into the formal structure of which 'knowing' is constituted" (Brown, 1976, p. 169). This thesis adopts categories of description as a means to interpret the participants' texts, combining participant's individual awareness and understanding of health literacy into a collective description of the fundamental aspects of the phenomenon.

Flick posits that presenting qualitative research findings can be anywhere between the two poles of where one is "developing a theory from the data and interpretations...At the other end, you will find the 'tales from the field'...which are intended to illustrate the relations the researcher met" (2009, p. 414). This thesis takes the first approach, presenting the categories of description, first outlining the logic for these, and then supporting these with the textual data interweaved with the researcher's pre-understandings. The linear presentation belies the cyclical hermeneutic process through which the large amounts of textual data were reduced and (re)interpreted, ending in the new understandings proffered via the categories of description. The interpretations are presented in a linear and structured fashion smoothing out the twists and turns of the interpretation process.

Five categories provide interpretive differentiation for the baby boomers' experiences and practices of health literacy; these are: seeker, decider, networker, sensemaker, and manager. The process of identifying and selecting the labels for these categories of description is explained earlier in Section 4.8.1. Each of these categories of description is a relatively abstract and complex concept that provides a way of 'seeing' the phenomenon of health literacy; each category expresses a qualitatively different aspect of experiencing and understanding health literacy

³⁴ Phenomenography's 'categories of description' are adopted in this hermeneutic interpretation of health literacy as they inform and improve the interpretative capability. Other outcomes of phenomenographic research (outcome space, dimensions of variation, referential and structural dimensions) are not adopted following the general pragmatist guideline to use "whatever works best" (Huber, 1973, p. 276), borrowing that which offers interpretive potential.

(Marton & Pong, 2005). Although the categories are interrelated, in describing these categories of description the distinguishing aspects are represented and the non-critical/non-defining aspects are put to one side.

This chapter begins by discussing the five categories of description, interpreted from the baby boomer participants' data, summarised in Table 5.1. For each category, key meanings are identified; these meanings emerged in the hermeneutic process as the researcher moved between the parts of the texts and the transcripts as a set, and between the various horizons of the researcher's pre-understandings and the phenomenon of health literacy. In this circular manner, the horizons of the researcher and the horizons of the texts come together to illuminate the phenomenon. After interpreting and discussing each category, baby boomers' health literacy is conceptualised according to two horizons (Section 5.3) - a self-horizon and an interactivity horizon.

The following notes outline the procedures adopted with regard to the interview excerpts used to support the interpretations in this chapter:

1. The baby boomer interview transcripts are identified according to ethnicity, gender, and age, followed by # for the chronological number of the interview schedule, as follows:

Ethnicity: A: Asian, E: European, Mi: Māori, PP: Pacific People

Gender: F: Female, M: Male

Age subgroup: L: Leading edge baby boomers born 1946-1955, T: Trailing edge baby boomers born 1956-1965

For example, Transcript AFT #34 refers to a participant who is Asian, female, and in the trailing edge age subgroup. The interview was number 34 of the 46 baby boomer interviews.

2. The transcribed texts have been kept as spoken by the participants. Where limitations in the spoken English prevent a clear understanding of the meaning of the text, added words are included in square brackets.
3. When the transcript excerpts include the interviewer and participant dialogue, the interviewer is identified as INT. These are included when it is necessary to provide some context for the text.

4. Pseudonyms are added when the dialogue requires the participant to be named for sense and comprehension.

5.2 Baby Boomers' health literacy categories of description

In this chapter, five categories of description frame the baby boomers' experiences and understanding of health literacy, emphasising the participants' nuanced behaviours and understanding of health literacy. Each category of description of health literacy includes the characteristic activities, effort, dispositions, skills, and focus that these baby boomer participants experience and employ. Participants experience and practise multiple health literacy behaviours and roles, taking up and relinquishing variable health literacy positions in their healthcare spheres. Therefore, these categories of description denote activities, efforts, and skills that differentiate them relative to each other and, later in the chapter, relative to the emergent horizons of self and interactivity (Section 5.3).

The five categories - seeker, decider, networker, sensemaker, and manager - are summarised in Table 5.1. The key meanings uncovered through the hermeneutic analysis provide differentiable aspects for each category and these meanings have been synthesised into three key words. The categories are explained using short excerpts from the participants' interview texts, providing the evidence for the narrative describing and interpreting the baby boomers' experience and construction of the health literacy phenomenon.

However, acknowledging the complexity of the phenomenon of health literacy, certain of the activities, efforts, and skills are common to several categories. For example, constructive questioning is an activity characteristic of the seeker category and is an important, but not distinguishing, activity in all the other categories. Similarly, the sensemaker category includes seeking and research behaviours characteristic of the seeker; what differentiates the sensemaker is that seeking and research activities and skills are directed, they are 'for' someone or 'for' some action, consequently positioning the sensemaker further away from the seeker on the self and the interactivity horizons. Both the manager and the networker categories include intentions of shared responsibility for health literacy.

But the manager behaviours are distinguished by their emphasis on directing and integrating various health literacy actors, resources, and skills towards a self-directed action, contrasting with the shared responsibility of the networker who has an altruistic concern to accumulate information and a developed sense of responsibility to share this information with network members, which could be considered analogous to health citizenship. Excerpts from the participants' interview data illustrate these categories of description, but no individual participant is portrayed as a single category. An individual participant may also move between the categories of description, constructing and experiencing health literacy in diverse ways.

The purpose of the categories of description is to gain new understandings of how baby boomers practise and construct health literacy in their everyday lives from the hermeneutic analysis of their interview texts. This chapter discusses how the baby boomers' health literacy roles and expectations are built on aspects of voice, choice, reciprocal (symmetric) relationships, and transparency. The participants are typically committed to being actively engaged in their health decision-making, for example, via constructive questioning and information seeking; they exercise choice when they are not satisfied; and, these baby boomer participants expect primary healthcare professionals (PHCPs) to be as informed as they are and to respect their individual health literacy levels, needs, and expectations in a reciprocal, health decision-making relationship. Furthermore, much of the baby boomers' understanding and experiences of health literacy were facilitated by social and family networks of knowledgeable people, their own experiential authority, skills from occupational roles or training, and practice in managing people and institutional processes. The participants often revealed a strong sense of individual responsibility for health literacy and health involvement which was, at times, felt to be onerous. Broom, Meurk, Adams, and Sibbritt (2014) refer to this as "the dialectical process between autonomy/empowerment and duty/responsibility. It is what we might consider a manifestation of precarious freedoms..." (p. 338). At other times, this commitment to individual health literacy and health responsibility led to frustration with PHCPs' lack of adaptability, collaboration, or expertise.

Table 5.1 Summary of health literacy categories of description and key meanings

Category of description	Key meanings	Description
Seeker	Searching	Purposefully employs information gathering and evaluative skills.
	Organising	Organises information in a predominantly cognitive process.
	Evaluating	
Decider	Choosing	Actively engages in health decisions.
	Acting	Exercises individual discretion over health literacy behaviours.
	Taking responsibility	
Networker	Relating	Is highly connected and keen to share their knowledge within their social network.
	Connecting	Is respected by others for their knowledge and advice; is the person others often turn to.
	Partnering	
Sensemaker	Experimenting	Makes sense of health information, pragmatically directing their own health.
	Experiencing	Experiments and seeks alternatives and opportunities, relies on evidence and outcomes.
	[Self] Understanding	
Manager	Integrating	Integrates multiple health resources and actors with their own competences, to manage and negotiate health literacy.
	Directing	Focusses on dependable relationships and an understanding of systems and processes for value creating practices.
	Growing	

Variable horizons of
Self
&
Interactivity

In defining health literacy behaviours and roles baby boomers also defined reciprocal expectations of relations with others in their health domains. These baby boomer participants did not consider that being unwell freed them from taking responsibility. Depending on the context, relationship, risk, and time, role responsibilities and expectations were often [re]negotiated. Health literacy roles emerged and receded according to the complex interplay of multiple dimensions (relational, individual, cultural, and situational) within the baby boomers' healthcare encounters. Consequently, role expectations of others in their healthcare spheres were also dynamic and variable.

At times, these patient-consumers expected PHCPs to 'fix' [their] health, negotiated according to the terms and conditions the baby boomers demand. At other times, the PHCP was expected to be both the partner/collaborator and expert who is given conditional/bounded credit for his/her expertise just as the patient-consumer moves between different health literacy behaviours. This 'paradox of expertise' (which Fox & Ward, 2006 discuss as being the assumption that the expert patient is both compliant *and* accepting responsibility for their health), handing over decision-making "sometimes but not always", reinforces the need to frame health literacy in its social and relational context, including the roles and limits implicit in these, and not as an individual characteristic.

Generally, the participants accepted individual responsibility and obligations regarding health, unequivocally considering themselves central to their health encounters and health decisions. When discussing their health literacy, these baby boomers focussed on relational and decisional dimensions. These participants understood and experienced health literacy as a composite phenomenon that was both action-related and contextual (as identified in the Institute of Medicine, 2004, definition of health literacy). For these baby boomers, health literacy was understood to simultaneously focus on *how* it occurs through participation and interaction, and *what* is acquired. Health literacy was embedded in [health] action.

Many of these baby boomers defined their own version of the neoliberal consumer's 'choice and voice'. Consumerism in health has often been considered as including participation, empowerment, and choice, requiring equal weight to be

given to lay knowledge and health professional knowledge (Gabe & Calnan, 2000; Lupton 1997; Shaw & Aldridge, 2003). While these aspects were valued by the participants, the interpretation of their texts also revealed that they do not unconditionally embrace health consumerism in their health literacy behaviours. Overall, the participants' understanding of health literacy underscores the empirical complexity of health behaviours.

5.2.1 Seeker

The health literacy behaviours, efforts, and intentions within this category share a common focus on health information and health information-seeking. The baby boomer healthcare consumer as a 'seeker' is characterised using the concepts of: a research predisposition, information gathering, constructive questioning to uncover health-related knowledge, and information verification. For example, this may be in the context of prevention or a chronic condition,

...I'm always enquiring about and always looking and reading about general health issues anyway, in terms of general maintaining of good health. Especially as I get older. EML#43

I use Google a lot now. I'm not on it all the time but I've got rheumatoid arthritis and I know that there's big changes in the treatment of that going on, so I want to be aware if anything changes. There are changes all the time. EMT#4

The key meanings interpreted for this category are: searching, organising, and evaluating (summarised in Table 5.2). These meanings are weaved through the participants' conceptualisation of health literacy discussed below. There were no discernible gender or ethnicity differences in the seeking role.

Table 5.2 Summary of Seeker category of description

Key meanings	Description	Illustrative Quotes
Searching	Research disposition	<p><i>...in terms of getting advice and information and so on, in my mind, there's nothing that can stop me from getting that. So I search for information. PPMT#14</i></p> <p><i>I'm a researcher by nature...so I bloody go looking and find stuff. MiFT#17</i></p>
Organising	Sorting information Developing and choosing sources	<p><i>Being very persistent...Kind of getting a feel of what [information] connections to follow up, where the best sort of information is likely to lie, because there's so much dross on the internet as well as the good stuff of course. And so I guess it's getting a sense of how to weed it out and how to assess it. EFL#8</i></p> <p><i>...All sorts [of information sources]. I just take all sorts of information because I'm thinking okay these people here have a lot of wealth of information...because I find very often, I don't know why [in relation to health information]. MiMT#45</i></p>
Evaluating	Constructive questioning Seeks justification & evidence	<p><i>I've got medical people in the family and I'd talk to them, "Do you know about this?" or, "What's your opinion of this?" Or I would ask my GP if I really wanted to discuss it or the physio. EFL#11</i></p> <p><i>I asked all sorts of questions. I always asked why, why do we have to do it? I even asked for my daughters, like what time do they need to do it? So that's always how curious we are when we have to do something we always make use of the opportunity to ask as much as we can. PPFT#21</i></p> <p><i>Yeah it's finding information about how this thing works. I mean if there was quite a few people that said "oh yes, this did this and this for me". If I found quite a few that said the same thing, maybe there might be something in it. But unless that happened I just say "oh well, good on them". MiML#4</i></p>

Seeker

Today's information-intensive context of health includes multiple information sources with variable reliability and understandability. These contextual factors underscore the importance these patient-consumers place on behaviours and intentions to "identify likely information sources and use them to retrieve relevant information, assess the quality of the information and its applicability to a specific situation, and analyze, understand, and use the information to make good health decisions" (Shipman, Kurtz-Rossi, & Funk, 2009, p. 295). Sources of health information and verification include healthcare providers and other people, as expressed by this participant,

All the health professionals say you can't rely on what's on the internet to be accurate. In those sorts of instances I always check with those that have had the training and talk to them. I mean, I might do some reading and say, "What do you think of this? Is that right or wrong?". AFT#12

The patient-as-seeker positions their behaviours in this category according to his/her health event, lifestyle, health belief, or treatment preferences; for example,

*...we had a family doctor who was overly into natural remedies- You'd have colds and sore throats he'd prescribe onion juice or lemon and honey, sometimes we wanted stronger. So it's a balance...we do talk to them [healthcare professionals] about things that we're doing and they tell us that yeah this works; that doesn't work; this is dangerous; that is not; you shouldn't be doing this, **but matched to how we want to look after our health.** AMT#2*

and for some participants their seeker behaviours reflect particular health risks they may be predisposed towards; for example, a Pacific Peoples participant stated,

I do my own checks on the computer on things like what is my number on Heart Foundation thing. I do that, or even go and do what's your mental state. PPFT#15

Participants repeatedly expressed a strong sense of individual responsibility in their conceptualisation of health literacy as seeking, researching, and becoming knowledgeable. For example,

if I have a problem then I will go to the internet or go to the library, so I could find the information from there. Because the doctor, you can see them but you cannot talk too much with them, you want to find out

what happens and don't have time to discuss like a friend, impossible. I realise that. AML#41

I don't suppose you're prescribed a tablet and told, "This is an opiate and it can be very addictive." That's why I think when we're prescribed something we should actually find out what the effects are. EFL#11

I think everybody should do some research before you go to see your GP, then you might have a big picture, more idea. And then when the GP tell you something you can understand. You can even give him some mention; I mean remind him about this part or that part And the GP might say, "Oh I didn't think about that part either". AFT#23

I thought, okay this is what I need to do, and so I started finding out where they pushed and where the pressure points were. Once I understood what had to be done, very often when it came back I was able to fix it. Basically within about two hours I was right. So I've learnt from that that you should never ever take anything for granted. Whatever comes your way regards to information soak it in and just keep taking it in and just keep learning from it. MiMT#45

For many participants health information-seeking also implied greater agency in their healthcare contexts. This was described by one participant as 'having nouse', in relation to identifying information sources, verifying information, and then leveraging these resources for their benefit in a healthcare encounter. This participant describes a typical seeking process,

I mean, there's an awful lot of information online. Probably, it's trying to find something that was relatively objective and I guess I've got enough nouse that I can work out what is objective and what is basically promotional material. It's sort of looking for facts I may not have, it may not give me all the answers but there's perhaps, looking at options and then once I've established that then going to my doctor
INT: *So you did some of that searching before you went to the doctor?*

Yeah.

INT: *And so you went with the information and then you talked about it?*

*No, well, I don't tend to go along and say, "Well, I've looked this up and this is..." But basically that's just stored in the back of my head. **Basically I go in there to have a discussion with the doctor** and probably it's a bit like a lot of other things, you know, whether it be purchasing any other item, you've got that information that you need that's gonna help you. Perhaps, determine whether the information you're gonna get from this case, your doctor, is going to be helpful or trustworthy. EML#13*

Interpreting the participants' perspective of health literacy as a seeker revealed their integration of health information with action - their health literacy behaviours were purposeful and focussed. For example,

So I was very conscious about making sure that I live longer than my father and the way to do that was lifestyle, diet and finding out what's going on inside my body. And go to the doctor and they do all these blood tests, they aren't gonna give them to you unless you ask. So, I was, "Give me all the blood tests you have". MiMT#30

Behaviours and experiences in this category of description (common with others) reflect participants' lay views of health (their belief systems and motivations regarding health, Hughner & Kleine, 2008); in this case, health is a moral responsibility that can be met (at least in part) through being informed, in turn enabling the individual to proactively achieve good health outcomes,

*I just kind of see it as I've got that choice - either get on and do it myself and try and nut it out or just keep being sick. I guess that's what motivates me **to find out for myself what I can do**. EFL#8*

*I found every information then I try to study. I think everybody need [to do] this because **this is our health, our self**. AML#41*

In addition, a consumerist orientation to health is echoed in the participants' perspectives, pointing to a sense of entitlement to information,

*You need information, yeah. You know, it doesn't matter what it is; a doctor shouldn't hide information from you. Your healthcare person should give you all the information that he's got about it, whether it's good or bad. You should be **given** [participant emphasis] all that information. And of course then you can start asking questions like I asked Dr XX. EML#5*

...if I have to fight to get someone to tell me what I need to know to understand then that just winds me up. MiFT#17

Participants considered that investing time and effort in these seeking activities was evidence that they wanted to be engaged in their health discussions, equal to their healthcare professional; information adding authenticity to their ability (health literacy) and their health issue. Therefore, participants' health information-seeking influenced the nature of their healthcare relationship since there were

implicit expectations of respect, trust, and reciprocity from the healthcare professional;

*I suppose I just research so I know what I'm talking about when I go in, so **no one can fool me**. Or I'll ask questions about, "What the hell does that mean? Don't be using big words because I'm not a doctor! Say it in a way that I understand." MiFT#27*

*Sometimes before I see them I have already do some research about my problem and I print a lot and then when I talk to them I show them. Sometimes I argue with them so **I'm not a very popular patient because they say, "Oh are you a doctor?"** AFT#23*

The challenges and contradictions of the patient-as-seeker role are illustrated in three instances where 'seeker' behaviours have patient-imposed boundaries, emphasising that health literacy is a negotiated practice. Frequently, participants had an innate sense of how much information they wanted or when they wanted the PHCP to be the expert, demonstrating the paradox of expertise,

*... **I don't want to do a medical degree while I'm sitting in the interview.** MiFT#17*

*I'll start talking to those professionals that I hope will give me some balance, but of course there is some vested interest in the medical health profession to promote where they're heading as well. So that's another issue. I'd like them to actually look outside the pharmaceutical aspect of it...if enough health professionals made those enquiries, perhaps they could debunk [what I'm doing] ...but until they can prove otherwise, **I'm going to keep doing my own research.** EML#43*

*But any other thing **I expect to go the doctor, check me out, either give me medication to tell me this is your problem, you need surgery or whatever and then end of story.** AFT#26*

Nevertheless, participants expect the PHCP to respect their knowing and to be equally knowledgeable or if not, to be motivated to research and verify information. Many participants are practised seekers of information and need their level of knowing to be taken seriously; for example,

...I find masses of research on arginine and citrulline and I think most doctors probably don't even know what they are for. EFL#8

I'm constantly looking to see how it's changing. So there's a whole lot of new research at the moment looking at nitrous oxide...looking at

amino acids and peptides - looking to see how they impact upon disease and well-being and health. So I'm taking two amino acids. I take them twice a day. MiFT#19

Often the participant's seeking was dismissed and discredited, as below,

He [GP] looked at the list of supplements that I'd spent about a thousand hours working out the programme for Ian [the participant's partner], which was all based on extensive research, and he looked very briefly at that and said, "Oh no, I think that's far too much to put all those together. It's better to just have lots of baby spinach and lots of green vegetables and lots of bone broths and good diet. That's what I would do." EFL#8

An informed patient-as-seeker expects the health professional to be at least as well-informed and research-capable as they are. Although, as one participant expressed below, this was sometimes not fulfilled,

*I've changed my GP. The one we're with now is very different from the previous one but I'll give you an example from the previous one because I think it's quite relevant. I went along with all the background scientific information on this [testing for Vitamin D], on one sheet, so it wasn't too stressful for him, and I presented this to him and it turned out that in New Zealand of course they only did the useless one [of the tests]. But aside from that he looked at my sheet... I said, "You might be interested to read this," and he looked at it and he said, "**Oh, I'm not into biochemistry.**" EFL#8*

and many participants shared the following participant's opinion that they had to develop and continue their own searching and evaluating behaviours because,

...don't start me on that; because the pharmaceutical aspect, I mean how often have they misguided us, because they're a money-driven organisation. For some of those more common things, if you look back; it's not so prevalent now, but you will find that over time certain doctors would be prescribing certain things for certain conditions, based on the fact that they were all looked after for doing so...people go, "Oh yeah; nah, a health professional - they'll just prescribe medicine." EML#43

Essentially, the patient-as-seeker expected the PHCP to be a co-seeker,

*He [the healthcare professional] said, "You continue what you're doing. I think that's great." I said "But have you ever looked into this?" and he said, "No." And I said, "See, that's the problem, I have. Maybe if you looked into it **there could be a balance here.**" It's like my blood*

pressure pills; they up my blood pressure pills and I said, "What I find interesting is; can anyone tell me why I have this issue?"
[PHCP response]: *"Well Dave, you're getting older and that's what happens."*
I said, *"But there must be something causing this."*
[PHCP response]: *"No, we don't really know." EML#43*

The seeker role enhances lay expertise through being a distributed practice across multiple information sources, including PHCPs,

So I will generally either go and contact a friend who's a doctor and say, "hey do you know?" Or I will contact the doctor's services down at the [clinic]. They are pretty up-to-date. MiFT#19

Being competent at verifying health information is part of this role, aptly described by an Asian participant as *"when you touch many then you will know what is correct, what is not"* (AML#41). Critical and evaluative checking was commonly accepted as an integral part of researching and health information-seeking; until verified, information was only data, rather than a 'resource' for their health literacy. For example,

Yeah, I always check, I always do check with somebody that's a professional and it would probably be my family first rather than the healthcare provider, depending on what it is. AFT#12

I don't trust a lot of things on Google. What I do is I just don't read one article, I read a few and then I see what the views are. But I wouldn't trust it explicitly as in 100%, it's just more information. Sometimes from the information I might just speak to family members who are in the medical field... they would be able to say, hey this is junk. AFT#26

Importantly, this information seeking was inseparable from individual judgment on validity, relevance, and ultimately, risk. One participant talked about the research he had done on statins,

Generally I like to look for both sides of the story because you will find lots of people going, "Yes," and then I look at all the ones that go, "No." Then you're trying to evaluate where they're coming from... Then you have to start weighing up where the risk factor is for you and what you're willing to accept and what risks you're willing to take. EML#43

Most participants desired a PHCP to be co-seeker, verifier or assurer of information. However, this often led to frustration with limited collaboration or a perceived sense of bias which diminished the efficacy of the patient's own efficacy as seeker,

I did ask the food health people, you know that sell the health products. And I did ask the doctor but they said there's no harm done to you, but doctors will never recommend you take things like that you know. They'd rather give you the hormone tablet and all that, which I don't want. AFT#16

Ultimately, though if I start getting confused then I'll start talking to those professionals that I hope will give me some balance, but then if you want to go down that path, of course there is some vested interest in the medical health profession to promote where they're heading as well. So that's another issue. EML#43

These participants did not subscribe to the view that e-health and technology-based information promoted a compliant and passive patient role. Online information was viewed as one of multiple sources of health information, and if they did not consider themselves competent to understand or validate that information, then their seeking health literacy role extended to others in their social and family networks. The seeker, while not distinguished by their connectedness, nevertheless used informal and infrequent contacts with network members to research healthcare recognising the value of both lay expertise and healthcare professionals.

If it's something that I am strongly suspicious that a doctor isn't going to be able to throw much light on, I would first of all start doing a bit of research myself to get an idea of what's going on, on the internet and books, and talking to people who I think are knowledgeable. And then if it's something that I want a diagnosis on to know that I'm right about what I'm dealing with... then I will head to a doctor to check it out. EFL#8

...a lot of it's just reading about it, you see it on TV and you read about it. My wife will do some research on it herself and she did some reading on the kiwifruit phloem tablets and so with her vote, I know it's pretty good. MiMT#30

I go with it in my head and then just see what he comes up with and question it, and suggest things that I've learnt to see if it's relevant or not, and just sort of try and gather as much information as I can. EML#5

The behaviours and intentions expressed by the patient-as-seeker can be likened to market gurus who “tend to acquire [market] information not from consumers but from elsewhere (technical reports and brand websites...)” (Chung & Woodside, 2012, p. 315) and who like to gain new market information for their own reasons and benefit. They are unlikely to care about how much they influence other consumers and have traditionally been considered as *not* seeking out information from other consumers. Participants who exemplified the seeker-as-guru role showed they were highly organised and dedicated to what was typically a long term role, as shown below:

...when I see things which I don't really know or understand then I start Googling. Even medication or something, if I don't quite understand, I'll Google and just see the reviews and comments.

INT: Is that about something that you think might be relevant to you?

...Just information. Not related to me as in I've got a problem, I need to check up. But whenever I hear something I think is interesting. It could be general, it could be related to cancer or some of the common diseases, then I might just Google and find out more. AFT#26

I was choosing [the treatment] I think, yeah. And I remember thinking, well... I'll find out more about these two different treatments and so that's probably when I started Googling them. Over time I realised that there's a hell of a lot of research going on right now and I thought I'm not gonna spend every day Googling but I'll just set up a Google alert so if anything changes I'll get a flag. EMT#4

Largely internet, but also books that I have accumulated over a period of time, and one particular source who gathers huge amounts of information and annotates everything, everything in her book refers back to the study that she's basing it on. And so I like that kind of thing. EFL#8

One participant had a large book which he explained as follows,

10 years ago I tried make a dictionary about what kind of information in Chinese is what equivalent. I do this because some maybe is not correct but I try to do this. So like I find the English and what it means in Chinese; you can see, ordinary medical words, I found this, and breath, and nervous system [showing detailed parts of the book of all the medical terms and parts of the body translated into Chinese]...So I also find all the equivalent for every word, I found every information then I try to study.

INT: So that was just out of interest for you to be?

Yeah, I interested everything. If I need then I study and find. In my opinion and my information on hand, it's enough for me because I correct many many about medical issues, what happen what I'm going to do in New Zealand.

INT: You've got a big book there of it.

Yeah, yeah, so I think no problem, and if I had some heart problem, my eyes have a problem, what's going to do. AML#41

Constructive questioning was an integral part of this conceptualisation of health literacy for these baby boomers, not just from an individual personality perspective – “*that's just the way I am*” (EFL#11) and “*because I'm a person who would ask lots of questions*” (AFT#16), “*I'm a researcher by nature...so I bloody go looking and find stuff*” (MiFT#7) - but also that this is part of the socio-cultural context of health literacy. For example,

*...I think I would be quite capable of it [questioning health advice/getting more information] if I wasn't happy certainly I'd feel quite confident to be able to go and question that, think about it...now I certainly would. **It's recognising that you can.** EFT#1*

Yeah you used to sit and listen and take everything they say. Whereas, yeah I question things. So if they say to me that I might need antibiotics for something I say, “Well why, what's antibiotics going to do to them that if I don't take it what's the difference.” Because I don't like medication a lot. So yeah I often will question, “Do I need it?”. PPFL#22

Yes because I'm very proactive in looking at, do you know like medicine is zooming along alright. I mean even though I don't work in medicine I keep an eye on it to see what happens. MiFT#19

[Dave]: Just about every time. I want to know [asking the PHCP], “Why? Why are you doing this?”

[PHCP response]: “Well, Dave, because this is the best we've got.”

[Dave]: “OK, any other reason?”

[PHCP response] “No.”

[Dave]: “So what about this?”

[PHCP response]: “Oh I don't know about that.” EML#43

The seeking role also included seeking justification, explanation, and evidence for applicability of health information, diagnosis or treatment in a specific situation - *- it's up to him [PHCP] to actually convince me (MiMT#45) - and*

I told her [the PHCP] what had been going on. And she said, “Oh I can see what's going on there”...she explained what I was doing

posturally that was causing this six months of constant pain...she told me exactly what she could deliver and why it would help. EFL#8

And so what he did was he explained the injury and then what he was doing and I thought, you know, it made sense to me so, yeah. Then I got another netball injury so I went back there instead. MiFT#7

Some participants sought information and were questioning but still delegated the decision to their PHCP; the patient-as-seeker did not always expect to exercise individual control over health decisions. For some participants there were contexts, or parts of healthcare contexts/encounters, where they negotiated their health literacy roles to be less ‘patient-as-active-engaged-consumer’ and more compliant and ‘I-expect-the-physician-to-fix-me’, for example,

I think I expect like if I went straight in there... ‘cause we all know when we go to GP you expect them to give you the right information, the right treatment so you can [be] cure[d]. PPML#40

For medical people I would definitely only go when I wanted information or diagnosis or something. I wouldn’t go preventatively because I am actually really afraid of the things that they suggest people do preventatively. EFL#8

...so that he [GP] can tell me what to do to stop it happening again. EMT#4

5.2.2 Decider

In the decider category the distinctive efforts, activities, and skills are those whereby individuals exercise their choices and are the deciders in their own health decisions (refer Table 5.3). Therefore, this construction of health literacy is categorised as being high on the self-horizon. The decider role is characteristic of the baby boomer participants’ emphasis on individualism, individual discretion over health literacy behaviours, active decision-making, and taking responsibility in their health. Their construction of health literacy includes proactive behaviours and personal judgment combined with an acceptance of individual responsibility for health. Proactive choosing and preventive ‘deciding’ and their translation into acting are fundamental in this category of description for the phenomenon of health literacy.

Table 5.3 Summary of Decider category of description

Key meanings	Description	Illustrative Quotes
Choosing	Exercises choice	<i>And so, if I have some really bad effects like real dizziness, I'll just stop taking them and think this isn't working; I don't want to go through this. MiFL#36</i>
	Uses discretion	<i>So I went to our GP and said, "Look, I want this [done] because I thought it's my body and this is what I want". EFL#10</i>
	Understands opportunities	<i>So no we didn't go back to him, no we haven't been back to him. MiFT#19</i> <i>You get the choice in the end don't you? I mean I feel you get the choice. As long as you're well-informed, you get to choose. MiFT#19</i>
Acting	Proactive & preventive	<i>So based on that kind of information and background, as a family, we've decided that we'll apply a conscious approach to our decision making about what we eat, encouraging ourselves to be engaged in exercise. PPMT#14</i>
		<i>There was a time where I was not very happy with stuff. So I went for an ECG and got a heart check-up just to make sure that everything was okay because I had a scare. AMT#2</i>
		<i>No I don't get a reminder [for a 12 monthly check-up]; if I've got a spare day I just either ring up or book a week ahead EML#29.</i>
Taking responsibility	Demonstrates self-determination	<i>I'm the person responsible for my health and using them [healthcare professionals] as advice really. PPFT#24</i> <i>I mean, it's my body and so it's up to me to know what treatment's happening and what I do accept. EFL#11</i> <i>I had four times the maximum recommended by the World Health Organisation So yeah, things weren't looking good. I really had to do that myself; come to that conclusion myself and follow up [myself] from that. EFL#8</i>

Decider

Participants' understand health literacy as a predominantly individual capability, lending support to Ruger's (2010) health capability framework that positions the individual as the unit of analysis. While relationships and contexts are apparent, the individual's health capabilities and exercise of choice differentiate this category from others. The patient-as-decider emphasises that health literacy is about the individual realising healthcare choices through their capabilities. Therefore, the three key actions in the decider category of description - choosing, acting, and taking responsibility - all assert the individual identity and presence in health literacy,

*I have annual medical check-ups as a preventive because I see our healthcare system as the ambulance at the bottom of the cliff and **I'm trying to be at the top of the cliff** before I get to the bottom. So I'm very conscious of my health. I go to my GP, obviously to get tests done. EML#43*

*Yeah I go with my own information. I went to my doctors and I asked them; you know I checked on the website; checked out where the clinics are and I found out what I needed to do; went to the doctor and said, "I want [xx] operation." And they were ooging and aghing, I said, "No, no, no, no, this is what I want you to do." **This is what I want you to do because I'm going for it.**" So they did. ...And I just said to the [GP], "If you don't give it to me I'm going somewhere else. Wherever I'm going I'm gonna get it done." So I got it done. MiFT#27*

The patient-as-decider role embodied the perspective that the patient did not want merely to be the recipient of the PHCPs' decisions, rejecting the professional as expert and the patient as passive and compliant; instead theirs is a central health literacy role, "Yeah, I'm calling the shots and it's not somebody else" (EFL#10). The healthcare meeting is a professional service encounter where the individual can choose to discuss options, care and treatment,

*I remember going to a GP and he said, "Oh this medicine is not working, I think it should be stronger." And I said, "No, I don't believe that's the case. I didn't realise that his Ventolin was out of date." I said, "Just give me an up-to-date one; **I'll see if it works first.**" So I said, "I want you to prescribe me some Ventolin and..." I said, "And [emphasis] **I want you to prescribe me that** and if the Ventolin doesn't work then I'll use that." I actually suggested that, they didn't suggest. AFT#12*

*I've been fortunate; maybe all the ones I've dealt with have basically given me real options and choice and **basically it's been up to me.** I've*

never felt as though I've had the wool pulled over my eyes over a treatment whether it be through my doctor or through any other health provider. EML#13

In consumerist terms, this patient-as-decider category could be characterised by 'choice' (compared with the Manager category emphasising 'voice', Section 5.2.5). Choice, at times, may be the patient following the healthcare professional's advice albeit explicitly acknowledging their presence in the decision,

I'll either stop taking them or continue depending on the effect; if it's a really bad effect I'll stop taking them and I'll ring my osteopath and talk to her about it. Like when I had the middle ear one she says to me, "Well I think you need to continue taking them because of the nature of the infection that you've got." Take probiotics, increase your fluid intake" and all those things. Yeah, so I just do that. MiFL#36

The participants clearly articulate their desire and experience in being active in their healthcare, characteristically expressed by one participant as follows,

You know he just plonked me with a box full of aspirins to thin my blood. A box full of pills to lower my cholesterol! And I looked at this box and I just said no I'm not going to do it. And everyone says you're mad, you shouldn't do that, you should do what the doctor says. And I said "Nah, I want to just try and do it through diet". EML#5

and exercising discretion over health literacy behaviours, even if the resulting choices contradict established practice or their PHCP's advice,

I should have [had the blood test] cause it was cholesterol but that's one example of me sticking my head in the sand. I thought, well, when there's an obvious problem I'll go back and deal with it. I don't want to know if I've got blood pressure 'cause I feel great. EFL#11

I know about my mental health and I manage that first and foremost so things that I've got...that I don't really wanna know about because I suspect they're not a lot, but they might be something really big, as soon as I go to the doctor and give them [i.e. the participants' mental health 'things'] some value it's gonna take over my life and I'm gonna be really obsessive, so I don't do that. MiFT#17

So [I've] been on the waiting list, but timing's not right [for me], so I've just left it and it's still like that today. MiMT#42

...Because when you taking pills to lower your high blood pressure you have to keep going; you have to keep going to take that tablet. Otherwise if you stop the blood pressure will be high again. So I

control myself with foods; with exercise; with medication and then it go down. Not take tablet. AML#33

The self-horizon (refer Section 5.3) is the predominant focus for the decider category. However, in circumstances where the self-horizon recedes, for example where the decider's actions, skills, and efforts focus on family and network members, this practice of discretion is moderated according to duties and responsibilities of those other roles. For example, one participant expresses how she exercises her discretion for "fear of finding something out", accepting that within her strong focus on patient-as-decider there are seemingly contradictory behaviours according to whether they apply to self or others in her networks,

There's a little bit of head in the sand, only in regard to me, not my children or my mother. MiFT#17

The patient-as-decider rationalises their discretion when they are the object of the discretion, "I ignored my leg 'cause I'd hit my hip and fell sideways. It was only the next day that I realised I'd actually hurt it and I ignored it" (MiFT#19), but typically when others are the object of their discretion and decision-making, the decider asserts individual responsibility and decisiveness; for example, the same participant who exercised her discretion above also asserted,

...I'm now re-educated about that. I tell S when she has to have her blood tests, I tell S she should be checking this, we check the levels. I tell the doctors, have you checked the levels? That sort of thing. That's because I think the GPs, in my view, they have a ten minute session, so they're there to treat us as quickly as possible and then get us out of there. That's fine, I mean they have to make a living but in terms of health it's a bit more than that eh? MiFT#19

Selecting or rejecting a healthcare professional was a fundamental aspect of this health literacy category of description,

...I decided to change my GP because I figure that a GP who's not into biochemistry is not somebody I want to spend a lot of time with. EFL#8

That person [healthcare professional] will always be tested as well, just like lawyers. The interview first, before you appoint them to do anything, same deal. So there's got to be an affinity. MiFT#17

Although, the patient-as-decider can exercise their choice to return to a healthcare professional, in many cases, voicing dissatisfaction was not considered useful or productive. Therefore, typically “exit won the argument” across all ethnicities, being a frequent behaviour described by non-European participants (Simmons, Powell, & Greener, 2009, p. 5, citing Hirschmann, 1970, who differentiated between exit, loyalty, and voice). Most participants did not confront or challenge their PHCP face-to-face but instead decided to “just walk away, change to another doctor, and never come back to see the first doctor” (Chiu, 2011, p. 1659). Generally, these participants said how they “...go somewhere else...they go sideways” (MiFT#19) to get to a PHCP where they are accepted and where they can satisfactorily engage in their decider role, “That’s when I Googled it and found that guy. So no we didn’t go back to him, no we haven’t been back to him” (MiFT#19).

Nevertheless, the ability to exit a healthcare service and the interchangeability of healthcare professionals is interwoven with other health literacy roles requiring ‘resources and nouse’ (similar to the phrase used earlier for patient-as-seeker) as expressed by one participant,

*...and for me being middle class, middle aged pakeha, well-educated and I’ve got the **resources to make some choices**. Not got the biggest resources in the world, but if I’m not happy here I can go there, I don’t have to stay at XXX ‘cause they’re cheap.... **And I’ve got the nouse, you know, I can move.** EFT#1*

Not only does the patient-as-decider require resources (see Bourdieu, 1986, on social, cultural, and economic capital), but the ability to exercise healthcare choice is often constrained, or even absent, in remote areas. Institutional processes and systems may also constrain the patient-as-decider, for example,

*...GPs are like a farmer drafting the sheep really. And I don’t think that’s good enough anymore. **I think people really would like action.** I think that the doctor’s become the middle man and we don’t need them. **Yeah there’s too much waiting around and having a guess.** Speculating about it [what might be wrong]... EFL#3*

...they didn't take the time to listen and he [GP] just brushed it off, "Oh we'll deal with that later, we'll have a look at that later on" the menopause thing. PPFT#24

One participant (EFL#3) tells a compelling story of the challenges and frustrations inherent in her construction of health literacy as patient-as-decider, her vulnerability, and the healthcare system,

Yeah it's me, it's my day, every day that's annoyed and upset by these headaches or whatever the issue is.

*You sit there and you say [to the GP], "Oh I've had a few headaches and I don't ever normally get headaches." And he'll go, "Oh well I think you've probably got a nose infection I'll give you some antibiotics for a month." And I'm thinking... "Okay I'm prepared to go for a month but then **I want some action.**" ...I'm thinking, "**Why don't you just give me a scan and then we can put it aside.**"*

*I think it's all about instead of giving us information that says, "You are well yippee", they go, "**Oh it could be this, it could be that.**" I think there's too many delays in giving people information to let them know you are well. There's like, "Well we'll try this and if that doesn't work we might try this." And then next thing you know you're either dying or the problem's worse.*

*I think it...becomes fear or scariness about where it might lead. And you want to be quickly informed that that is not it. **And so to me putting someone on pills for a month to see if it'll go away is not okay anymore.** Yeah because we do have equipment out there...*

Despite variable health contexts, opportunities, and resources, the participants clearly experienced their health literacy in terms of 'options' and choosing, along with their sense of entitlement and abilities to explore and act on their options,

*So I understood what they were saying but I also believed that **we've got control over what we want to do and what we don't want to do and ultimately it's our decision.** If he [GP] wouldn't do it, well, you had to go somewhere else and find what you want. EFL#10*

...if there's anything serious that requires doing I'll take a flight and go to India and get it done there. If it's a knee operation or a hip operation or a heart transplant or something I'll get it done there. I've got that option why do I have to sit over here and wait. They're the same doctors; the same Indian doctors here or the same Indian doctors there. And the facilities there are equally good so there's no big deal. So we've always got that option there. AMT#2

If I find the GP here is not suitable for me, is not reliable, then I maybe change GP but until now is work good I think. AML#41

...so I got the next guy in the practice. Then when I gleaned that he wasn't really on the same wavelength at all and that view was solidified by the vitamin D experience, then I made the decision to go. EFL#8

*And the cholesterol, he keeps going on about that and I said, "Well look, I don't really want to start taking cholesterol tablets. What else can I do?" I said to her [a locum], "No, I'm not taking pills." And she said, "Oh, why not?" And I said, "Well, I don't really wanna start another lot of pills. I would rather not take pills. I'd rather do it myself." **So that's what we're doing.** EFT#6*

The participants may sometimes demonstrate less knowledge than PHCPs and at others considered themselves to have more knowledge. These baby boomers expected to be the active decision-maker; and depending on individual priorities, values, health context, or information [a]symmetry, they simultaneously expect the health literacy role of the PHCP to shift from "knower to facilitator" (Aujoulat, d'Hoore, & Deccache, 2007, p. 18). As illustrated in the following excerpts,

But the hospital said, "You should really be taking aspirin forever more." I'd already done my homework on that and there are lots more effective ways of thinning your blood than aspirin and they don't mess up your stomach for the rest of your life too. So we've got that one covered so that was all right. He just knows that we will [use alternatives] anyway. They can't force you...that's what he said, "If I prescribe this stuff for you, you won't take it so there's no point me prescribing it." EFL#8

I'll go there with some pointed questions and say, "What am I missing here? This is how I understand it, what am I missing?"

INT: So how do they react when you do that?

Well it depends what it is. Quite often there's a little bit of that smirking thing like "here we go, another bloody home-learned doctor". But generally they'll fill the gaps.

INT: They'll fill the gaps and not be opposed to your proposition?

No, because I've left the room if they're not going to be open to that before we ever get to deciding what I'm gonna do about it. And I have, many times, saying "I don't think we should pursue this conversation it's finished about now". MiFT#17

INT: Let's just talk about the cholesterol thing. You did your own research and at that time did you go back to your doctor with that research to have a discussion with him or her?

It was, I guess, a process of trying to get my mind around accepting I was gonna have to get on medication so I had a number of years to work through that. So when I had done the reading and decided that, “Yeah, we do need to get it down.” That’s a decision I made and we actually agreed and started me on medication. MiMT#30

This active choice is not without interpretive processes, information, or support from resources (health networks and healthcare professionals), but the self-horizon is more in focus as these ‘others’ recede,

The thing that I liked - he [PHCP] was basically there to provide me support around a decision that I was wanting to make and that was it. EML#13

...went through lots of websites; talked to lots of nurses and it’s really a personal opinion. So in the end I was given that information and I had to make my own decision, which I did. MiFT#27

...So I just took the initiative myself. PPFT#24

These patient-as-decider roles were intentional, focussed efforts to resolve certain health demands,

If I feel unwell I will try to do something by myself. Take some medicine. I have a drawer, old drawer full of different type of medicine and ointment. I took it here from my country because I know that kind of medicine is good for me. AFT#23

...very often I’ll say to him [GP], “What do I need to do in order [to be healthy] because”, I said, “I want a full evaluation, whatever that means.” ...He’ll say, “Well, that’s your blood pressure, diabetes, we’re looking at your cholesterol” and he’ll give me the list...and also with regards to prostate testing I said everything. I said, “Whatever it is men at my age need to have done just do it. That’s it. End of story. Regardless of whether you think I’m healthy or not, just as part of preventive so that I know.” MiMT#45

Understandably, the participants’ understanding of health literacy around being the patient-as-decider implicated the relationship, role behaviours, and perspectives of the PHCPs. Sometimes these aspects were barriers to the decider role of health literacy; one participant illustrates this when she sought diagnosis and treatment for a stomach complaint, she had a blood test and then,

...I said, “What’s happening?” and he [GP] got on the phone and said, “No, doesn’t show anything. Nothing. If you had an infection or you

had this, that would show up, and there's nothing; your blood's fine except your cholesterol's a little bit high." I said, "I don't want to know about that at the moment. I'm worried about my stomach, thinking, gosh, what's happening. Okay, I will come back for that but I don't really care that my cholesterol's a little bit high at the moment. I'm really worried about my stomach." He says, "Nothing. We'll just see what happens in a week and then if nothing else happens you'll have to come back again." EFT#6

The self-determination intention underpinning the patient-as-decider role found common expression in participants wanting to be the one deciding how healthy they were. For example, this excerpt illustrates how one participant expressed frustration due to him feeling his health literacy was thwarted by a system he perceived as only dealing with the unhealthy,

...if you want a full health check for your whole body why can't you go to the hospital? even if it costs you a hundred dollars or whatever, and just say, "Right I want a full [check-up]," and they do all that. EML#29

Although choice could be considered as empowering (summed up succinctly as choice gives power to voice, Le Grand, 2006, but also see Aujoulat, d'Hoore, & Deccache, 2007; Lupton, 1997), these participants associated choice and the decider role with elements of risk and uncertainty, understanding this decider role as a precarious freedom - where effective choice is mediated by resources, education, and affluence. The burden (or paradox) of choice for these participants emerges from, in part, incomplete information, verification of information, lack of influence over available options, vulnerability, and/or uncertainty over efficacy of options for meeting needs. Being a patient-as-decider carries inescapable responsibilities,

I would really love to have a doctor I could go to and just not have to bother with all of this stuff when things happen and just hand it over and get the information, but it's not there. And I doubt that it ever will be anyway because no one human is going to know everything and they're not necessarily going to take on board everything ... in the end a lot of it comes down to judgement and they're not necessarily going to have the same judgements. EFL#8

Participants considered that their patient-as-decider role in health literacy helped to affirm their value as a worthwhile patient, these behaviours and intentions

signalling that they had both an ability and desire to be engaged in managing their health. For example,

*I think that I arrive well-informed and prepared to have a discussion. Yeah, so I guess I do my work to actually say and if something goes wrong with my health I know it's because, you know, it's usually overwork or it's maybe something in the environment that might have brought that about; because **I try to look after my health.** MiFL#36*

In this role health literacy is experienced when the individual regulates their help-seeking behaviour with regard to PHCP consultations; deciding when there is genuine need and being parsimonious with regard to the healthcare service resources,

*So some of it is self-diagnosis based on what I know and then I might talk to some of my health, family and friends and **I'll just decide from that so it just really depends.** I only go to a GP if I really need medicines or I might need a blood test or something like that 'cause I want to check my cholesterol or something like that. AFT#12*

Many participants “just get on with it” (EFL#3) acting, choosing, and taking responsibility,

...initially with this arthritis treatment, I had to have regular blood tests, and I'm pretty sure from memory I had to push it...make sure it got done. Not that it was a major but I don't remember them ringing up to say you're due for another one of these. EMT#4

You've got to be in charge ...I don't remember him ever saying you need to do this, you need to do that. It was up to me. EMT#4

...once a year, I do a full battery of blood tests and then every three to four months I do a series of blood tests for cholesterol and those sorts of things. Just to make sure my cholesterol allocation is okay. MiMT#30

However, the meaning of responsibility is multi-faceted. Dworkins' typology of responsibility is useful for understanding the patient-as-decider role (cited in Minkler, 1999, p. 122) as being: role responsibility (one's body belongs to oneself and 'I know my body the best'), causal responsibility (one's health status is in large part determined by personal behavioural choices), and responsibility based on liability for costs and other undesirable consequences of one's ill-health. For example, role responsibility,

I think a lot of it's to do with attitude and I think it's our responsibility to keep ourselves healthy by being aware of what's good for us. EFL#11

...if what they said is not good for me well I'll just stop taking it and I'll just go in and see them and I'll say, "I don't trust this drug." Because sometimes you feel worse for taking it rather than going without it completely. That's the way I've lived my life. MiML#44

causal responsibility,

I think sometimes it's a combination of facing up to perhaps bad patterns that have set in or bad habits and changing that cycle yourself, because a pill doesn't change things long term. I think you've gotta actually look and think, well what am I doing that is exacerbating this, or what could I do to change it? EFL#11

and responsibility based on liability,

...now that I've just turned 60, I did when I was 50, I do what I call my 'warrant of fitness'. My philosophy with regard to health is that your body is your responsibility; if you don't want to become a problem to society, look after it. MiFL#36

As expressed by these participants, their responsibility does not exist in a vacuum. Even as patient-as-decider, there exists a crucial interdependent role for the healthcare systems, processes, professionals, and the community to be responsive to individual priorities for health literacy, for example,

I am hoping I'm strong enough to say, "I'm sorry but I don't wanna do any more guessing about this headache, can you just take a picture of it, of my head. And then we can say "that's what you've got; that's what it is; it's not tumours or anything else." EFL#3

5.2.3 Networker

Interpreting and combining the health literacy experiences of the baby boomer participants, a patient-as-networker category emerged that describes intentions, activities, and skills emphasising social and family networks. From the participants' perspectives the high interactivity embodied in this category of description builds/contributes to health literacy among all the network actors; the network is a context for sharing, dialogue and learning. The networker role does

not emphasise individual decision-making (low to moderate on the self-horizon, refer Section 5.3). Nor is there strong intent regarding the integration of multiple aspects/resources concerning a health condition (moderate compared to the patient-as-manager category, Section 5.2.5). Therefore, the networker category brings to light one way of ‘seeing’, at the same time downplaying other ways of seeing health literacy (Morgan, 2011).

The impact of social and family networks on individuals’ health information and healthcare seeking is nothing new. McClean and Shaw (2005, p. 746) identify how lay people use friends and relatives in their processes to “adopt, mimic, critique, or rewrite expert positions”. Furthermore, Dew, Chamberlain, et al. (2014) emphasise that households are “...hybrid centres of therapeutic practice...and a central site of health practices and decision-making...” (p. 40), rejecting the notion of the individualised patient in healthcare decision making. Participants in the current research also described stable networks that were given prominent status in their health literacy; some of the networks being specifically established for health. The patient-as-networker expended effort in participating in these networks. Drawing on marketing literature, this category is typical of ‘market mavens’ (Kontos, Emmons, Puleo, & Viswanath, 2011) who deliberately network for the benefit of other network actors as well as for themselves. These individuals are keen to share their knowledge within their social network and were acknowledged by these baby boomer participants as a person others turned to and respected for their knowledge and advice.³⁵

³⁵ By contrast, ‘market gurus’ are considered just as knowledgeable but their knowledge and information seeking is not for the benefit of the network members.

Table 5.4 Summary of Networker category of description

Key meanings	Description	Illustrative Quotes
Relating	Committed to relationships	<i>So I just took the initiative myself but the key factors for me were talking to my friend and following my gut and my son's partner, she's such a cool girl and she said, "Come on ma we're going and I'll come with you." PPFT#24</i>
	Shared values	<i>Normally very often, because my close friends, doctor, some is in XXXX society, some is not but is close friend, we gather together and we discuss about health and everything. AML#41</i>
Connecting	Shares advice	<i>[I use] my networks - family and friends, social networks, yeah, professional networks. People that I know that may have had some similar sort of issue or have mentioned something. But that's how I work in everything so that's me. Connected. MiFT#17</i>
	Market maven	
	Altruistic concern for others	<i>...she gave me this information which I've kept and I've been able to hand it on to other people who've got similar things. EFL#11</i>
Partnering	A shared enterprise	<i>...we know how to look after ourselves because sometimes the information we gather is very good because we have a group, we just research how to keep your health good. AML#33</i>
	Leveraging collective knowledge	<i>...once I've thought about what I know and what's gone past me, I use my networks for a steer, for a recommendation. MiFT#17</i>
		<i>Yeah if there's stuff out there that is available for our people then we try and inform them so that they can try and access it too. PPFT#21</i>

Networker

The key meanings interpreted for this category of description are: relating, connecting, and partnering (summarised Table 5.4). These meanings are weaved through the participants' conceptualisation of health literacy discussed below. Both men and women participants constructed health literacy in terms of patient-as-networker. Among the research participants the Asian baby boomers clearly demonstrated highly structured and formalised roles as networkers. This contrasted strongly with European baby boomer participants who were often highly-networked but less formally, and the Māori participants who, while indicating considerable variability in their connectedness, were typically networked with their whānau.

The respondents constructed health literacy embedded within a network of referral, information, and advice from family, friends, and colleagues,

I've got quite a few friends who still, like they're doctors and things and if I don't know I'll give them a bell, I'll Facebook them or whatever and I'll say hey... MiFT#19

My mother first, always comes first and then I go to the doctor. AFT#16

...she's got great information regarding drugs and everything like that; antibiotics, I'd just ring up and say, "Well what's the medication," I'll tell her and she'll say, "This will do, da da da da." I feel lucky in that way. MiFL#36

According to the baby boomer participants the patient-as-networker was a connected identity for whom health literacy was a shared and distributed practice. The network was an influential part of health information seeking, not always preceding the consultation with a PHCP but often being used to verify options or to develop alternatives. In this role the participant networked with others relying on them as mentor, coach, and referrer, for example,

Sometime I ask Ann [participant's good friend], she teach me how to talk to doctor. Send email, email come in and I write down, show my doctor, because of sometimes I say something doctor didn't understand.

INT: You talk to Ann about what's wrong with you and she gives you the questions to ask?

Yes, yes, give me some questions; I want to say something to my doctor. So I write down and show my doctor. AFL#34

I do have a very close friend and mentor in town that I see on a regular basis so if things are ever troubling me I drop in and see her. ... so I talked to my mate, Sue first and she said, "Mate I told ya, get in and see that acupuncturist." She'd mentioned it to me before and of course I've always had my funny ideas about that. But I went, I went. PPFT#24

I was getting more and more miserable because it was at the point where just doing anything with that side and I'd get electric shock, horrible pains, and I felt very debilitated. And one day a friend said to me, "I haven't seen you for ages," and I told her what had been going on. She said, "Has anybody ever suggested to you that your posture might have some issues?" She said, "I've noticed that you tend to be a bit more compressed on one side," or something like that. She told me about this person. So I went to her. We were going away and she had a half hour appointment and I said, "I'll take it. I'll do anything. I'm desperate." EFL#8

Being connected with their networks is a deliberate and reasoned choice made by participants that echoes and overlaps with the categories of seeker and decider, "I value things that she has to say. So she's my other person that I would consult as well...I check them out with her" (MiFL#36). Despite numerous network memberships the participants only rarely mentioned contradictory information, since typically the network members had shared values that reinforced individuals' health beliefs. For example,

*We talk to the family members. There's plenty of medical knowledge within the family. So there's plenty of grandmothers who know what's going on...through talking to family members, "What's happening; what do you think it is?" And **we know our history**. AMT#2*

*People that I know and **I know what they would expect** when they were getting information or making decisions or being taken care of or whatever. So it's that domino thing around that person's not gonna put up with any [shite] and she's gonna have done the research. So, "Who do you talk to when you've got stuff going on?" MiFT#17*

In these cases, the individual 'weighs up everything' within their personal yet networked context, overlapping with their experiences as sensemaker (refer Section 5.2.4); participants experience health literacy within their networks of family and friends as shown below,

...most of them [friends] help, even though my problem may not be 100% matched to their information, but they have some relevant idea about it. So if I have some problem I ask this one she might say, "You should do this way." And if I ask that one, they might say, "Oh don't do that that's too dangerous." And they have some fact or something, "You should do this." And every one they thought, "We are the best." But I make a decision for myself. AFT#23

Sometimes, the information [from other sources] I just email it to the other family members and ask them what do you think of this? Sometimes I get a reply that "yeah it's good to follow up" or they might say, "yeah that is the new way". AFT#26

...we were talking about cholesterol or something and they [family members] said, "Oh, don't go on those pills, they're horrible." And I'm going, "Oh, okay then. Right, I don't really want to go on any more pills." I've got one set of pills, that's enough. I'm sure there must be other ways...They'd been on these pills and they were horrible or something, so I thought, okay, it's nice to know. EFT#6

There was frequently a grounding of participants' health literacy experiences in formalised health-specific networks, distinctly manifest among the non-European participants. The excerpt below is from a Pacific Peoples participant,

Two weeks ago we had a group of Pacific women, we got together cause there is a contract [Ministry of Health programme] on sexual health but because it's a taboo thing to discuss, I suggested, "Why don't we do a women's night?" So we had a very wonderful night. PPFT#15

Casual informal networks were common among the European participants, for example, "Us girls get into the sauna and we talk about all sorts of random things and if someone's got something wrong with them..." (EFT#6).

In all cases the patient-as-networker role embodied a strong sense of collective endeavour in the participants' construction of health literacy,

***We can do it** [health information, lifestyle, good health outcomes] **collectively**. We could manage to do it on our own, **but with the help of others** its really boosted up what we are doing. You know, I believe the other information, the other resources that we have from them, it really helps. PPMT#38*

Furthermore, the patient-as-networker negotiates the healthcare system via these relationships, networks, and referrals. In this way, their connectedness equally

extends to the healthcare professionals and thence, as if in outwardly extending concentric circles, to those professional's own networks. The strength of these overlapping networks was acknowledged as participants readily availed themselves of the benefits,

*...through association with him and other physios, **I've got** a couple of **choices** but often I liaise between two if one says go to the other. Or I would either ask my GP if I really wanted to discuss it or the physio, because **they're so in cahoots with each other**. EFL#11*

*Well, because of the **contacts I've built up over the years** I can generally go to the individual that I need to see if it's specialised healthcare. EML#43*

... if I go to the doctor he will then say "talk to so and so", and he'll ring up the person and say, "Dave is going to get hold of you," and I'll go and see the specific person I need to see. EML#43

Participants typically followed their networking processes by internalising the advice and taking action. Therefore, the connected identity of the patient-as-networker was counterbalanced by the individual 'presence' and their subsequent practice or behavioural outcome. For example,

*Ian's [the participant's partner] dentist in Auckland had just been to an alternative health convention where there was a cardiologist from Sydney who had talked about research she's doing using, it's called magnesium orotate, and how he now thinks it's absolutely fundamental for any heart patient. So that was very timely so we added that and then **I came home and researched it to make sure**, and sure enough it was all extremely positive. **So we added that one to the list**. So, then things like that that **people have told us about; but then I always go and check it out**. EFL#8*

*That coincided with this other guy coming to town who I already knew about from a woman I know who does Bodywork and she had worked with him. They'd sort of done various things together and she had told me about him and how different he was and how he had similar nutritional ideas to me. He came from [location] to [location] at that point. I saw a wee thing in the paper about it **so jumped in and put us all down for him**. EFL#8*

Therefore, alongside the networks of family and friends, PHCPs form part of the individual's health literacy community. The patient-as-networker engaged in relationship building, interacting with their healthcare professional as someone they "could have a chat with" (MiFT#19), and acknowledging

...the spin-off benefits from meeting a healthcare giver who's not just, "How do you do. Sit down. We're going to do surgery," and blah de blah. Somebody that you're seeing on a regular basis - yes, I think it has huge benefits because it builds up a trust, a relationship, it's totally professional, you get to know them as well. EFL#11

Individual responsibility in the patient-practitioner relationship building was fundamental to the networker category of description. According to this construction of health literacy, partnering and purposeful relational behaviours created the favourable conditions important to the reciprocity the baby boomer participants expected within their health networks. For example,

*I think you get back what you give too. I think you reap what you sow, so to speak. "It's my personal business, I don't want to tell you too much" doesn't work - but I think if you do tell them a little bit more then they can **read you a wee bit better**. EFL#11*

*We've pretty much stuck to the same crew [healthcare professionals] all the way through; they've moved around a bit so we just followed them. **You get a good one and you just follow them and stay with them**. EML#29*

Some patients-as-networkers demonstrate behaviours characteristic of market mavens. Mavens are typified as people who specialise in being sources of information, who are influential in their social group, and who are willing to share their knowledge and experience (Kontos et al., 2011). They are influential disseminators of health information that they have collected and sorted. The health maven can be likened to Belbin's specialist role in a team (Batenburg & van Walbeek, 2013); specialists are passionate about their learning in a particular field, providing in-depth knowledge and enjoying imparting this knowledge to others.³⁶ The health mavens strive to build on their information and expertise for their own benefit and for their network members.

Market mavens consider it important to share their knowledge with others in their social network, for example,

³⁶ There is no suggestion however that the health maven exhibits other specialist traits, such as the self-centred focus on the specialist's own subject of choice and the privileging of self over the team's progress (Batenburg & van Walbeek, 2013).

...I tried to talk to men, I mean, to change their lives, you know, do other things. It's more or less like trying to promote good health. ...Yeah, I went and a few friends of mine around here they invite me because I like talking and I think I like constructive talking. PPML #40

The patient-as-networker, similar to a market maven, is committed to the network with a sense of obligation to share information,

..he have always a problem and whenever he have some problem I do some research and I print it out the information and show him, "That's your problem, you have to pay attention of this part, this part, this part." AFT#23

Within this category is an altruistic concern to help others in the participants' network without seeking personal gain; the [health] mavens are knowledgeable people often continuously searching for health information. Below, one participant discusses her connection to others and her obligation to help others by engaging in seeking specialised medical information, organising, and recording it,

Sometimes I collect this information from internet and because I have a book; this book is about 100s of problem; the book, very thick. Any kind of problem is kind of alternative treatment or something.

*Most of the programme about medical in the TV has something to do with myself or my family or my friend. If that topic, I think, "**Oh somebody else I know they had that kind of problem,**" I'll pay attention of that programme. And if they have some information, because I can't write it down so I take my camera and take a photo and put it in my computer.*

*So in my computer I have a file and the file is about health and different type of disease or problem. Stomach is a folder and heart disease a folder; arthritis a folder, yeah. **Then can let friend know.** AFT#23*

In addition, health mavens use their network knowledge for referral behaviour, for example,

And Terry [the participant's son] had been reading something because he was in the middle of all his health dramas with his chronic fatigue and he said, "You should get those root canals out"...So he actually came up with a dentist in Australia, Brisbane, who has a practice dealing with mercury poisoning and takes out amalgams in a very different way. EFL#8

Sometimes these networked people accumulated information incidentally through their routine use of health-specific sources, compared with purposively seeking or scanning for health-related content,

I mean I watch a lot of all these health shows and when I see things which I don't really know or understand then I start Googling. Even medication or something, if I don't quite understand I'll Google and just see the reviews and comments. Just information. Not related to me as in I've got a problem, I need to check up. But whenever I hear something I think is interested. AFT#26

I think everybody need this because this is ourself...so you study everything because can use ourself. Also can help my friends. AML#41

The interpretation that baby boomers' constructions of health literacy encompass market mavenism emerged from the texts of both men and women. The reported reluctance of men to consult medical professionals and seek social support was not supported by these data (e.g., Bradlow, Coulter, & Brooks, 1992; Cameron & Bernardes, 1998; O'Brien, Hunt, & Hart, 2005; Reddin & Sonn, 2003) - this finding is particularly noteworthy given that many participants were in the age group (over 60 years of age) of men typically considered to be less accustomed to taking an active role in their health. Indeed, the majority of the male participants were enthusiastically committed to and connected with their networks; this was particularly evident among the Asian participants.

Finally, the patient-as-networker, by constituting health literacy through and within layers of social networks of other health consumers and healthcare professionals, effectively co-creates value for others by providing ideas, sharing knowledge, and offering referral advice (e.g., Rihova, Buhalis, Moital, & Gouthro, 2013; Witell, Kristensson, Gustafsson, & Löfgren, 2011). Therefore, health literacy is conceptualised and experienced in this category of description as an intra- and inter-subjective practice and phenomenon. The networks described by these participants are both informational and social, integral to which are health mavens who both contribute to and obtain value from the network. Therefore, the relational network acts to extend the opportunities, capacity, and mobilisation of individual agency.

In summary, this category describes how participants' understand health literacy as contributing to, and constituted through, the networks they participated in. While some patients-as-networkers were especially knowledgeable and active referrers, acting as health mavens, all were aware of their presence/position as reciprocating actors in networks of varying formality. The collective 'we' was experienced among friends, social groups, PHCP relationships, or whānau,

What we tend to do is, if we see someone, for example, my sister was saying she was talking to one of her friend's children...She just said to him, "Look, we know of someone that you can go and see. Would you like to come?" And he said to her, "Well, what do you think, Aunty?" And she goes, "Well, I've used this person and I think it would be good for you." "Oh, well, then I'll come. Will you take me?". MiFT#7

5.2.4 Sensemaker

The sensemaker category for health literacy describes a balanced disposition (of an individual) toward taking responsibility for making sense of health information and a pragmatic direction of his/her own health with acceptance of the authority and expertise of the healthcare professional. Sensemaking competences include individuals' experiential expertise, self-knowledge and pragmatic expectations for evidence and health outcome (refer Weick's seven key properties of sensemaking, 1995). In terms of primary healthcare, this category includes behaviours and intentions whereby individuals experiment with alternative medicine approaches when they are supported by evidence and outcomes - paralleling Weick's (1995) extracted cues and plausibility. In this sense, dissatisfaction with conventional medicine was that it 'doesn't make sense' for them and does not align with their health beliefs or identity. Participants constructed health literacy in this category as encompassing both consumer choice and accepting reliance on PHCPs' expertise and advice,

Wherever there's a gap or a question or when the dots just aren't joining. What am I missing here? I'm happy to do the, "I'm missing something, something's not lining up. You're gonna have to run that by me again or fill me in" ...It's got to be logical; it's got to make sense. MiFT#17

...probably [go to GP] to try and figure out why. EMT#4

Interestingly, the Pacific People participants characteristically constructed health literacy according to sensemaker activities, efforts, and skills. These participants recognised individual responsibility for health but they were also predisposed to relying on healthcare professionals for health-related information and treatment decisions.

The key meanings within this category of description are: experiencing, experimenting, and [self] understanding which are summarised in Table 5.5. This sensemaker role includes contemplating goals and information, exploring information and possibilities for health, reflecting back on past experiences, individually and collectively. Health literacy is experienced as an awareness of experiential authority in health that has been accumulated through life and networks, similar to phronesis or practical wisdom (Rubinelli, Schulz & Nakamoto, 2009). The sensemaking construction of health literacy can be understood as a means by which participants reduce intrinsic uncertainty, complementing rather than contradicting the seeker who aims to reduce informational uncertainty, and is tacit acknowledgement that both these forms of uncertainty (intrinsic and informational) exist in healthcare and health literacy (Seeley, 2013).

Table 5.5 Summary of Sensemaker category of description

Key meanings	Description	Illustrative Quotes
Experiencing	Experiential authority	<i>So I'm always just checking with the information I've known before in terms of what's happening...information that I've been building on for a lifetime. MiFT#17</i>
	Knowledgeable	<i>I suppose having lived through that, maybe you then have the confidence not to get in that situation again. So maybe that experience gives you the maturity or you survive it. EFL#10</i>
Experimenting	Engages in trial and error	<i>Well, he couldn't explain what was wrong with me so I thought, well, I could do something else. It was carrying on and he had no answer for it and so I thought, oh well, I'll just keep looking. EFT#6</i>
	Triangulating and testing	<i>Sometimes I'll wing it cause I just think something sounds like it's got a lot of potential and the description of it is sounding like it should do what they're talking about and flying a kite to some extent. And it always is when there are not people around who have all this at their fingertips and who can be consulted. EFL#8</i>
	Pragmatic	<i>They [PHCPs] explain it to the best of their ability but the fact that I can see it and experience it working is what I need. PPFT#24</i>
[Self] Understanding	Self-aware	<i>I sort of knew I was better. I could hear him saying to the nurse, "I can't understand this, I can't understand this." And I didn't tell him I didn't take the tablets. EML#5</i>
	Interpreting experience to facilitate problem solving	<i>I'm very good at listening to my own body and I know it well enough now to know when things don't feel in balance or feel right. EFL#11</i> <i>...whereas now I'm 56, I'm not a kid. I know right from wrong...what I feel right about and what I don't feel right about...It sort of presented a good balanced picture. PPFT#24</i>
	Reflecting	<i>Yeah, having to weigh it up really; yeah just have to judge it by externalities. EFL#8</i>
	Contextualises health	<i>Certainly it's a balance between the trust you have in them and the advice you're getting...you already have a degree of knowledge about this stuff that they're advising you on. So that you're sort of like, just checking them a little. MiMT#30</i>

Sensemaker

Sensemaking can be evidenced in all of the categories of description from information seeking, through to networking and managing (Section 5.2.5). The distinctive component about this category is the explicit desire and action for sensemaking, involving different strategies and processes to enable individuals to create meaning by connecting and contextualising health messages and information; *I got the connection you know (EML#5); everything fell into place and I thought, "Oh, is that why" (MiMT#45)*. This category is identified as being most salient in those situations that are ambiguous, uncertain, and confusing.

Sensemaking effort and behaviours work to preserve an individual's self-understanding and self-identity (Weick, 1995), albeit multiple identities influenced by socio-cultural norms and expectations. A predominant health 'sense' among these participants was the preference for non-invasive and natural interventions, similarly espoused across gender and ethnicity, for example,

I think that I'm conservative in terms of intervention with your body. Once they poke something in your body or muck about with something, it's now trying to repair what they did. MiFT#19

Every day you read in the papers, hormone tablet can cause you cancer, that the contraceptive cause you blood clot; what do you do. I don't believe in all this medication anymore. And after that you think too much of this is bad for your kidney. AFT#16

Because normally we like buy natural cure, not chemical we don't like. But we more trust the natural cure. AML#33

But I don't take medication on a regular basis, I'm certainly not gonna do it for something that may or may not ever happen again [talking about her reaction to an episode of gout]. EFT#1

These participants' texts fitted the larger picture of how they perceive and interpret their identity. These shared identities resonate with a stereotype that characterises baby boomers as questioning of the status quo, individualistic, and environmentally and socially conscious (e.g., Sudbury-Riley, Kohlbacher, & Hofmeister, 2012). However, the behaviours and intentions of this category may also reflect the "normative rules of the community or status group to which these baby boomers belong" (Abel & Frohlich, 2012, p. 237) and their life stage. Notwithstanding the antecedent conditions, the baby boomers frequently made

sense of health information shaping it according to their self-identities and these shared norms and expectations,

I think there's some merit in those things [health supplements]. I mean for example; I drink constantly large doses of Vitamin C, Lysine and several other nutritional supplements, in the hope that some of these things will assist in maintaining a decent level of health and also improve my immune system. Fortuitously, some of what I've been doing; I've been able to get measured as well. Because there is a lot of alternative medicine therapies which may be unproven in terms of scientific proof. Lysine for example is meant to help with cholesterol and clearing up the binding in the arteries. I've had a CT scan and they were kind of a little astounded in the fact that they could see where the plaque had been deposited but they couldn't find the plaque. That kind of supported what I was doing because that was actually what was meant to happen. EML#43

They did not discount medical science, experiencing this sensemaking health literacy as being a critical interplay between interpretation and action (Weick, Sutcliffe, & Obstfeld, 2005),

...preventive maintenance is only when you understand and when you know why you have to do it. 'Cause you can do a lot of things but it's no good doing a lot of things when you don't really know why you are doing them. So I want to know why I do or why I have to do what they say to me that I should be doing...so whatever they say to me I've got to take that on board and then I'll use that to my advantage. MiMT#45

These participants appeared to implicitly understand the informational uncertainties by reframing professional advice according to their past experience and health goals and beliefs, *If I don't understand I'll ask...So give it to me differently...so no one can fool me (MiFT#27)*. Their inescapably subjective sensemaking applied information and advice to their individual context, which paradoxically could be construed as risky by those adhering to other health beliefs. One participant (Jim) was told that one of his heart chamber muscles was dead through lack of blood...

I was absolutely mortified and I came home and I thought nah, nah...I was given heaps of pills down in W [location] for that...they're still in my drawer in the bedroom. I just couldn't; didn't want to go down that path so I did it by just changing my lifestyle and exercising more, running more...I didn't tell him [doctor] I didn't take the tablets. EML#5

In this example, Jim balanced the risks of his actions with his presumptions and plausible explanation – that is, sensemaking - of his condition (diet-related). His choice to act in the way described above arises from his self-examination, reflection, and application of his own skills in this sensemaking and in subsequently effecting behavioural change. Was there a place in this healthcare event for improved sharing of values, patient goals, and sensemaking with the health professional’s information and expertise? If the patient’s multi-faceted sensemaking (their construction of health literacy) is overlooked in healthcare encounters ‘good’ health outcomes may be foregone. At what point does the patient-as-sensemaker relinquish his or her health literacy in order to make ‘good’ health choices? The Kantian view of autonomy would answer that only those choices that are arrived at rationally (not those arrived at idiosyncratically or non-rationally) are to be respected.

The participants’ sensemaking often demonstrated resilience when confronted by contrary advice, reinforcing the original sense the patient has made,

...he wanted to put me on statins, which I reluctantly agreed to. He said, “Dave, what you’re doing is good and please continue with it. However, the difference between what you’re doing or what I’m doing is the difference between you using a fire cracker and me using an atom bomb.” I said OK. I said, “I guess then the fall-out from the atom bomb is going to be a lot greater than the fire cracker as well,” And that’s kind of where we got to. EML#43

Sensemaking was a social activity as participants used networks and conversations in evaluating hearsay, anecdote, expert advice, and scientific evidence; in this way they were making sense of how others make sense of events or conditions. For example, this participant described her health literacy experiences as a process of triangulation and testing what she learned,

What I learn, that’s the best, that’s the correct one. So if I have some problem if I ask this one this part she give me; she might say, “You should do this way.” And if I ask that one, they might say, “Oh don’t do that that’s too dangerous.” And they have some fact or something, “You should do this way.” And this one might say, “Oh that’s not strong or something. So sometimes I have to have a judge by myself. AFT#23

Reflection allows the individual to incorporate their experiential knowledge...*because those medicine have been taken by myself for quite a while. So I know it work (AFT#23)*, and perspective to make sense of health information and health choices.

I guess having a bad experience or feeling that you're not empowered and knowing what that feels like was enough to say, "All right, I'm not gonna let that happen again." Or, "I'm not gonna put myself in that position." Maybe it's just something that you have to go through and experience and then take control and say, "Well, I'm not going to let that happen again." EFL#10

Using reflection, past experience, and dialogue with others, they were trying to answer the question of 'what is the story?' to build a plausible interpretation out of ambiguous cues,

I read it in a magazine that how they cause you blood clot and all that. I don't wanna do that. So I don't wanna take it you know what I mean. And now they say hormone cause you breast cancer, I don't know what is right and what is wrong. So I've never taken it; my mum never taken it. AFT#16

Well, he couldn't explain what was wrong with me so I thought, well, I could do something else...he had no answer for it and so I thought, oh well, I'll just keep looking.... EFT#6

But the cholesterol, I thought... someone else said to me we were talking about cholesterol or something and they said, "Oh, don't go on those pills, they're horrible." And I'm going, "Oh, okay then. Right." We were just all discussing it - I don't know where it was - and I said, "Right, I don't really want to go on any more pills." EFT#6

Within this combination of reflection, testing, and interpretation, these participants showed that sensemaking was equally interactional and relational in closing the gaps caused by incomplete information or contradictory explanations,

***It's around the relationship** [with the PHCP], understanding the credibility, whether I've tested it or not, whether it's proven or not, whether it lines up with other stuff that I know out there. MiFT#17*

*Well because he [the PHCP] has built up the relationship - the advice is sound; it seems to work. So it is building up, you know. **So over a period of time you know** whether it's good or it's bad. AML#28*

*I think the ability that we are able to communicate and build a relationship, not shy away when you need help or you need to clarify something. Ability to take the initiative, to find out more about something...That has helped us not to be **locked up**. PPMT#14*

It is interesting to note the atypical analogy in this last declaration of sensemaking as that of freedom, not being 'locked up', compared with the image of closure and providing structure through sensemaking. Intuition, too, was a part of sensemaking providing one means by which individuals accommodate the intrinsic uncertainty of healthcare described by Seeley (2013). For example,

I had confidence in her as soon as I met her. That's how I am with people. I know whether they've got it together or not in my opinion. I know whether I can trust them or not. I don't have that with everyone, but I trusted her. PPFT#24

I respect their training but I also think we need to give people the ability to stand up for what they think is right as far as their own healthcare goes. EFL#10

For other participants, this intuition or inner sense was likened to a spiritual dimension that resonates with them as a person and serves to bridge the gaps. When confronted with discontinuities, unresolvable gaps, and change, many participants experienced health literacy as this sensemaking, allowing them to justify decisions and [non]actions,

I guess when, like all things, when you read a book or a poem or something on telly or in a song, it speaks to you. It's like that thing knows you, knows your heart, knows your mind, knows what you're thinking, feeling, going through. It gels with who I am and what I'm experiencing pretty much. PPFT#24

...sometimes some of the information I get, I don't know where they get the information from. I mean they have their things and they put it on; well I don't know nothing about that, but spiritually, if I feel good I'm good. MiML#44

I feel that, the things that I am given and the advice that I am given, resonates with my thinking as to how I think that the body should be taken care of. MiFL#36

Just an awareness, I guess. Certainly it's a balance between the trust you have in them and the advice you're getting, but then an awareness... MiMT#30

While not abandoning other health literacy roles, these expressions of the ‘spiritual’ dimension to sensemaking as health literacy emphasise that these baby boomers implicitly acknowledge the irreducible uncertainties in the health domain.

Sensemaking allowed the participants to reduce the tensions they experienced around uncertainty,

So I guess I've just made it a point to always ask, "What's its purpose? And what are the consequences if I don't?" So I'm always, I've always got that in the back of my mind whenever I go, just so that for myself I guess it's just more the peace of mind. MiMT#45

...I'm very sorry for me to questioning your job but I think it's my job to worry about my daughter. PPFT#31

So an important aspect for sensemaking is the question of what is going on here, the subsequent question is what the sensemaker does (Weick, Sutcliffe, & Obstfeld, 2005). A common mechanism for this phase in sensemaking is interpreted as participants experimenting and engaging in trial and error - being prepared to “wing it” (EFL#8) and improvise. For example,

*And I explore my options, **explore every avenue**...for almost two years I try physiotherapists, I try acupuncturist, it didn't work. So I look for alternative. AML#28*

*So I just racked my brains, 'cause at the same time the doctor said my cholesterol was just way up, and that's something I just couldn't fathom...And then four days later I thought of this [diet element] and **then went to work and didn't have any of that**, and I cut down on all sugar and fat. EML#5*

*Sometimes I just think, "Hey, look, certain things help with certain ailments, **just give it a go and if it works it works**, if it doesn't, go and see your GP." AFT#12*

*And so somebody says, "This is fantastic 'cause of this and that." And another one she swears by stuff like ...Try it and **give it a go and then give it away**. EFT#1*

These trial and error behaviours implicitly recognise that health literacy and health decision-making exist within a domain of equivocality,

It would be nice to be as informed as you can as a lay person when you're going for professional advice; same as going to your

*accountant, same as going to your lawyer. When it comes to your health I'm quite limited because; you know the health professional says, "Well this is it," and that's all you can do. Well, you know you're kind of limited as to what you can and can't do. You've gotta sort of rely a little bit on what they're telling you. I just sort of question the veracity of what they're telling me; get some information, go back ask more questions; so I reach a point for me that says "**okay there's not too many other options** based on what he's telling me and what I can find out". EML#43*

Through all these intentions and behaviours of patient-as-sense-maker, these participants expressed their sense-making both within themselves and between others, summed up as, *Hunch in the first instance about the person I'm talking to and second opinions, every time, every time there's any doubt (MiFT#17)*. The patient-as-sense-maker is pragmatic, *I will use my way to find out what I should do (AFT#35)*, and *I have to have evidence that it works (MiFT#27)*. Finally, in the words of one participant,

...where, you know, as long as I've got a logical map towards understanding or making decisions if necessary or at least understanding the course of treatment or the response that's being offered then it's fine...it has to make sense and I think so often it doesn't. MiFT#17

5.2.5 Manager

The final category of description interprets and explains the combined experiences of the participants according to the classification of manager. The manager deliberately and purposefully organises, decides, and manages health, integrating multiple health resources and their own competences with other network actors' literacies, skills, and competences. This category of description relies on dependable relationships and an understanding of systems and processes occurring in individuals' health spheres. The patient-as-manager collaborates with other experts and network actors, incorporating and organising experiential expertise and scientific information to enhance health literacy. This category is therefore classified as high on the two horizons of self and interactivity (refer Section 5.3 and Figure 5.1).

The key meanings that emerged in this category of description are: integrating, directing, and growing, summarised in Table 5.6.³⁷ The behaviours and skills participants experienced as health literacy as-a-manager do not replace the expertise of the PHCP. The manager category describes someone who is both a sharer of responsibility (re-embedding) and a decider; a delegator or an active researcher; a user of alternative medicine, or accepting of biomedical healthcare. The manager brings ‘on board’ credible and respected partners (healthcare professionals, health mavens, or other network actors) negotiating health literacy as a social and interactional practice. Similarly, the manager considers PHCPs as guides and facilitators, often as trusted and credible partners, “*Yeah well that relationship’s based on my perception of their credibility and competence*” (MiFT#17), but also considered to be replaceable, “*We didn’t go back to him*” (MiFT#19). The manager expects options, information, and resources appropriate to their health needs, ultimately expecting other (equally) well-informed actors to be partners in their healthcare. For example,

A very good experience would be that they then give me some advice about preventing anything going forward as opposed to only looking after me as a result of me going to see them because I have a problem. ...If you're looking for that definitive, where I sit down and have a parlay with my doctor; and we come out, where he said, “Yeah Dave, look I think you should do all these things; this is a good thing for you.” I don’t think I’ve ever had that experience...”
EML#43

The behaviours, roles, responsibilities, and positions encompassed in this category were frequently illustrated in the health literacy experiences and understandings among the European baby boomer participants. However, there were no discernible variations on gender or age regarding this role.

³⁷ The manager category of description parallels many of the outcomes of health empowerment – I have purposefully retained the label of ‘manager’ for this category, avoiding the use of empowerment that refers to a complex psychological construct.

Table 5.6 Summary of Manager category of description

Key meanings	Description	Illustrative Quotes	
Integrating	Manages resources	<i>...it's really the ignorance that gets to me. I don't mind if somebody says, "Okay, I've researched magnesium moratate and I don't agree for this and this and this reason," and then I'll go away and think about that. EFL#8</i>	} Manager
	Collaborates		
	Encourages continuity of relationships	<i>It's just communication I believe. I also communicate to him what I want, or what I would like out of the health system. EML#5</i>	
Maintains constructive relationships with PHCPs	<i>Not just to go there and load him [PHCP] with a lot of things, but to actually find out how he is, how his day's been, which is what you basically do in any relationship. MiMT#45</i>		
	<i>Honest, we're honest with one another. MiML#44</i>		
Directing		<i>...as medical professionals they would naturally see [a particular option] as the only choice and outcome, but they were happy to give me the options. When I decided to go with the option furthest away from their profession they were sweet with it. MiFT#17</i>	
	Negotiated practices & responsibilities	<i>I have taken him [the GP] information on things which he has taken on board which I really admire him for. EFL#8</i>	
	Develops a repertoire of actions	<i>...he [the GP] said, "Oh there's a new one out and its actually proven to be a lot more effective and you can take a lower dose; it works a lot more effectively." "Oh why can't I have that?" "Oh it's not on the Pharmac list." So I said, "If there's a better option and I can afford it I'll take it." He was a bit taken aback with that. EML#43</i>	
		<i>...Sometimes with this doctor we go to now, he might say, "Oh, no, I don't think it's necessary to do such and such for this and this reason," and I'll listen to him. EFL#8</i>	

Key meanings	Description	Illustrative Quotes
Growing		<i>...he's gonna give me something to try and fix me, but I don't see them actually looking outside the square too much. EML#43</i>
	Expects options	<i>I really think the whole allopathic medical approach is very medieval. I know there's so much out there that is effective and so much more gentle and so much more in accord with nature and with true health. EFL#8</i>
	Responsive and adaptive	<i>Generally what I find is - and that's the disappointing thing - there is such a disconnect between mainstream professional health providers and alternatives. EML#43</i>

**Manager
ctd**

The patient-as-manager finds little contradiction between those behaviours clearly emphasising patient autonomy and responsibility, and other practices that embrace an acceptance of PHCP expertise and guidance. At times, the latter can translate into the patient-as-manager delegating health literacy responsibilities to others in the network or to the PHCP since participants adjudge this to be the most effective for the health event or outcome. For example,

...if anything does happen, my thoughts go straight away to my GP. I've never really thought of looking anywhere else because after all that's my GP and they know everything about me. If something comes up then I just go back to them and see them. MiML#46

We let the GP do what the GP has to do. AMT#2

These participants utilise the PHCPs' expertise and intuition as resources for their health encounter. Furthermore, participants' behaviours relying on their family doctor (or another PHCP) should not be interpreted as representing the passive sick role of a patient; in these instances the PHCP is 'counted on' as participants negotiate a different form of involvement with the PHCP, managing resources as part of their health literacy. For example, –

So I think what's really important too is that when you've been with a GP over a long time...he's more than just a doctor, I mean it's almost come to a point where basically if you've got that trust in him if he said jump you would, 'cause you've tried what he's said [his advice] so many times and each time he's been correct. MiMT#45

They've learnt a lot of things about medication I'd never ever want to learn. So if I want the answer to this I guess hopefully they'll have it [the answer]. MiML#46

The manager category of description is distinguished by patterns of behaviour, intentions, and skills that individuals use to integrate the multiple resources in their health spheres. The baby boomer participants identify their centrality in value-creating health processes, “*I want to be part of the process of getting better or staying healthy, as opposed to just going there and getting fixed*” (MiFL#36). Valuable health outcomes are achieved through the organising and managing of resources and multi-actor contributions beyond the individual's own resources. Frequently, participants expressed this in terms of information resources, but it

also related to relationships and networks wherein others were valued partners in the patient-as-manager's health process. Implicit in this way of seeing health literacy are the reciprocal flows of 'value' - information, advice, support, and the expectation of results. For example,

*I have a really good relationship with the GP down there. He's really cool. He's pretty up to date. He's pretty matter of fact and if he doesn't know he'll tell me, but he is really good at referring you to a specialist or knowing somebody that does know. I've always found that, a good measure of how, of **their integrity** really. If they don't know they don't blow smoke at you. He just says, "look I'm not really sure about this".
MiFT#19*

*My physio is a very, very good friend of mine; generally I have a great experience you know. We know each other so it's a bit of a social occasion and **he fixes me**.
EML#43*

*For me it's their ability to engage properly with the patient and know that patient, but also that they're reasonably well-informed and up-to-date with their information.
MiFT#19*

However, this construction was often expressed in terms of what was absent in the interaction, for example,

*Most of the time they just don't deliver - the GPs and people - and so they just go on doing the same old thing and getting away with it.
EFL#8*

*Quite often there's a little bit of that smirking thing like here we go, another bloody home-learned doctor. But generally they'll fill the gaps.
MiFT#17*

*You come away and you think, oh, he [GP] didn't do anything about this. And then you think, well, but I didn't push it either I suppose.
EMT#4*

If the decider category characterises the logic of choice (Mol, 2008) and the seeker category emphasises knowledge-gathering, then the manager category characterises the logic of care whereby the patient-as-manager integrates resources, developing behaviours and strategies for everyday living with the reality of health. These ways of managing are directed by the individual (*to find out for myself what I can do, EFL#8*) utilising whatever resources are available. They are goal-directed activities that are pursued despite healthcare system barriers or practitioner reluctance to participate in the individual's value creating

processes. The following excerpt follows the participant describing how she wanted tests undertaken to measure a family member's progress, in order to adopt and modify behaviours and strategies for health improvement; after being told that the healthcare system was not going to proceed with any '*further involved testing*', the participant's plan was,

...we want to monitor improvements and make sure that things are going according to plan...What I'm doing next is just continuing on with our programme and as he improves we'll just have to judge it by externalities and how much energy he has and how well he's feeling and so on, and then we'll gradually slow down on some of the stuff.

INT: So you're having to really just monitor it yourself?

Yeah, having to weigh it up really; yeah. EFL #8

The patient-as-manager exhibits a repertoire of behaviours and skills similar to expansive action (Jayanti & Singh, 2010), adapting these actions according to particular conditions, concerns, or contexts. Table 5.7 illustrates a selection of one participant's repertoire of behaviours that they experience as health literacy.

Table 5.7 An example of the patient-as-manager repertoire

Excerpt from interview transcript (EFL#8)	Analysis
<i>if I'm worried and I want to have a test of some kind, then I will head to a doctor to check it out.</i>	Seeks straightforward answer, objective measure, perceived low risk
<i>...if it's something like the sort of symptoms I had for mercury poisoning, then I would tend to start researching it myself and looking at what sort of different techniques there are for detoxification.</i>	High involvement, high complexity, no objective measure, mistrust of PHCP knowledge
<i>I went along [to the GP] with information on vitamin D tests. I wanted to get myself and Jane [the participant's daughter] tested. I researched this before we went and discovered that there are various ways they can measure it...</i>	Informed, objective measure, seeks responsiveness from healthcare system
<i>He [a new GP] came from N1 to N2. I saw a wee thing in the paper about it so jumped in and put us all down for him and within about six weeks his books were closed.</i>	Decisiveness, aware of events in their health spheres
<i>I couldn't get any useful help for a long time despite trying. I would go to doctors and I would go to acupuncturist who's good on some things, and various people, naturopaths...</i>	Goal-focussed, persistent, open to alternatives in resource integration
<i>I asked her if they tested for lipoprotein A and that was when I wondered if she actually knew what it was. And conventional medicine looks at cholesterol as the key to what's going on with your blood vessels, but in actual fact HDL and even LDL cholesterol can be quite... well, HDL is very positive to have it high and LDL isn't necessarily a bad thing if it's high - well, not high but if it's a bit above average. But this LPA lipoprotein A, if that's high then you're really in trouble because that's the oxidised cholesterol which is what you don't want. Obviously they don't think it's important enough to test for because they are in the dark ages</i>	Expanding capability and knowledge for action in the context of their own health
<i>So, the one [GP] I go to now is very different. He's very open-minded. He is very much into nutritional approaches to healing that are fairly similar to my own ideas, and he's a lot more open and aware.</i>	Choice of PHCP partner based on compatibility of health perspectives

The patients-as-managers are deeply engaged in their processes of health. They are continually involved in interaction, debate, and dialogue with multiple actors in their health domains, building their lay knowledge, which “can become the basis for a powerful form of knowledge production” (Gibson, Britten, & Lynch, 2012, p. 536). Consequently, the experiences of health literacy in this category were those that most frequently coincided with PHCPs discrediting and dismissing patients experiential authority and knowledge (“*I just really felt, she treated me like, you’re not a medical person; you don’t know what you’re talking about*”, *EML#13*), and PHCPs providing inadequate resources or time for the patient,

Sometimes when I’ve been there I get a feeling of I’ve interrupted and that they’re annoyed. Like it’s quick, it’s fast and it’s all over and out you go. So to me there’s no real one-on-one relationship type talk.
MiMT#42

The lay expertise of the managers supports their desire for a democratic and participatory healthcare encounter. However, PHCPs’ responsiveness to individuals’ health information expectations is a complex matter, since participants exhibit varied preferences ranging from those individuals expecting sufficient detail to make sense of health information and experiences (refer earlier, “*I don’t want to do a medical degree while I’m sitting in the interview*”, *MiFT#17*), to those who are exceedingly knowledgeable and expect the PHCP to be equally well-informed. For example,

I don’t like a doctor saying to me, “Oh no, it’s a waste of time taking high dose vitamin C,” with absolutely no backup information and then I find there’s been masses of research on that for a very long time for heart conditions. *EFL#8*

As demonstrated above (Table 5.7) the repertoire of behaviours varies within individuals, as well as variability in skills and behaviours existing between individuals. The manager category nevertheless reveals how these participants construct health literacy as an interdependent practice. Despite the negotiated practices that include patients seeking, researching, networking, they still want the GP to be a doctor. While the patient-as-manager acquires information and makes individual choices, the role of PHCP as expert may at times be expected and required, particularly if the knowledge is out of their reach (“*I’m a bit limited,*

because ultimately they are my health professional”, EML#43). The PHCP is expected to be a partner, collaborating with the patient in seeking alternatives, validating information, or confirming choices, *“if it’s something that I want a diagnosis on to know that I’m right about what I’m dealing with” (EFL#8).* Hence, this category of description comprises a “complicated dance of exerting or avoiding guidance around decisions” (Thorne, Oliffe, & Stajduhar, 2013, p. 294). In the following excerpt a participant tells about her lay expertise and her construction of ‘managing’ as health literacy which was constrained by insensitive healthcare professionals,

*I had more experience. So I saw the symptoms and even though you don’t want to believe it you think “oh my gosh”, I came to a point where I had to believe it. So I went, because I’d seen it before I sought medical help, advice and **I was brushed aside I felt because what I felt was they, it was kind of like, well what do you know? You haven’t got a degree, you’re not a doctor.** MiFT#25*

The key meanings in this category of integrating, directing, and growing find parallels in a manager’s behaviours and skills in the organisational world of organising, recruiting and leading, and negotiating. The patient-as-manager can never be dissociated from the PHCP expertise, variably dependent on them to validate their ideas, critique their findings, and check their choices. Sometimes poor (possibly absent) information prevented the patient being part of her health creating processes,

Yeah, really casual about it and I have to say that was disappointing and I thought this isn’t good enough...and then he sent me a letter saying, explaining that and sending a copy to the doctor that I had a goitre and nobody had ever mentioned the word goitre. I was like, “Really? Why didn’t you tell me this?” EFT#9

The manager wants action, and reflects on how to best get desired outcomes from better managing interactions. The patient-as-manager expressed determination and perseverance even, as in the illustration below, when these responsibilities and actions could cause discomfort and/or dissonance,

No I would never give up; I’d just keep going back. Saying, “Right what are you gonna do now about this.” Yeah and I’m bold enough to. ‘Cause I had someone say to me once, “Oh you’re really good at

going to the doctor”, [but participant replied] I don’t like going, I don’t like going and finding out. EFL#3

In the pursuit of their health outcome goal, a manager also displays clear focus and single-mindedness,

But I still won’t let the service blur me. It’s still what is outcome the most important to me. Not the massage; not the green tea; not... I mean you get treatment for two hours it doesn’t heal; it’s still no good for me. AML#28

Within the manager category, participants experience health literacy as including a desire to ‘do it their way’, managing health how and when they want to. Therefore, from the patient’s perspective, the phenomenon of health literacy encompasses an appreciation of how individuals envisage their health and the nature of their health goals. The manager understands health literacy behaviours to include coordinated and concerted action that is timely and goal-directed. As illustrated below, this understanding extends beyond themselves to expectations of other actors and collaborators within their health spheres,

Actually I would like to go on the list to have a scan. I think I’ll be doing more of that. EFL#3

[...it’s as if the PHCPs’ attitude is] “Yeah, but you’re not dying; we haven’t got time to muck around with you”. You know [almost like they are saying], “Come here when you’re turning blue and you can’t breathe.” EML#29

Yeah well I think it’s not fixing; as I say I still have my trust in western medicine. Just because it doesn’t fix it I go to elsewhere. I go to elsewhere as an alternative you see. If they fix me I would still carry on. AML#28

I think, “Well stop mucking around then, I’m gonna end up doing what we should have probably done six weeks ago.” EFL#3

The nuanced responsibility in participants’ construction of health literacy was not so much one of taking charge but rather the responsibility that is associated with integrating multiple facets and resources, negotiating, and managing relationships within their health domain, comparable to the manager in an organisation,

That’s why I started to seek the help but I wanted to do it combined with letting my doctors know what I’m doing so they know and...[the

participant also involves others, for example, by]...*talking to my son's partner. PPFT#24*

*I have said, "Yes **can I have blood tests.**"... 'Cause I have to have blood tests for my medication that I get, I've said, "Oh no it's time I had some blood tests again." And he'll [GP] say, "Oh yeah okay." EFL#3*

*I think that as a family we worked through all these things together...these people [PHCPs] don't know everything; that's always been my thinking anyway, that people don't know - **one person or a body of people don't have all the information; you have to use your own measure yourself.** MiFL#36*

The patient-as-manager recognised and appreciated the PHCP as a collaborative value creator with certain attributes,

*She'll [GP] spend a lot of time and she takes it really seriously and **she feels very dissatisfied if she can't nut it out.** I really like that. I think that's how medical people should be. EFL#8*

Health literacy is experienced as 'juggling' different options in order to grow their health literacy resources and enhance health and well-being. Part of this meant that the participant expressed frustrations with the healthcare systems and processes and some participants revealed reluctance to uncritically accept professional guidance, suspicious that the training of healthcare professionals produced a narrow clinical pathway. For example,

*Well we do know that the GPs will prescribe one particular stream of medicine. We also know that there are other streams of medicine that work very, very well. Like homeopathy has worked very well for us in the past and they will not accept homeopathy. So we know that **they are looking after a particular stream.** AMT#2*

We know, you go to the doctor you're gonna get steroids; you go to the doctor you're gonna get this. So that becomes the last option really. AMT#2

...medicine is changing so rapidly these days. It's not just a matter of giving someone a Panadol and telling them to go home. MiFT#19

*There's no point going any further than that because all it will do is rark them up and make it more difficult for that positive relationship and because it was obvious that she [PHCP] was working within **the constraints of what she's told and what she's taught** and that's as far as she wants to go. EFL#8*

Critical to integrating resources in optimising health was the building of constructive relationships within this manager category, as illustrated here,

I said [to my partner] “What we need out of these people [PHCPs] is the ability to get measurements of things periodically,” and it’s probably a good idea to have a peaceful, positive relationship because there is certain information they can tell us that’s quite useful and what should be happening when and so on. EFL#8

Supportive, reciprocal dialogue and concordance between patient-practitioner perspectives were sought in the patient-as-manager interactions for effective health literacy practices. For example,

[I look for] GPs and ones that tend to, I guess, listen to slightly alternative things; they won’t baulk at them. I’ll suggest something, I’ll say, “Hey, look I’m not sure if this is gonna happen but can I have some medicines just in case?” You know, knowing that I’m not going to OD or anything on them. They’ll be accommodating, you know, it might be travel medicines and I might just say, “Hey, look, I need this, this and that.” And they’ll say, “Yeah, fine.” AFT#12

[GPs with] Straight answers, no fobbing off. An acknowledgement that I will probably get it and if I’m not getting it it’s their responsibility to explain it so I do. MiFT#17

The participants were acutely aware of the benefits of relationship symmetry in the manager’s negotiated practices and responsibilities. Mutual respect, mutual sharing of information, agreement on action, and shared values (Charles, Gafni, & Whelan, 1997) emphasise the construction of health literacy as interactional, as frequently expressed in the participants’ interview transcripts,

...especially if it’s like “I’ve read about this dietary approach, do you think that would work?” It’s not worth an appointment for but if he [GP] comes back and says, “Yeah, give it a try,” or, “No, don’t do that because of the...” EMT#4

That there’s a sense of openness and willingness to hear one another; that there’s not condescension; that there’s no arrogance involved. EFL#8

...like the relationship I’ve got with my doctor is that it, pretty much, I can be totally open and honest with him and I know that he’s gonna be the same with me and that he’s gonna respect my opinion and I’m not

gonna be someone who's gonna be pushing my limited knowledge on the situation, bearing in mind that I respect his position. EML#13

...But it's still the information transfer isn't it? EMT#4

Honest, we're honest with one another. We don't beat about the bush or anything like that. We just say it as it is and yeah, nah he's good. MiML#44

These participants wanted consistency in a relationship with a PHCP (“*But if something really bad I insist on seeing him, because he has built up the relationship - the advice is sound*”, AML#28), more time spent with their PHCP (“*that's a problem with GPs, it's 15 minutes and really what can anybody do or say in 15 minutes that solve the chronic health problem*”, EFL#8), explanation and justifications that met their needs, and they wanted the PHCP to have at least equal information resources (“*he [GP] could say I've researched magnesium moratate and I don't agree for this and this and this reason*”, EFL#8) and if not, then at least the motivation or intent to search for information. All of these reflect Giddens' (1984) notion of structuration - the interaction between resource-related rules (the system of access to healthcare and time pressures) and resources (information, individuals, networks). Despite the interactional emphasis of the behaviours, skills, and intentions of the patient-as-manager, this category also incorporated a degree of individuation – that the day-to-day health literacy practices include options appropriate to individual needs and information, for example,

I want them available. They don't have to like say, “It's you Mrs XXX, sure come in whenever you like we'll just make a space.” I don't expect that. But neither “A fortnight away without alternatives”. “Look one of our doctors is away, they're in Raglan. But look if you're out that way you can see her out there.” Give me some options, do something. I could have been really sick, well in fact I was, but just bear through it. EFT#1

Finally, the manager envisages PHCP insights, expertise, and instincts as resources in the interaction, where responsibility and even choice is re-embedded as a PHCP obligation,

*I expect him to give me information about what it is that's wrong with me and **what I can do about it, or what can be done about it.** I don't expect to just be given some antibiotics and go away. I want to know*

what it is. I'm just as happy for him to say, "Look, there's nothing major. Don't do this, do that, and it will come right." It doesn't have to be a bottle of pills. EMT#4

*...give me the once over so I get it. I really believe that's their [PHCP] responsibility to make sure I get it and I won't walk away until I've got it...Well otherwise you walk away without the information so you've made a decision by not making a decision because someone didn't give the information so you could make a decision. **Where does the onus for that sit? Not on me, I've gone in to that health provider and said I need this information. So I've done my bit**, so if I'm going away with not enough information to actually explicitly make that decision, then they've done me a disservice. That's straightforward to me. MiFT#17*

Maybe they [PHCPs] can advise you in this age you should do some exam. You have to be aware of something. [They should say] "I'll give you a list or some website". AMT#37

This category of description also reflects the individualism that is considered to characterise baby boomers but, paradoxically, it also emphasises the interactional and negotiated constructions of health literacy. As one participant explained, the centrality of the patient-as-manager to health-creating processes carried with it equal expectations of roles and responsibilities for the PHCP. The open-mindedness and responsiveness to options exhibited by the patient-manager in their health literacy is expected to be reciprocated by the PHCP, as illustrated in the following excerpt,

The dissatisfaction for me doesn't come from the experience of my visit; it comes from the lack of overall approach by health professionals to my wellbeing. I mean I go and see my doctor and he gives me what I want. He may not fix me instantly but generally he's gonna give me something to try and fix me, but I don't see them actually looking outside the square too much. They follow what has been tried and true. It's a bit unfair to say that about the medical profession, but if you have a look they live inside a box and they don't look outside of it; and if anything is outside of that box it's unacceptable. So that's their limitation. So there's my dissatisfaction. EML#43

As a manager, the baby boomer participants construct health literacy as also encompassing the growth and development of PHCP partners and network actors in the directing and organising to achieve the goal of health. In this sense, while the achievement of health is an individual one, it is perceived as a shared and distributed responsibility. The diverse repertoire in the patient-as-manager

category of description adds complexity to the multi-faceted and dynamic patient-practitioner relationship regarding health literacy.

The manager category at first seemed too cumbersome and incoherent to be valuable as an interpretation of the participants' constructions of health literacy. The plurality of behaviours and intentions, the diverse ways of seeking health and wellbeing, and the negotiated practices undertaken by individuals as they lived health, presented highly differentiated constructions of health literacy. However, the participants readily integrated and rationalised their repertoire of actions in certain contexts. Eventually, and iteratively, the pattern of managing behaviours allowed a picture of heterogeneity to emerge that has been collectively described in this category of description.

5.2.6 Categories of description - A final note

These five categories of description provide a nuanced understanding of health literacy among New Zealand baby boomers. Based on this interpretation the following section proposes a conceptualisation that addresses the complexities inherent in the [re]negotiation of health literacy as a social practice. This conceptualisation is based on the interpretation of how individuals experience health literacy and how they contextualise it for their own health. Furthermore, relating the five categories of description to each other also helps deepen the appreciation of how the participants experience health literacy.

5.3 Conceptualising Baby Boomers' health literacy

The first part of this chapter interpreted the baby boomers' textual data after the iterative hermeneutic circle of understanding, describing categories of description for the phenomenon of health literacy. These categories offer a way of seeing the phenomenon in relatively unstructured form emerging from the interview transcripts, coding, and new understandings. Continuing the circular and iterative hermeneutic process and seeking to understand the phenomenon more as a whole rather than in parts, this section proposes an improved conceptualisation for a

deeper understanding, reaching “a place of sensible meaning...for the moment” (Laverty, 2003, p. 25) of the phenomenon of health literacy.

The present conceptualisation characterises the categories and the baby boomers’ understanding of health literacy on two horizons – a self-horizon and an interactivity horizon (refer Figure 5.1). The term horizon plays an important part in hermeneutic inquiry and is consistent with the desired meaning of the conceptualisation developed through this process. In hermeneutics, as in this conceptualisation, horizons refer to an individual’s “...assumptions, ideas, meanings and experiences... [they are] fluid and open to change...” (Lopez & Willis, 2004, p. 730). The term horizon in this conceptualisation similarly conveys the ‘self’ and the ‘interactivity’ as points of reference for the categories that emerge from the textual data. The two horizons that frame the five categories of description emerged iteratively from the participants’ experiences of health literacy as patient-consumers, providing a logical structure for framing the participants’ construction of health literacy.

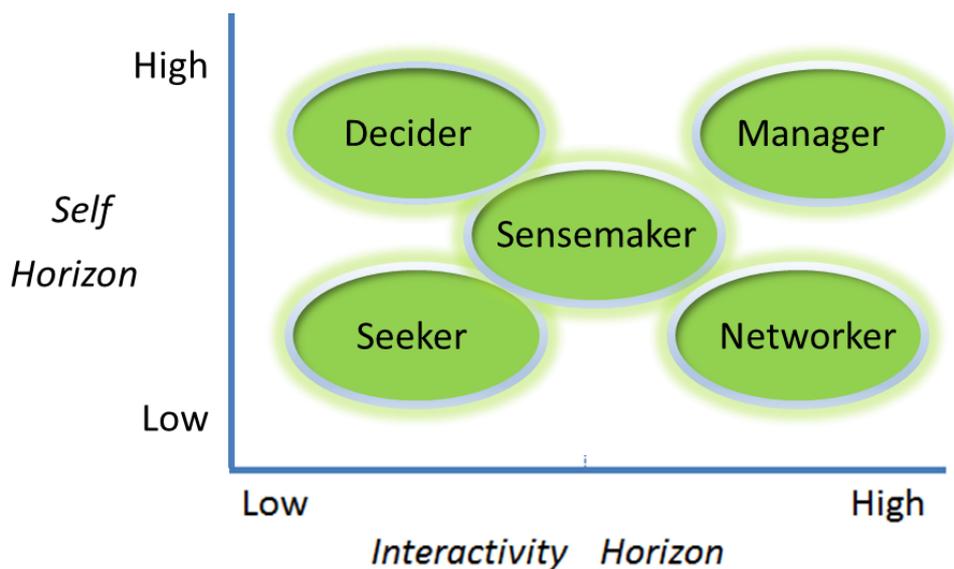
The conceptualisation visually represented in Figure 5.1 has the advantage of simplifying a complex phenomenon into “a form of social scientific shorthand” (Ragin, 1987, p. 149). At the same time, this representation acknowledges the complex and complementary nature of health literacy roles as experienced and constructed by the baby boomer participants. The participants’ texts described complex and dynamic health literacy roles, responsibilities, and intentions.

Although five categories of description have been conceptualised, the diversity of health literacy activities and efforts does not always map tidily onto these five categories. For any individual there is a range of potential health literacy experiences that lie within and across these categories. Indeed, the categories are not mutually exclusive; health literacy constructed as patient-as-decider does not preclude a construction of health literacy as patient-as-manager or networker.

Phenomena exist in time and context, and hence dynamic temporal aspects must be appreciated. The nature of the health event, context, and patient-practitioner relationship dimensions all influence an individual’s particular understanding and

practice of health literacy. As a negotiated dynamic practice an individual's health literacy may shift from seeking or sensemaking-dominant health literacy roles and behaviours to ones that are network-dominant or managing. Therefore, the two horizons should be considered as continua along which individuals' health literacy experiences and constructions can be positioned.

Figure 5.1 Conceptualisation of Baby Boomers' health literacy



None of the categories were classified at the origin point on the matrix of self and interactivity. A health literacy category of description low on the self-horizon and low on the interactivity horizon would be closest to Nutbeam's (2000) functional health literacy of demonstrating numeracy and literacy competences with limited actions of self-direction and self-management of health. The conceptualisation provides a visual representation of health literacy as constructed by these New Zealand baby boomer participants interpreting their textual data linking back to the research question. However, since this research was not longitudinal, further work is required should this matrix be used to 'plot' individuals according to their health literacy and to understand temporal changes in individual's health literacy constructions.

5.3.1 *Characterisation of health literacy*

The conceptualisation (Figure 5.1) along the two horizons of self and interactivity provides spaces for multiple behaviours, expectations, and networks that support different constructions of health literacy, highlighting areas for improved information and relationship management by primary healthcare professionals. This provides a compelling argument for the distributed, negotiated, and social practice of health literacy, providing a detailed understanding of these participants' health literacy. The following discussion compares the five categories of description according to the two horizons.

The seeker role, classified as low to moderate on both horizons, is predisposed to seeking information, uses constructive questioning to uncover health-related information, seeks justification through information, and verifies information. The activities of the seeker role are nevertheless purposeful and goal-oriented, often responding to a specific health event (refer Anker, Rinehart, & Feeley, 2011). These information and knowledge gathering activities make use of PHCPs' expertise, but also relate to researching alternative health approaches to conventional medicine. The seeker employs information gathering skills, evaluative skills, recognising and comparing information, and evaluating information sources. The seeker is not distinguished according to connectedness, using informal and infrequent contacts with network members to research healthcare.

The decider role emphasises active choice with the intent, activities, and skills that enable the individual to be an agent of his/her own health; therefore, this role is high on the self-horizon. The activities and skills of the decider role have less of an interactive horizon and more of an emphasis on individualism, individual discretion over health literacy behaviours, and active engagement in their health. This role includes skills and competences such as reasoning, judgment, and evaluating risks and consequences that, when combined with an acceptance of individual responsibility for health, translate into the active choices for individual health management.

The networker role is described by intent, activities, and skills that emphasise and develop the participant's social and family networks as part of their health literacy. The networker role does not emphasise individual decision-making (low to moderate on the self-horizon) nor is there strong intent regarding the integration of multiple aspects/resources (moderate compared to the manager role) concerning a health condition; although the high interactivity contributes to health literacy among all the actors. Within this role are those participants who can be termed market mavens (e.g., Chung & Woodside, 2012; Kuntos et al., 2011) who deliberately network for the benefit of other network actors as well as for themselves. These individuals are keen to share their knowledge within their social network and were acknowledged as a person others turned to and respected for their knowledge and advice. (By contrast, the market gurus are considered just as knowledgeable but their knowledge and information-seeking is not for the benefit of the network). Among the research participants the Asian baby boomers clearly demonstrated highly structured and formalised roles as networkers. This contrasted strongly with European baby boomer participants who were often highly-networked but less formally so. The Māori participants indicated considerable variability in their connectedness but were typically networked with their whānau. Both male and female participants displayed this networker role, in both structured and unstructured variants, suggesting no marked gender differences.

The sensemaker role balances self-directed health literacy intent and activities with connectedness being moderate on both self and interactivity horizons. The participant provides evidence of both cultural and emotional disposition to making sense of health information, pragmatically directing their own health but less engaged in managing and integrating resources than the manager role. The sensemaker role acknowledges the authority of the PHCP; the PHCP is considered the expert who can be relied on in healthcare decisions. Therefore, this way of constructing health literacy does not usurp the healthcare professional (Schulz & Nakamoto, 2012a). Sensemaking competences include experiential authority and self-knowledge. Trust in healthcare professionals is explicitly dependent on evidence and health outcome, both of which contribute to the individual's sensemaking. Pacific People participants often exemplified this sensemaker role,

recognising individual responsibility for health but also being predisposed to relying on healthcare professionals for making sense of health-related information and treatment decisions.

The manager deliberately and purposefully organises, decides and manages health literacy through integrating multiple health resources and his/her own competences with other actors' literacies, skills, and competences occurring in their health contexts. Therefore, this role is high on both self and interactivity horizons. This role calls for dependable relationships and an understanding of systems and processes; activities in this role [attempt to] transcend the 'silos of care' that often typify healthcare services and systems. Since they are the person for whom the health decisions matter the manager directs the relationships on his/her terms, but their expertise and negotiating skills do not replace the PHCP. The manager expects results but more importantly expects options, information, and resources appropriate to their health needs, ultimately expecting that the other equally well-informed actors are partners in their healthcare. This role supports the view that "healthcare is a shared enterprise which embodies partnership" (McDonald et al., 2007, p. 431). The manager is likely to be using online tools for information and support, and conducting their own health monitoring. This role was frequently illustrated in the health literacy experiences and understandings among the European baby boomer participants, however, there were no discernible variations on gender or age regarding this role. The patient-as-manager may seek to bypass the PHCP if their health literacy expectations are not met or the participant's health literacy roles and behaviours are not accurately recognised by the health professionals. However, they are proponents of shared-decision making practices as well as activists for healthcare policy and system improvements.

Finally, across all these ways of experiencing and constructing health literacy the inescapable precarious freedoms of responsibility were frequently expressed by these participants,

Time consuming, very time consuming all these things but sometimes you've got to do it to get things back on kilter EFL#11,

and,

...no one human is going to know everything and they're not necessarily going to take on board everything ... in the end a lot of it comes down to judgement and they're not necessarily going to have the same judgements. EFL#8

5.3.2 'It's not my health literacy, it's ours'

Consumerism, patient involvement and the individualisation and democratisation of healthcare has provided both risks and opportunities, from the sick patient passive role to the active informed consumer. However, the precarious freedom in these baby boomers' health literacy experiences indicates that, rather than endorsing the dis-embedding of activities from the healthcare professional domain, these baby boomers are seeking to re-embed health literacy in the relationships and networks of health - it's not my health literacy, it's ours. Hence, for example, participants were frustrated with limited knowledge expressed by healthcare professionals and lack of sense of urgency, but conversely inspired when primary healthcare professionals genuinely brought their resources, expertise, networks, and responsibility (logic of care, refer Mol, 2008) to the health literacy partnership. This health literacy expectation can be likened to that of citizenship (compared with the closely associated yet different term, consumerism) with its emphasis on reciprocal relationships of rights and responsibilities (Aldridge, 2003; Petersen et al., 2010). In other words, health literacy for these baby boomers was about negotiating a shared responsibility, not always preferring market choice or presuming neoliberal consumer responsibility, since "when consumer responsibility is evoked and produced, the responsibility in question is also taken from other political and corporate shoulders" (Giesler & Veresiu, 2014, p. 854). Hence, the conclusion that health literacy is a distributed and negotiated social phenomenon.

At the same time, when there are disruptive processes in the re-embedding (for example, when the actors fail to recognise others' health literacy understandings and responsibilities) then health literacy processes and behaviours will not be facilitated. If primary healthcare professionals respond to health consumerism by

being reactive rather than proactive, paying limited attention to the unique and variable patient health literacy practices, then the patient-practitioner relationship and health decisions are likely to be compromised. One solution to the asymmetries of health information and expertise evidenced in the baby boomer participants' understanding of health literacy is for patient-consumers to utilise resources together – that is, integrating the resources encompassed in the categories of description (and their roles, behaviours and intentions) into practices for health literacy. Communication is crucial to the understanding and [re-]alignment of health literacy as a negotiated social practice, enabling the flow of information, resources, competences, and expectations. Importantly, this also requires an appreciation of the mix of baby boomers' health literacy constructions, practices, role behaviours, and expectations which this research seeks to understand.

5.4 Summary

This chapter explains and interprets the baby boomers' interview texts. The pre-understandings (Chapters 1, 2, and 3) provided the lens for these interpretations. The hermeneutic process of iterative interpretive cycles revealed health literacy practices, roles, and behaviours, which were described according to five categories of description, drawing from phenomenographic research. These five categories of description were conceptualised according to two dimensions of self and interactivity, adding to the coherence of the interpretation.

The key interpretive comment is that health literacy is a distributed, social, and negotiated practice. The baby boomers described complex and dynamic health literacy roles, responsibilities, and intentions, which were framed according to two horizons of self and interactivity. These horizons are considered as continua along which individuals' health literacy experiences and constructions can be positioned. These interpretations reveal new meanings of baby boomers' health literacy some of which challenge pre-understandings of the baby boomer cohort. The participants did not unequivocally embrace consumerism in health literacy, preferring instead to re-embed health literacy in health relationships and networks.

The next chapter, the second of two results chapters, interprets the construction of health literacy from the perspective of primary healthcare professionals.

Chapter 6

Primary Healthcare Professionals' Experiences and Practices in Baby Boomers' Health Literacy

6.1 Introduction

In 2004 the Institute of Medicine acknowledged that health literacy goes beyond individual competencies and motivations to include “Health literacy [as] a shared function of social and individual factors” (Institute of Medicine, 2004, p. 4). At the same time, the definitions of health literacy have widened in scope from concern with literacy (reading and numeracy) in solely medical (or clinical) encounters to include health literacy in everyday life contexts. Despite the potential for significant involvement of healthcare professionals in the expanding conceptualisation of health literacy, research has predominantly focussed on assessing individuals' health literacy capabilities overlooking the relational and interactional dimensions of health literacy. This thesis proposes that health literacy is not exclusively an individual responsibility or attribute but is co-produced as a complex social phenomenon.

This chapter addresses the research question:

How do primary healthcare professionals (PHCPs) practice health literacy?

Specifically,

- *How do PHCPs perceive their behaviours in relation to health literacy and baby boomers?*³⁸

³⁸ This research has not directly observed the PHCPs' behaviours and interactions, relying on the evidence of participants' perceptions of their own behaviours, roles, and relationships.

In-depth interviews were conducted with a purposeful sample of 11 PHCPs from general practice, pharmacy, complementary medicine, dentistry, audiology, and healthcare planning. Although this created a diverse range of responses and experiences, it added value to the research by providing a richer set of experiences than interviewing PHCPs from one specific discipline. Similar to the baby boomers' textual data a hermeneutic analysis of the PHCPs' interview data was undertaken (refer Chapter 4) allowing the researcher to bring pre-understandings to the texts, and moving between these pre-understandings, the texts, and then to new (post) understandings in a recursive circle reaching new understandings of healthcare professionals' practices of health literacy.

Initially, the interview texts were understood in detail descriptively. After moving back and forth between readings of the texts, moving between parts of the interview texts and considering them as a whole, and moving between pre-understandings and re-interpretation, the interpretation widened to three key categories of description which are conceptualised at the end of this chapter as managed empowerment. At the same time as these interpretations are grounded in the participants' textual data they are also consistent with the research questions, remaining faithful to the research purpose and methodology. The process of identifying and selecting the labels for the three categories of description - knowledge brokers, ethical agents, and enablers - is explained earlier (refer Section 4.8.1).

The categories of description summarise practices, capabilities, and understandings that form part of the complex dynamics of the patient-healthcare professional relationship regarding health literacy. The knowledge broker, ethical agent, and enabler categories of description provide a valuable means for framing and making sense of the PHCPs' emergent behaviours in order to gain insights into the complex phenomenon of health literacy as constructed by these participants. In addition, the hermeneutic analysis revealed three key contextual, social factors that underpin these key categories of description: the questioning of authority; the consumerist trend in healthcare; and, the communication and information revolution. The interpretation of the themes considers symmetries and asymmetries between these and the researcher's pre-understandings of health

literacy. Finally, the chapter concludes with critical reflections on the similarities and differences in the categories of descriptions for PHCPs' health literacy behaviours and understandings. These reveal insights and challenges for health literacy research and practices.

6.2 Health literacy and primary healthcare professionals' categories of description

Health literacy researchers generally believe that processes of accessing, managing, understanding, and appraising health-related information underpin an individual's capability to make sound health-related decisions similar to the theories of learned effectiveness. For example, Ross & Mirowsky (2010) argue that education improves health through the mediators of productive and creative work, sense of personal control, and healthy lifestyle. Education increases effective agency on the part of individuals, therefore education allows health-producing behaviours. As the construct of health literacy has evolved to include [patient-as-]consumer rights and empowerment, there is growing appreciation of health literacy as a shared responsibility between individuals, healthcare professionals, health systems, and society. In other words, it cannot be wholly attributed to, or owned by, patients. Most definitions of health literacy assume that people will be motivated to use their skills to behave in ways that enhance their health (Peerson & Saunders, 2011). In addition, there is growing evidence that relationships play a part in motivation, suggesting that relationships between patients and healthcare professionals play an important part in health literacy (DiMatteo, Haskard-Zolnierok, & Martin, 2012; Weinstein & DeHaan, 2014).

Although healthcare professionals seek to enhance their relationship with patients to facilitate improved health-related outcomes and are significant agents in an individual's health literacy (de Leeuw, 2012; Martensson & Hensing, 2012; Neal, 2007; Peerson & Saunders 2009), this dimension of health literacy has been largely overlooked in the conceptualisations and research of health literacy. For example, Ruger's (2010) health capability framework, which explicitly seeks to capture both agency - individuals acting as agents of their own health - and valued

health outcomes, makes no mention of practitioner roles. Ruger, using the capability theory of Sen (1997), recognises the social dependence of health capabilities but emphasises that the health capability paradigm rests on “the individual as the unit of analysis” (Ruger, 2010, p. 43). Social networks and contexts are identified, but the nuances of the relationship between the individual patient-consumer and the healthcare professional within this health agency and capability are not. In contrast, this chapter explores the behaviours adopted by PHCPs in their relationships with baby boomer patients, specifically in relation to health literacy practices.

The baby boomer research participants experienced health literacy as a highly contextualised, negotiated social practice linked to [a]symmetries in health-related information, power and autonomy, and patient-practitioner behaviours (refer Chapter 5). Given the reciprocal nature of patient-practitioner relationships, exploring both sides of the healthcare relationship is urgent yet is an area that has been under-researched in the health literacy field. Therefore, the emerging behaviours healthcare professionals practice in their relationships and encounters with baby boomer patients can offer new insights into health literacy as a complex, relational, and social phenomenon.

The majority of the PHCPs agreed that functional language skills (as in Nutbeam’s, 2000, conceptual framework, Chapter 3) are often the basis for health literacy to emerge. However, individuals’ capabilities of participating in health decisions and of making sound health-related decisions are nevertheless situated in the dynamic, distributed relationships and practices of an individual’s health context - including networks of information sources, people, health experts, and health systems. PHCPs agree that the individual skills aspects are not sufficient to conceptualise health literacy,

...I think health literacy is often put in a box about reading and writing and it’s not...to me that is part of it but I only see that being about ten percent of it. PHCP#6

This chapter therefore explores what one PHCP refers to as “the other 90%” discussing them according to three key categories of description – knowledge broker, ethical agent, and enabler.

The PHCP participants commonly understand their experiences and roles as co-producers in health literacy, including being interpreters, strategic managers, and information gate-keepers. The category of description of ethical agents - undertaking practices in a non-opportunistic way to encourage health literacy, for instance, by providing rational support or developing authentic and trustworthy health information - was further evidence of the interactional dimensions of PHCPs’ emerging behaviours in patient health literacy. These key health literacy enacted behaviours draw on pre-understandings, the participants’ own language, and the hermeneutic cycle of iterative rationalisations as discussed in Chapter 4. The categories are summarised in Table 6.1. For each category key meanings are identified with key quotations that exemplify each category. The chapter finishes by proposing the construct of managed empowerment as the collective theme reflecting the PHCPs constructions and practices of health literacy.

Table 6.1 Summary of PHCPs' health literacy categories of description and key meanings

Category of description	Key meanings	Description	Synthesis of PHCP health literacy roles & behaviours
Knowledge broker	Interpreting and validating health information	Expertise and experience to sort, interpret, and validate health information for patient-consumers.	<div style="font-size: 4em;">}</div> Managed empowerment
	Being an information gatekeeper	Practices that evaluate the patients' needs for information and the information that is supplied to them.	
	Acting as a gatekeeper to healthcare options	Evaluating and screening information for relevance and meaningfulness to patients.	
		Practices that direct patients through the healthcare system and treatment options.	
Ethical agent	Being fair & equitable	Fair, unbiased practices developed in a non-opportunistic way to encourage health literacy.	
	Acting with professionalism		
	Taking responsibility for patient well-being	Perspectives and practices that use professionalism as the basis for trust and authority.	
	Promoting health & health services	Emphasises the use of authentic professional knowledge.	
Enabler	Facilitating informed consent	Actions that encourage, motivate, and support patient-consumers to be health literate in the broadest sense.	
	Integrating resources	Uses diverse resources in exchanging health literacy ideas and insights.	
	Being a partner		
	Being a co-learner	Sharing in learning new knowledge and engaging in new forms of health knowledge.	

6.2.1 Knowledge broker

The practices and behaviours within this category share in common an emphasis on PHCPs as interpreters and gatekeepers who impart and broker knowledge, diagnoses, and treatment options in a largely paternalistic manner. The key meanings within this category of description are: interpreting and validating health information; being an information gatekeeper, and acting as a gatekeeper to healthcare options. These are summarised in Table 6.2.

PHCPs see themselves as having the expertise and experience to sort, interpret, and validate information for patient-consumers. The PHCP participants recognise that they no longer enjoy privileged access to health information, but nevertheless consider their skills and behaviours as similar to “choice architects” (Thaler & Sunstein, 2009, p. 159) and information interpreters who are instrumental in co-producing health literacy, akin to Rapley’s “paternalistic adjudicator” (2008, p. 430).

Health literacy practices of these PHCPs include the translation and interpretation of their own and patients’ knowledge into practice, nudging patient-consumers in directions that are ‘right’ health decisions that can make their lives ‘better’ (‘right’ and ‘better’ as primarily defined by the healthcare professional). For example,

*...the GP and the nurse are still like the interpreters if you like. We’ve got all of this health information out there with all of these big words and all of the stuff...So **we’re the interpreters really of healthcare.***
PHCP#7

So the biggest challenge is being able to describe blood pressure in different ways depending on the patient’s understanding of it. And some want to know about sodium potassium, channel blockers and others want to know that it’s just like an engine in a car that gets over heated. And that’s the challenge I think as a doctor... if you’re comfortably ticking over at sort of 20 to 30 patients a day you can probably manage that. PHCP#8

Table 6.2 Summary of Knowledge broker category of description

Key meanings	Description	Illustrative Quotes
Interpreting and validating health information	Information handler	<i>...I've got to take complex clinical information, digest it, and turn it into a form that's going to be readily digested by somebody who has some knowledge without changing what that really means. So that's what I try and do. PHCP#5</i>
	Interpreting information	
Being an information gatekeeper	Arbitrator of knowledge	<i>...a lot of the time the information that's given back to the patients by medical and nursing staff is complex, or unintentionally often uses jargon. PHCP#3</i>
		<i>I try and direct patients to sensible and reputable information/sites...we give them [patients] trusted websites. PHCP#9</i>
		<i>The thing is recognising what's good and what's not on the Internet and that's where it's our job to guide people. PHCP#11</i>
Acting as a gatekeeper to healthcare options	Facilitating preferences & choices	<i>...we're the gatekeepers as the GPs and we generally open the gate; we don't generally close it or keep it locked. PHCP#7</i>

Knowledge broker

PHCPs acknowledge information seeking is a natural tendency or habit for many patients; behaviour associated with the consumerist influence in healthcare as well as being one of the dimensions of patient empowerment. Health information is now distributed across many sources, technologies, and healthcare situations with competing forms of knowledge and conflicting viewpoints.

I welcome patients to go and do their doctor Googling. PHCP#7

Everything is available, yeah, the patient could search anything and the answer is sitting out there and if they do the right searches they find good stuff. PHCP#11

...there's the public pool of information, be it your peers, parties which is where a lot of it seems to happen is over the dinner table at a party. PHCP#11

Although the PHCPs accept that the communication and information revolution along with changing patient-practitioner relationships have demystified medical expertise and health information, on occasions, they override the reflexivity of patient-consumers. The symmetric information relationships sought by many baby boomer participants (refer Chapter 5) are supported only to the extent that these PHCPs retain final interpretation of the 'right' health information that will lead to the 'right' health outcome. For example,

*We still have to have the health professionals even though, as a layperson they can go onto the Internet and they can access all the information and they can even go on and watch surgeons doing surgery, you still have to have the health professional. You still have to have the nurse, physio, the doctor, the GP, **to be able to interpret and to be able to narrow down and treat that patient appropriately.** PHCP#7*

Matching the person - there's certainly things you can do to bring your education up or down to somebody's level of understanding. PHCP#8

Traditional health information asymmetries have been reduced by the Internet, Web 2.0 communication, and sophisticated search engines significantly changing healthcare professionals' roles in health literacy. The tension between the primary

healthcare professional as libertarian paternalist (Thaler & Sunstein, 2009)³⁹ and trustworthy knowledge broker (Sørensen, 2013) versus the empowered patient is manifest in many different ways. For example,

...if you don't give patients enough they'll go find it somewhere else and you want the patients to come back to you and get the information that the practice nurse or the GP wants to give them. PHCP#2

...But people come in with their misconceptions, preconceptions, correct information or whatever and it's our job to help them understand what they've worked out or what they think their problem is. PHCP#11

PHCP participants recognised that the approach by some healthcare professionals of “I am responsible for looking after you and I know what is right” was a form of protection and control. However, patient autonomy can result in practices and choices that may not lead to appropriate health decisions and care. Patient-consumers can lack full information, expertise, or experience, limiting their capability to discern accurate from inaccurate information, collectively hindering their ability to make the best health decision or to secure the best healthcare. This distributed health literacy context can present the PHCP with unpredictable decisions, challenging and unsettling their role as expert; for example,

The patient wants to listen to the friend who says, “I'm on this great medication this is what you need.”...It's even more important [now] to go slowly and to get the patient on board and get the patient to exhaust their strategies and their treatment options... PHCP#7

As information interpreters PHCPs also exercise expert control practices, gatekeeping access to health information that they consider part of their obligations as healthcare professionals. The excerpt above shows the PHCP articulating an attitude common among the participants, that the PHCPs share with the patient-consumer a “legitimate investment” in the healthcare decision (Butler et al., 2001; Charles, Whelan, & Gafni, 1999). The PHCPs are accountable for providing the right diagnoses and appropriate treatments, which have rational support and which are increasingly evidence-based. In addition, PHCPs have a

³⁹ Thaler and Sunstein (2009) define libertarian paternalism as weak non-intrusive paternalism such that policy makers, employers etc. attempt to move people in directions that will make their lives better.

duty towards patient welfare and upholding diagnosis, treatment, and care standards as part of their professionalism. The category of description of PHCPs as health information interpreters also reveals tensions that occur between PHCPs' expert control and patient autonomy. Frustration, issues of conscience, and futility are expressions of these tensions particularly when the PHCPs' judgment of what is good medicine is challenged by patient-consumers preferring different logic, alternative rationale, and different strategies. The excerpts below illustrate how these PHCP participants express these challenges,

So this little communication I've had with the patient three days ago and then now in an email, these are the sorts of things that I'm dealing with all the time. You think that the patient is listening and you're giving all of this information but they're only hearing what they want to hear. PHCP#7

...it can be frustrating from a practitioner's point of view particularly if you're trying to achieve a particular outcome and you want somebody to be compliant. PHCP#5

Questioning the healthcare professional's authority challenges their status as professionals and contests the boundaries over responsibility in health decisions, all of which require health literacy practices to be re-constituted by PHCPs. Part of this [re]-constitution of the professional boundaries to [re]-claim competency and trustworthiness appears in the relationship they seek to establish with their patient-consumers. For example,

...people do come in with information. And I see that our role in that instance is to be a translator; and that can be difficult...I see the paramount goal when they do that is to build the relationship. PHCP#3

*...so what I do is give them information about whatever's wrong and then we'll sort of basically talk about what they can do to fix it. **It's really like a negotiation.** PHCP#1*

Interpretation of information can be enhanced or constrained by the patient-practitioner relationship. PHCPs' perceptions of their own obligations, behaviours, and expertise, as well as their expectations and assumptions of patient roles, understanding, and motivations significantly influence this relationship and, subsequently, the health interpretation practices PHCPs enact. For example,

Everything comes back to, I mean the core of it, is relationships. You can never build trust until you've developed a relationship with someone and that comes through communication. I can sit down and shut up and let people just tell me their story, whatever their problem is, you work out quickly whether they understand their problem or whether you need to support them with decisions. PHCP#11

...but you can't turn around and tell somebody that they've come in, that this is garbage. It might be garbage. So you've got to have the capacity to be able to read and assess and seek more information, and try and explore the understanding that they have. PHCP#3

...Not so much your technical skills but that relationship of having someone seeing you through that illness or whatever or knowing your whole family and knowing how that fits into the dynamics of the family. PHCP#1

As interpreters of information PHCPs reinforce their role as expert advisers given the proliferation of information and the blurring of boundaries between patient-consumer and medical expert. Incorporating competing forms of knowledge and critically investigating the challenges to medical science claims are behaviours that PHCPs employ to reinforce their capacity and capabilities as experts. Such health literacy practices are particularly significant in a context where patient-consumers place less trust in their PHCPs and more trust in their own decisions. For example,

*...if they have concerns certainly I'm going to try and allay those concerns and certainly go and look up any information they give me to see if there's any validity in it because obviously I don't know everything and **it's trying to expand my knowledge base as well**. It is difficult sometimes to assess some of the information they give me 'cause it's like so way out or there's just no other information there that you can validate it with, so it's difficult sometimes. PHCP#1*

*...Once upon a time it would have always been written advice or printed sheets with exercises or diet information or things of that nature on it. Whereas **now I am more likely to go online and look up things that I think are relevant for that person and then give them a web reference** and say, "Well look I think the best thing is for you to go online look up that reference and then that information is there for you." And it might be YouTube so they can watch a video of how to do something and those sorts of things. PHCP#5*

We just try and put them right. We've got approved printouts for everything they want to know; we've got access to just everything.
PHCP#9

The postmodern health context and the communication and information revolution have meant patients sometimes adopt more active roles in their healthcare. Moreover, individuals can be their own producers of health information, traditionally the privilege of healthcare professionals. PHCP participants typically responded to informed patients (often internet-informed) by adopting a strategic approach aligned with budget interpretations, possibly as a means of protecting their professional hegemony as experts. PHCPs therefore construct health literacy to include planning a course of action in place of prescribing a course of medication. For example,

...by the time they come to me, I guess they want to know a plan of what to do; and so I pretty much give them a plan of what they should do. PHCP#1

...But it often means that what we're seeing a lot more of is actually that personal stuff; and I guess in health literacy terms we're doing an awful lot more of sitting down with our patients and customers that come in; and a lot more I suppose strategic planning...but when we can't what we always try to do is to make sure that we help that person devise a strategy... Really, a lot of what we're doing as contemporary pharmacists these days is not anything that we were ever trained for; it's basically strategic management... PHCP#3

I'll give someone a treatment plan that's got two or three tiers in it. This is the ideal, this is the next level of what we could do that will still be more than adequate, but it won't have the longevity if we do it this way... you've got this treatment plan, it's this long, [so I say] "I understand your budget constraints. Let's put it into blocks. If we start at this end and do this bit, if we get to this next bit in the next six months we can keep you away from expensive toothaches and root fillings. It might take us 18 months to get you fixed". PHCP#11

As interpreters, PHCPs perceive an informed patient more likely to be agreeable to choosing the right (as in recommended by the PHCP) option. The practices of PHCPs as information interpreters include the association between critical and communicative health literacy and adoption of the PHCPs' recommendations. In other words, the PHCPs' behaviours as information interpreters encourage patient-consumers to comply with the diagnosis and treatment options offered by the PHCP,

[Health literacy] is about trying to encourage a person to follow your line of thinking obviously because that's what you want of the desired outcome. But in such a way that that person feels that they've been part of that decision making process. PHCP#5

This may not simply be a contrast of paternalism versus patient-centredness, but may reflect the nature of the healthcare profession as perceived by these PHCPs, that is, they are there in the medical profession to achieve the best health outcome for the individual. The PHCPs consider these interpreting behaviours to be rational persuasion, not manipulation, which at the same time enhances a patient's ability to evaluate information and which, in other words, encourages patients' critical health literacy.

The PHCPs have a construct of what makes a health literate patient - someone who is willing and motivated to act/change their behaviour, who has spent some time doing their research, who has considered the expertise of the PHCP, and who has read the material provided for them; for example,

So I think there's information out there that people can pick up if they want to but it's assuming that people are interested and will act on what they read...then it's up to the patient...there's quite a few assumptions made that the person will take it home and read it and that they will want to do that and then understand it. PHCP#2

Yet overall there has to be [eventual] compliance with what the PHCP is advising them,

Our practice is about taking people on a journey from a particular level of function to a better level of function and trying to maintain and improve that all the time. And so that involves discussions about those lifestyle issues, about eating and sleeping and thinking and exercising and so forth. So that it's not just about correcting the spinal issues or extremity issues that they come in with, but how do they prevent that from happening in the future and how do they go to live well. PHCP#5

In this environment of potentially contested health information and contested health interactions the phrase 'getting on board' connotes that the patient is complying with the healthcare professionals preferred way forward in the healthcare encounter, for example,

*...It's even more important to go slowly and to **get the patient on board** and get the patient to **exhaust their strategies** and their treatment options before they will sometimes come for traditional medicine. PHCP#7*

*...particularly if they've formed some fairly fixed views about those things that they've brought along with them. So that can be challenging...when it comes for the person to make their decision and to consent to management or consent to suggestions that I might make about what their next approach could be. If they've come with that information and it's contrary to what I'm suggesting. That **takes some time to change** that viewpoint. PHCP#5*

...Sometimes they feel they have a very clear idea of what has to be done and sometimes that's not correct because they have read just so much. It can be challenging. PHCP#10

This patient pressure appears to PHCPs as a form of regulation; patients can demand certain forms of care or treatment, declining other care, and choosing or refusing certain providers. The following excerpt demonstrates the patient as regulator from the perspective of one PHCP participant:

But if there is a conflict of interest and the patient says, "This is what I want to do, I don't want to take your medicine, I don't believe in your medicine, I don't actually trust what you're saying," then your therapeutic relationship has broken down... I was thinking "no I'm not going to be bullied around and pushed around". PHCP#7

...We've now got it [the interaction] occurring between me, the other health professional, and my patient; "I don't like what you wrote in that report, can you change that letter, can you change that sentence". PHCP#7

But basically the patient expects that what they ask of you is going to be done. It's almost like the patient takes control; this is the modern patient. Comes in, "I want this, I want this medication I'm travelling, I want this and this, I want this vaccination, someone's told me I need this vaccination." That's a big one that we've got travel clinic doctors and travel clinic nurses, so that's often a source of conflict with patients coming in. "I don't need to see the travel doctor, I don't need to see the travel nurse, I know exactly what I need." But basically you're almost held to ransom with some of these patients coming in. PHCP#7

Compliance and concurrence by the patient-consumer confers power to the PHCP, yet as shown above the power-knowledge nexus is shifting and blurring under the

contextual influences of questioning authority and loss of trust in professions, the communication revolution, and the consumerist trend, collectively requiring adjustments in the health literacy practices of PHCPs,

...when I first began practice, patient information was not available for the patient particularly. I mean it was their record but it was sort of mine really. Their access to that was quite limited and their access really to my knowledge was fairly limited. PHCP#5

...Certainly open communication and having nothing hidden and the doctor-patient relationship, changing from one of a God-type relationship to a partner. PHCP#7

The PHCPs' behaviour as interpreter of health information also raises the issue of the boundaries of responsibility in a primary healthcare relationship. In some cases, professionals may seek to have less responsibility, for example, they partner with the patient in trying to get the best health outcome but distancing themselves from taking responsibility, compared with taking control, retaining authority of diagnosis and treatment through expert knowledge.

These PHCP participants also perceive themselves as health information gatekeepers evaluating and screening information that is relevant and meaningful for patient-consumers' particular needs. For example,

...clinicians make real assumptions about, "Oh no, we can't give patients that medication 'cause it's too complicated." Or, "We can't do this sort of treatment." Or, "People don't want the long term treatment; they just want the short term fix." PHCP#6

somebody might have read up about particular symptoms...and by a series of processes through discussion and examination you [the PHCP] have to provide information from your perspective...the consumer has to rely on the provider to give the range of options. PHCP#5

Health literacy gatekeeping also includes selecting and directing patients to the appropriate professional and information resources,

...the PHCP knows where to pass the patient to and they have to assess the patient's health literacy requirements; when people are first diagnosed with something you need to have some resources available at that first stage. PHCP#2

The justification for PHCPs' gatekeeper behaviours is based on the very aspect that also encourages patient empowerment, the significant information availability via the worldwide web, but also the "*amount of misinformation that comes up when people search online*" (PHCP#2). Gatekeeper practices also implicate dimensions of expert control reinforcing the behaviours and roles of PHCPs as professionals (refer section 6.2.2), for example,

*Well we have to guide them [the patient] because we do have the professional filter there. They start telling you stuff and you listen to it going, "Yeah that's fine, I'll leave you with that, that's fine." Then they'll come up with something that's a bit off where it should be and **you can subtly sort of guide that knowledge** if you're listening to what they're saying to the point they understand their issue, rather than getting out of whack. PHCP#11*

These gatekeeping health literacy behaviours demonstrate another aspect of the contested healthcare interaction. The screening and brokering of health information fulfils professional obligations to de-mystify the intricacies of informed consent. Individuals regularly make decisions under conditions of imperfect information, uncertainty, emotional involvement, and risk. However, Schneider and Hall (2009, p. 27) corroborate the importance of gatekeeping roles in health decision-making contexts, since "sickness can be painful, exhausting, debilitating, disorienting, terrifying, isolating. People so afflicted lack the energy and acuity to ask smart questions and demand smart answers".

Gatekeeping and health information interpretation provide checks and balances on health information facing patient-consumers. Proliferation of choices and the fragmentation of expertise in the post-modern world support the primary healthcare professional exercising his/her judgment on the patient's behalf, particularly with competing knowledge claims, for example,

*...people that are into their wellbeing, doing [using sports drinks] what they believe is the right thing but from another perspective it's the worst thing they could possibly doing. This is where the patient-consumers may be literate about the requirements [of their physical health], **but they're doing it the wrong way and often it's because of a company's marketing**. It's pure self-interest from the company's perspective and I tell those people you have to eat your energy and drink water for your hydration. PHCP#11*

Although many healthcare consumers, including baby boomers, are actively engaged, accessing the Internet for health information, and using technology to gather information about their health (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010; Lustria, Smith, & Hinnant, 2011) the PHCP participants underscore the significance of their gatekeeping practices given their misgivings regarding the degree to which many patient-consumers are self-managing,

*...you can put a lot of information out there and we find it very hard that people just don't hear or **in their opinion they [the individuals] just don't need to listen to that message.** PHCP#10*

*...if they're only coming when there's symptoms they're going back into that "I've come to be fixed" kind of mentality...and not even doing an eye health check to make sure everything's okay. **I don't know if we've moved very far.** PHCP#10*

These misgivings and frustrations reflect the tensions over variability in relationships, roles, and responsibilities in healthcare relationships, which contribute to health literacy as a complex interactional phenomenon. Patient-consumers listen to many voices and multiple sources of knowledge, not solely the PHCP. According to these PHCP participants a more-informed consumer is not necessarily always better equipped to make health choices.

With patient-consumers' variable needs and multiple knowledge sources, the patient-practitioner relationship is integral to the PHCPs' practices and behaviours as a gatekeeper,

*Maybe you have to have level 1, 2, 3 because if you don't give patients enough they'll go find it somewhere else and you want them to come back to you and get the information that you, as in you being the practice nurse or the GP, want to give them. But if you're just giving them this superficial information, they'll go and get it somewhere else and you've got to hope that they then find a reliable source...Whereas if you give them too much then they're not gonna read it and not understand it and then feel embarrassed and not want to ask questions...**But then that depends on the relationship.** PHCP#2*

The PHCPs recognise the potential of creating customised higher quality sources of information, relevant to the patient's own context, understanding, and readiness to use the health information, as one participant states,

*...what I want to do is try and have my own videos and do my own articles on the net; so that **it becomes more relevant and trustworthy**... 'cause there's so much information on the net that's not right and very hard for people to evaluate what's right and what's wrong. So I want to try and get it more packaged so that **they can come to a website and know that it's true, that I've really researched it and put it together.** PHCP#1*

In this instance, the gatekeeping behaviour appears less paternalistic and more patient-focussed with the PHCP acting as a trustworthy broker of evidence.

6.2.2 Ethical agent

In the category labelled as ethical agent the distinctive PHCP practices and behaviours are summarised according to the key meanings of: being fair and equitable and engaging in non-opportunistic practices, acting with professionalism, taking responsibility for patients' health and wellbeing, and promoting health and health services. These key meanings are summarised in Table 6.3.

As ethical agents PHCPs undertake fair and unbiased practices in a non-opportunistic way to encourage health literacy, including providing rational support for decisions, supplying authentic and trustworthy health information, such that patient-consumers are “not intentionally misled, manipulated, or exploited” (Karpen, Bove, & Lukas, 2012, p. 28). For example,

I think that getting that [health promotion] information out to the public is very difficult. I guess there's a bit of 'patch protection' as well as what's good for the public to know and not. And the ethics of that is how much marketing of health issues a PHCP feels comfortable doing... so it is hard for us to get those messages and for people to believe that there is a real issue and that we're just not trying to get them back in to make more money out of them. PHCP#10

Table 6.3 Summary of Ethical agent category of description

Key meanings	Description	Illustrative Quotes	
Being fair & equitable	Non-opportunistic practices Actions that avoid self-interest	<i>It's hard to get those health promotion messages across and for people to believe that there is a real issue - that we're [PHCPs] just not trying to get them back in to make more money out of them. PHCP#10</i>	} Ethical agent
Acting with professionalism	Professional boundary keeping Application of specialised competences and technical knowledge	<i>...although they think they know and they think they've got all the information they [patients] can't make those decisions. PHCP#7</i>	
Taking responsibility for patient well-being	Clear role responsibilities	<i>...I'm responsible for looking after you and I know what's right. PHCP#5</i>	
Promoting health and health services	Prevention practices Concerted network action	<i>So that's been a constant challenge for us - how do you get people to listen and the cost of getting that message out there is significant but we still see it all the time, if they'd had an eye examination earlier they could have been treated for their glaucoma and probably not lost vision that they can't get back. PHCP#10</i>	

In this category of description, elements of trust, knowledge sharing, and uncertainty are implicated in the PHCPs' behaviours as ethical agents. Reassurance of non-opportunistic behaviours reduces uncertainty, increasing trust and consequently encouraging health literacy. For example,

...you're [the PHCP] showing that you're not doing this out of self-interest, you're doing it out of wanting to help. I use a phrase, "Do you want to stop transferring money from your retirement fund into mine? 'Cause that's what you're doing at the moment and I can help you stop that, are you interested?"...I use that as a sort of circuit breaker to try and get their attention, because until I've got their attention they're not going to hear the message you're trying to give them as regards their own personal care. PHCP#11

PHCPs appreciate the tension between their perceived pecuniary motives and the goals of public health and social betterment. Healthcare advertising and promotion is often construed as opportunistic behaviour, acting as a deterrent to effective health literacy practices by healthcare professionals and resulting in resistance by patient-consumers to engage with the health promotion message (and associated behaviours). For example,

...You know patients still probably think, "I'm okay and they're [PHCP practice] just calling me back to make me pay again." And that's very hard for a healthcare professional to crack. PHCP#10

*...we send people reminders, after two years after we've seen them, that it is time to come in again, and in that reminder we always have the eye health message. **We never promote any products or anything like that in it. We just make it as an eye health reminder that you should be having your eyes examined. We probably get about a 25% return on that. PHCP#10***

PHCPs recognise some of the challenges to reconciling their ethical agent behaviour role in health literacy with actions guided by pecuniary benefit. However, the pecuniary pressures differ with institutional, business, and employment frameworks. For example, some healthcare professionals operate within a system of key performance indicators, such as cardiovascular risk profiles, that constrain ethical action since there is less focus on the patient-consumer needs and more on the institutionalised (or employer's) processes. Therefore, the contextual dimensions of PHCPs health literacy practices must be recognised as extending beyond the somewhat restricted context of the healthcare encounter.

Healthcare professionals may seek to distance themselves and lessen their responsibility in those areas that provide limited pecuniary benefit. In this situation, their health literacy actions are less than ethical as practitioners engage in negotiating their responsibilities. For example,

*...if GPs didn't have a **prescription pad** what else would they have? Most of them wouldn't have anything. Most of them would have no other tools...*

*So people are getting episodic care; through the course of their illness they are seeing quite a few different providers and **none of those providers is taking a long term view, they're all just thinking, I want to get this guy out of here.** So whatever's gonna get him out of my door...*

*Yeah **the KPI is on time...** What is gonna make me money is I'm gonna get them out the door. I don't care what's gonna happen to him half an hour from now, I just wanna get him out in my 15 minutes...
PHCP#1*

Included within the PHCPs' construction of health literacy as an ethical agent, are behaviours and practices they identified as concerted network actions. For example,

*...And so either we can help them find a strategy or a solution that they can afford without going to see them, or otherwise, we make a few discreet behind the lines phone calls [to others in the healthcare professional network] and say, "We think you need to see this person."...because we've got this privilege of actually still being in a cohesive community, **if it's one of our local docs they'll do it for us;** you know that they'll do it for us and they'll do it for the patient...but when we can't what we always try to do is to make sure that we help that person devise a strategy. PHCP#3*

Inter-professional health literacy that integrates literacy across professional health networks is also included as health literacy, for example,

...there was a real disconnect from the hospital with patients that were getting head and neck radiation and the extreme requirement for dental care because what happens is the salivary glands get fried and their mouths go dry and they get rapid decay in a flash, six months and they're in deep trouble. They need very aggressive maintenance and it wasn't until I had a patient who turned up with just every tooth in his head needing work, he'd had the radiation, he can't have his teeth out now because his bone's dead. So I actually wrote a big letter up to the oncology department saying you guys have got to get your

*act together on head and neck radiation patients and get aggressive dental care instigated before they receive radiation. From that day forward, every four to six months, those patients have to be seen and managed. ...That's **inter-professional communication and understanding**... I jumped up and down on that one and yes they have put things into place up in the oncology department now. PHCP#11*

*We are at the moment busy talking to a lot of the GPs to try and make sure that even from their end there are some screening processes available, because with a lot of the other health issues you get to a certain age and the GP tells you that you need to get this and this checked, but hearing is one of those things that I think too often even the doctors will say, "You're just getting on a bit." ... **it's about educating I guess our colleagues as best we can, trying to improve that communication between professionals as well.** PHCP#4*

Therefore, PHCPs understand collective action behaviours to be part of health literacy, which increases inter-professional awareness and mobilises system resources within the healthcare service users' networks. These network dimensions of health literacy parallel the social and networked practices of health literacy experienced by the baby boomer participants (Chapter 5). Underpinning these paralleled constructions of health literacy is the individual's intention to take action since better health outcomes are undeniably the desired outcomes (Jordan et al., 2013),

...health literacy is implicit in a person saying "Well what can I do; how can I help myself; what changes can I make?". PHCP#5

In addition, the PHCP participants understood their health literacy practices as an ethical agent to encompass health promotion, such that their practices engaged and motivated individuals to take personal action; PHCPs underlined that for them health literacy and action are interdependent, using the words 'change' and 'moving forward' to indicate the implementation of choices and decisions (also refer Section 6.2.3). Experiencing health literacy in terms of responsiveness to PHCPs' preventive and health promotion communications suggests a complex relationship, for example,

We probably get an alarmingly bad return [on health promotion messages]...because there's things like glaucoma that's the biggie that they can be ongoing and by the time they find the symptoms it's often too late. They come in; we diagnose they've got glaucoma; they go away to a specialist to be treated or we will be able to treat that in

future and once you lose that vision you just can't get it back because it kills off nerves in the back of the eye. PHCP#10

It is clear from the research findings that PHCPs enact multiple behaviours and practices in their involvement in health literacy. Described in this chapter using categories of description, these may not always reconcile with each other, some may directly challenge others; for example, PHCPs' professional authority and expertise may be challenged by enabling patients to be more informed and responsible for their health. The PHCPs were explicit about themselves as professionals, at the same time articulating the tensions that emerge between patient autonomy and professional views of the *correct* information and/or the *right* health decision, as exemplified in the following comments,

*So I send her [my patient] back an email a little bit terse and said, "Your friend is not a health professional and you mustn't seek that medication; that medication that your friend is telling you about is old fashioned, addictive, it's not what you need, please try again at half the dose. **And I am the health professional here and I know what I'm saying.**" PHCP#7*

***I have to own him, he's one of mine. I am a health professional and I can't not pick up some responsibility for his behaviour.** PHCP#3*

The PHCP participants voice a paternalistic approach of "trust us we know best what will help you" but they also reveal perspectives reflecting a more patient-centred approach of "Let us know what you need and want and that is what we'll offer". The majority of PHCPs acknowledge that democratisation of information challenges their expertise with patient trust no longer automatic or guaranteed,

My day to day challenges are often around getting patients to believe and trust me. PHCP#7

Healthcare interactions are typically characterised by risk and uncertainty, therefore disclosure of information relies on trust. With disclosure of full information the healthcare professional can potentially discover what is wrong and decide what then needs to be done. Although the participants acknowledge their involvement in patient empowerment, there are underlying paternalistic perspectives; firstly, that patients do not always or readily disclose the 'right'

information; secondly, that the healthcare professional has the expertise to apply the ‘right’ technical knowledge to the problem and/or patient need. For example,

*...for me personally it’s always been a case of the more information you can give patients the better – [as people] we’re all capable of deciding what’s right for us. But I think certainly the challenge as a healthcare professional has been more around how to implement that and to make sure that **we ask the right questions so that we’re getting the right information.** PHCP#4*

This PHCP voices how the category of description of PHCPs as professionals, following a positivist tradition, is based on the perspective that there is a right treatment to be uncovered. The PHCPs seek to retain their power and professional authority by asserting their expertise at eliciting the right information. This suggests that PHCPs see redefining the healthcare relationship as key to enhancing professional expertise given the postmodern healthcare context and proliferation of information. Professionalism continues to be the application of specialised competences and technical knowledge which can co-exist with these contextual factors, as one participant notes,

*the doctor-patient relationship is changing from one of ‘Doctor-as-God’ type relationship to a ‘[Doctor as] partner’ where you discuss everything; everything is open...**communicating with the patient as an equal and as a peer often to make mutual decisions based on the best kind of practice.** PHCP#7*

However, this does not necessarily resolve the tension over who has the responsibility for that decision. If there are gaps in expectations, information, trust, or competencies, then co-production of health literacy will be limited. Competing claims of evidence and knowledge add to these tensions and potential constraints for health literacy by challenging the expert control PHCPs perceive to be their professional obligation. The internet provides information previously (largely) limited to health professionals; moreover, the patient-consumer listens to multiple sources of information distributed over many people and practices, some of which may be mundane and others significant, for example,

...they’re getting information from their friends ‘cause friends all talk now. Nothing is taboo; everything is talked about and it’s not just talked about face to face it’s talked about on what I call ‘Spacebook’, Twitter and YouTube. PHCP#7

...they'd [patients and clients] listen to their neighbor rather than their doctor or their pharmacist. The neighbor says to do this or so and so says to do this. PHCP#9

...another family member or something like that suddenly comes home and tells them, "Well I've just been diagnosed with glaucoma and I've been told that it runs in families so you better all go and have it done." And so then they come puffing up to the door and want to have an examination to confirm that they're okay. PHCP#10

When it comes to literacy probably there's more learning done about dentistry at the dinner table with friends, particularly from the delivery side of it and what's available, than almost anything else... they're finding out from Dr. 'Not-Dentist' and taking advice because someone had a bad experience. PHCP#11

The PHCPs recognise the increasingly blurred distinctions between experts, lay people, and patient-consumers in healthcare but maintain that however well-informed patient-consumers are they will not be the health professional. Furthermore, PHCPs are uncomfortable with patient autonomy if they are expected to resolve patient health after the patient's autonomous decisions. If responsibility is not clearly identified in the interaction, then frustrations emerge when role expectations and responsibilities are reversed at the whim of the patient [or practitioner]; for example,

*Then you've got people saying things like you should never have a root filling because they cause all sorts of illnesses. We struggle with patients like that. I just had a patient in today, we were gonna save a tooth. She read up on the internet, talked to her friends, now this is literacy. **She did her research, talked to her friends, she's had this tooth extracted. Now she's asking me what can I do with the space?** I said, "Well we were actually just gonna root fill it and put a crown on it and it had a 95% chance of being there ten years later. Now you've got no tooth in your mouth, your only solution's an implant, it's gonna cost you twice as much." I said, "I advised you on that." She said, "Oh well I can't afford that." And I said, "Well your solution's live with the gap." PHCP#11*

Changing role expectations also demand responsiveness by PHCPs to the variable information and healthcare-relationship needs, for example,

People ask for more - more understanding, more involvement, more evidence...But that's not a bad thing really. I mean it makes [healthcare professionals] like me have to be a little more on guard

and more informed and more willing to participate in that, because otherwise the baby boomer person will go to someone else who is prepared to do that for them. PHCP#5

Responsiveness to the shifts in power to the consumer can also be seen in the provision of patient records from traditionally when “...*patient information was not available for the patient particularly*” (PHCP#5), to shifts in communication where,

...you discuss everything; everything is open and nothing is hidden. PHCP#7

...we've got so many methods of communication it's frightening and the speed at which we can communicate. We freely use texting, we freely use emailing, and we have a website. PHCP#7

and where current consumer expectations are considerable regarding online medical records, mobile phone apps, and ‘always-on’ remote access communication; for example,

...the patient can login and they can look at their blood test results, they can look at what recalls they might be due for - the mammogram or when did they last have a smear - and then they can email us and communicate through that secure portal. PHCP#7

...I was just on my remote access doing my results - I don't start my week until this afternoon but I'm checking emails and checking results from when I was last in at work which was Friday afternoon. PHCP#7

The provision of online patient records, email communications, and customised online information are evidence of patients becoming regulators of healthcare professional practices. However, tensions over the changing power relationships in the medical interaction and the questioning of professional boundaries mean some PHCP practices can be interpreted as protecting their professional patch from the influences of consumerism, autonomy, and patient choice. One participant notes the resistance to loss of professional authority,

*[patient online portal] is slightly more open – it's going to be a secure portal that the patient can go in and they can look at their results, their consultation notes - **although we're not going to turn that on just yet, some of us are a little bit scared, not me, but some of the others are a little bit scared about patients seeing what we've written.** PHCP#7*

To involve patients in shared decision-making requires the information gap to be bridged and part of this information is a patient's own records and consultation notes. The exercising of professional expertise and judgment will be renegotiated as behaviours and responsibilities adjust to the evolving healthcare context. In certain defined health situations, there is a single way forward (e.g. a broken arm needs resetting) but for many primary healthcare decisions there may not be a single best option but several options, based on value systems, social norms, costs, competing knowledge claims, and patient preferences. To explore these options requires a different professionalism,

*Yeah I think **patients are always willing to participate it's about whether the practitioner is.** And more often than not that's not always the case or the practitioners want to participate at this level [hand at waist level], not at this level [hand now raised high]. PHCP#5*

6.2.3 Enabler

Finally, through the hermeneutic interpretation of the PHCPs' textual data, a third category of description emerged to provide a new understanding of healthcare professionals' experiences and practices of health literacy. The enabler category includes behaviours that have been described as: facilitating informed consent, integrating resources, being a partner, and being a co-learner. These key meanings of the enabler category of description are summarised in Table 6.4.

PHCPs are highly influential regarding informed consent given their activities in accessing, understanding, interpreting, and disclosing information, discussing treatment options, appreciating healthcare uncertainties, and responding to patients' individual healthcare understandings and perceptions. Consideration of informed consent is significant for PHCPs as enablers, for example,

...as health practitioners we're charged with a responsibility to provide informed consent, before a person proceeds with procedures or treatments or management of any particular sort. PHCP#5

Table 6.4 Summary of Enabler category of description

Key meanings	Description	Illustrative Quotes	
Facilitating informed consent	Engages in meaningful relevant dialogue	<i>...the consumer has to rely on the provider effectively to give the range of options and so forth to be able to make that consent. PHCP#5</i>	} Enabler
Integrating resources	Develops and capitalises on patients' strengths and competencies	<i>...[the PHCP has] to understand what the patient's understanding is and by letting them talk I get a really quick grasp of where they're at. PHCP #11</i>	
	Recognises patients' experiential knowledge	<i>...actually the patient's worked this one out, I just need to do a little bit of fine tuning, a little bit of micro guidance to take them to the point where they can make their own choice...and if they've made a decision that's right it makes my life so easy. PHCP#11</i>	
Being a partner ...	Networked Emphasises relatedness with patient	<i>...my health literacy perspective [as a PHCP] isn't about me holding the health literacy and bestowing it upon you... we don't see ourselves sitting above somebody; we see ourselves as sitting alongside people. We're there to be used as a resource. PHCP#3</i>	

Key meanings	Description	Illustrative Quotes	
Being a partner ctd	Mutual acknowledgement of choices	<i>...we give people choices, "Well if you don't want to go on that journey with us, that's fine, we'll fix your current problem and you can go off and do whatever you like. But if you'd like to go on this journey with us well then that would be even better from our perspective because we think we might be able to assist you on a longer term basis. PHCP#5</i>	} Enabler ctd
Being a co-learner	Sharing in knowledge gathering Acknowledges patient expertise	<i>I will always try and work with my patients to help explore other options and other resources, which often include the internet and the amazing amount of information that's out there. PHCP#7</i> <i>...a lot of what I do is trying to get the patients to get the wider picture...how connected it is because health is a big picture. PHCP#1</i>	

One PHCP participant recounted the importance of an enabling perspective to informed consent. The health management decision concerned the fitting of hearing aids. In this interview excerpt the PHCP's understanding of the baby boomer patient's health literacy highlights the mutual acknowledgment of the authenticity of patient expertise.

In the last two years since we've been doing more of these discussions around people's own perceptions[of their hearing loss] I've had certainly two or three clients where even now if a colleague had shown me their hearing test results I would have said, "No, no hearing aids." But from that discussion [with the patient] it became apparent that their demands on their hearing were such that even though it wasn't a big deficit in terms of our classification, it was impacting on their day-to-day life significantly.

...
I've been astounded at the outcomes. One in particular - even though I was quite happy to offer a trial I thought that it might not do what she was wanting to, but it seems to have made all the difference in the world; and I think that's because as good as the technology and the assessments have become, there's still areas that maybe we're not assessing as accurately as what we can.. it comes down to how they process the information that they get [to make an informed consent].
PHCP#4

Although the principle of informed consent is firmly part of the contemporary healthcare system and integral to health literacy (refer to principles on the opportunity and ability to make choices, Sen, 2002), some PHCP participants questioned whether informed consent genuinely enables patient-consumers to extend their influence in health decisions. Several PHCPs expressed misgivings about the capability of individuals to adequately make these types of decision, for example,

I have grave doubts that a consumer can adequately have reasonable informed consent to make those choices. So I think it is a misnomer in many respects...And without a detailed understanding of the issues behind the decisions I think a consumer is at a significant disadvantage. PHCP#5

Therefore, even if informed consent is an institutionalised practice akin to the enabling practices of health literacy by PHCPs, these participants doubted its efficacy to be genuinely enabling.

Furthermore, in their practices of enabling, PHCPs face significant challenges, for example, in providing the right information and making the information comprehensible in order to enable patient-consumers' understanding and engagement with that information to make good choices. The PHCPs perceive their enabling behaviours in health literacy as helping to mobilise patient-consumers to develop and capitalise on their strengths and competencies to reach the best decision together. For example,

...because that's what health literacy is about; it's about my capacity to meet their needs; it's not about their capacity to reach some sort of standard.

...we're doing an awful lot more of sitting down with our patients and customers that come in...

*...what we try to do as pharmacists, with our patients is not only dispense medicines correctly but we spend quite a bit of time talking with our patients about how they're managing medicines and **finding out what works for them what doesn't work for them**; encouraging them to talk to us. PHCP#3*

Health literacy actions that help individuals to mobilise their competencies depend, in part, for their success on PHCPs' appreciation of and responsiveness to the complex dynamics of the patient-practitioner relationship. For example, without authentic participation from the patient-consumers then conventional health literacy practices may have only limited effect,

*Some nurses get patients to leave with two or three bits of paper as well as their script, and those will just be things that are printed off again and again and again and then it's up to the patient. I guess they've given the patient something, it's then up to the patient 'cause they haven't got time to sit them down and say, "Do you understand this?" **I guess there's quite a few assumptions made that the person will take it home and read it and that they will want to do that and then understand it.** PHCP#2*

PHCPs are also uncertain and distrustful of whether patients introduce the subjects they really want to discuss and whether all relevant information is being communicated. For some of them, enabling means engaging in meaningful dialogue to allow the 'right' questions to be asked so that the patient-consumer receives the 'right' information in order to take the 'right' action; the desired

outcome may be as much about developing a patient-practitioner health relationship as well as about orienting patients towards health-promoting choices:

...it's a whole change...it's much more open they're not coming to me as like their god, their sole source of treatment, or information; there's a whole lot of information out there...a lot of what I do is trying to get them to get the wider picture, not just health; but nutrition, how connected it is and all that sort of stuff. Because it is a big picture. And you can see it in them as they come through with each visit that they are becoming more and more interested and aware of how it all impacts on their health. PHCP#1

And so I think to some extent for me personally it's always been a case of the more information you can give patients the better- [as people] we're all capable of deciding what's right for us....So I think one of the challenges is to get the conversation to a level that they understand why you're asking them these questions, 'cause some of it can seem quite invasive in a way. PHCP#4

At the same time as illustrating the practices and behaviours of enabling and co-learning, this latter quote also implicates elements of health literacy as ethical agents (refer section 6.2.2). A conversational interaction and trusting relationship are means whereby the PHCP gathers more information to better apply his/her expertise knowledge, reminiscent of a paternalistic perspective.

The PHCP practices and experiences as an enabler regarding baby boomers' health literacy are seen as key elements in a strategy to increase individuals' control over their health and their ability to take responsibility. For example,

But I think we're spending a lot more time, I think comparatively probably 50 percent more time, to when I first started having those discussions - if not more really. I think when we first started we'd do maybe a half hour discussion around some of the issues surrounding what their own perception of their hearing health is and what their daily situation is and what challenges it presents to them. Now sometimes we'll spend an hour or even longer than that just on that particular part, so it's certainly been one of the areas where things have changed quite a bit.

And I think it's very true with the technology that we deal with; you know on paper it might be really well suited but if they can't come to grips with using it then it's never gonna mean anything for them. PHCP#4

These PHCPs recognise the complex processes between providing information and the patient-consumer's health-related relational, cognitive, and emotional responses. For example,

*People are very receptive to the idea of better information about a condition and they just feel really lost about where to get more information...**they can feel quite intimidated, they don't feel it's a very equitable power relationship** so if their doctor says this, if they don't understand it they don't want to appear silly. **They don't see questioning as a positive thing** sometimes. PHCP#6*

One of the challenges for PHCPs as enablers of informed consent is that of shame. The PHCPs acknowledge that shame is often experienced by patients regarding literacy, which significantly detracts from the PHCP's capacity to be an enabler,

*Everybody in our society expects you to be literate; you are expected to be literate. It is the norm. So not to be literate is this thing that gets hidden, this thing that you don't talk about, this thing that must not be named. And people who have poor literacy skills go to great lengths to hide it. They don't tell their nearest and dearest, and **so if they don't tell their nearest and dearest are they really going to own up to you [the PHCP]?** PHCP#3*

In addition, the PHCP as enabler involves other system actors and the system itself, which may entail integrating resources and setting up the right processes or structures within the healthcare system, for example,

So it's kind of, primary healthcare practice might be the home where people are kind of managed, their medical home, but there's specialist information outside of that and I think it's making sure that nurses etc. who do a lot of this know where that is. A lot of them do have their contacts, "Oh ring Bernie at Alzheimer's for more information and support". PHCP#2

...[it's important to appreciate] just how complex the overall system is - it's almost impossible to navigate without building a whole lot of knowledge around a specific condition or a specific service and a lot of this knowledge is assumed. There's a huge amount of knowledge that needs to be built by people when they're diagnosed with a condition and there's not a lot of help to do that. PHCP#6

...when they come to us it's because they're either too scared to engage with the health system they say "hell honey I'm not going there". So you see total resistance [in patients] to actually engaging with the [health system] environment - they don't really know how to negotiate their way around the system; they don't know how to do it in

a way that actually makes that system work in a time frame that actually allows them any degree of comfort. PHCP#3

Therefore, enabling behaviours require PHCPs to understand when and where patients want to be enabled or when they want to be more self-responsible; in some cases, patients may choose to rely on expert advice depending on a range of variable factors. Choices are time-consuming and difficult and health issues are not the only thing happening in individuals' lives. Similarly, the healthcare professional is faced with their own constraints imposed by system structures, time, work flows, and costs that contextualise their enabling behaviours regarding baby boomers' health literacy. For example, one PHCP explains the effects of these contextual pressures that can counter the enabling practices and behaviours a primary healthcare general practitioner may aspire to,

When you get into some of those busy rural areas that are short staffed and doctors are struggling to see the kids with fevers, when you get someone with a bit of high blood pressure it's easier just to chuck them the pamphlet and the pills and get on with the sick kid kind of thing. PHCP#8

Ultimately, the PHCPs perceive their enabling behaviours as effecting changes in individuals' decision making and behaviours. This change-oriented goal of PHCPs' health literacy practices implied decision-making and typically these decisions were seen as being the patient's responsibility, for example,

It's really like a negotiation, how much they're prepared to do to change lifestyle-wise to get to that goal of being healthier. PHCP#1

...part of it is saying to people, "Well, yeah you've got options, but you have to stick to them." PHCP#3

...health literacy is implicit in healthcare choices or the ability for a person to make choices about their healthcare...to go from a particular level of function to a better level of function and trying to maintain and improve that all the time. PHCP#5

*...being health literate involves that interaction or relationship **that allows the patient to either express or implement that information ...** PHCP#6*

This understanding of PHCPs' roles in health literacy as enabling, juxtaposes the partnering behaviours (see above) that the same PHCPs described. This

paradoxical combination of partnering alongside entirely patient responsibility may be the practical face of the consumerist trend in health, as acknowledged by the following PHCP participant,

I think probably one of the biggest things that I've noticed is that people want to participate in their healthcare, which they didn't use to. It was a case of come and see someone like me; get fixed; not have to change anything about their own lifestyle or attitudes and behaviours; and then go away and carry on as normal.

Whereas now there's a group and particularly baby boomer people, even in the older group, are saying, "Well what can I do; how can I help myself; what changes can I make." PHCP#5

The consumerist approach to health is that patient-consumers are active, participatory, and evaluative actors in their health; these attributes collectively result in more successful health outcomes for the individual. The PHCP participants suggest that their enabling behaviours contribute to more effective and efficient healthcare delivery since they are more patient-centred and more effective in creating baby boomer patient-satisfaction than the practices and behaviours grouped under the knowledge broker category of description.

Within the category of description of PHCPs as enablers, PHCPs also enact behaviours that can be termed co-learning. This describes practices where the PHCPs actively seek, evaluate, and share information, often combining evidence and information from multiple sources, including the patient, to improve both doctor and patient health knowledge and awareness. These PHCPs co-construct authentic information and collaborate with their patient-consumers in the health-related decisions (a practice that could be also considered as overlapping with practices and behaviours as ethical agents). For example,

*In this job I get a lot of questions about the effects of possible alternative treatments and whether they're effective or not. And the problem with alternative treatments is that, because they're alternative they're not proven; so you have to try and figure it out for yourself whether there's some sound rational basis for it, and try and give advice on that.... **how do I answer them? I do my own research ...** certainly go and look up any information they give me to see if there's any validity in it because **obviously I don't know everything and it's trying to expand my knowledge base as well.** PHCP#1*

Co-learning implies shared power and reciprocal value among the knowledge sharers in which the relationship is a key element. The participants emphasised the patient-PHCP relationship as the bridge between asymmetries in health knowledge, power, and autonomy, and that it may also be influential in adjusting to changed expectations of healthcare encounters. For example,

INT: So what do you do when these health literate baby boomers come in with their own research maybe from the internet that conflicts with your advice?

PHCP#8: It depends again on the relationship, the relationship you have with them plays a big role... it makes it slightly easier.

The PHCP's experience and patient-approach significantly impacts the co-learning practices and behaviors in health literacy. For example,

...part of it is your working experience and the more you do things; ...I've worked with a GP who did alternative medicine so I'm quite comfortable and happy discussing those things with patients. Other GPs I guess who don't know anything about it; they just kind of say, "Oh don't do that [follow alternative treatments]..." rather than maybe exploring it. PHCP#8

As an enabler, the PHCPs perceive themselves as integrating resources for mutual benefit and value. These resources may be drawn from multiple sources by the PHCP; the participants include as resources their own [self-generated] resources of medical philosophy, cognitive capabilities, and sense-making abilities. The PHCP can also integrate resources by drawing on other patients' experiential knowledge as described by one participant,

*We talk to people with stage four cancer and things who aren't gonna be coming out of this, but they're really happy to share things that they think would have made a difference when they were first diagnosed **to try and make other people's journeys better.** PHCP#6*

The medicalisation of everyday life has contributed to PHCPs' co-learning behaviours, demanding up-to-date and well-informed healthcare professionals, reinforced by baby boomers as patients who are questioning, seeking information, and receptive to new ideas. These PHCPs consider enabling health literacy behaviours as appropriately responsive to the expectations and characteristics of baby boomer patients. For example,

...it [the acts of seeking more information and alternative opinions by patients] can be frustrating from a practitioner's point of view particularly if I'm [the health professional] trying to achieve a particular outcome and I want somebody to be compliant. But then in terms of motivation - motivation needs to be at a fundamental change level where the person says, "Okay right I can relate to that; I'm on board with that, not because you're gonna give me something and not 'cause you're gonna scare me out of something, but because I [the patient] agree with your line of reasoning". PHCP#5

*...it makes **healthcare professionals like me have to be a little more on form and more informed and more willing to participate.** PHCP#5*

Finally, the PHCPs' perceptions of their enabling health literacy behaviours are based on the premise of individual goals for health enhancement. Despite the complex process between PHCPs as enablers and patient behaviours, the PHCP as enabler has elegantly simple outcomes,

*...even in our [audiology] field, more effective probably than doing the hearing test, someone's evaluation of their own health status and how well they're managing is a better predictor of **how well they'll do.** PHCP#4*

As part of the repertoire of an enabler, one participant reiterated his professional purpose statement,

***Our purpose is to help you achieve the balance, harmony, and vitality you need to achieve vibrant health and a long productive life.** PHCP#5*

6.2.4 PHCPs' categories of description - A final note

Despite the centrality of patient-practitioner relationships to health literacy, healthcare professionals' roles are scarcely researched in health literacy (Sykes, Wills, Rowlands, & Popple, 2013). While there are aspects of health literacy that can be attributed to characteristics of the actors or to system capabilities that may facilitate or hinder its emergence, this research shows that PHCPs' emerging behaviours can be understood in terms of three key categories of description, contributing to health literacy in a complex and interconnected manner. Taken

together these categories of description are described as the PHCPs enacting managed empowerment in their health literacy practices (refer Section 6.3).

The three categories of description are part of the social structures that embody information [a]symmetries in patient-practitioner relationships, power [a]symmetries in patient-practitioner relationships, patient autonomy versus paternalistic professionalism, scientific authority versus the democratisation of health, and the proliferation of competing knowledge claims. These contextual influences are categorised into three overarching contexts for PHCP health literacy involvement: consumerist trends, the post-modern world and questioning authority, and the communication and information revolution (developed in Chapter 7).

This chapter extends the understanding of the nuances and dynamics of PHCP involvement in health literacy. Education to improve functional health literacy has been the healthcare mantra over several years. This chapter has shown that beneath the surface of ‘health literacy as information-and-better-education practices’ are complex and interconnected health literacy behaviours enacted by PHCPs within the social context and systems of healthcare.

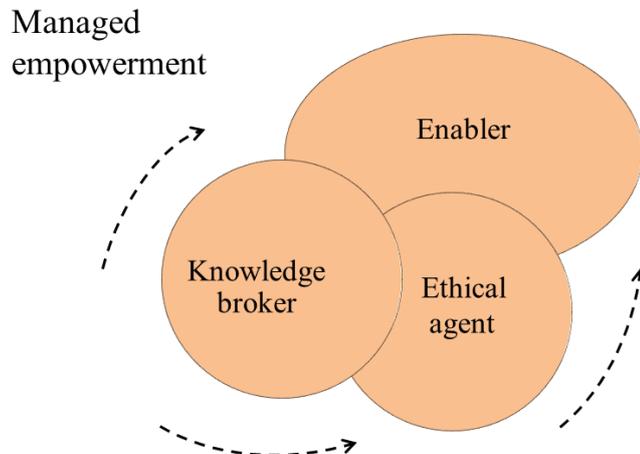
6.3 Managed empowerment

The notion of managed empowerment is the collective theme reflecting the PHCPs constructions and practices of health literacy (refer Figure 6.1). Synthesising the categories of description as Managed Empowerment explains the variability of health literacy behaviours enacted by these PHCPs and the fluctuating symmetry and asymmetry in healthcare interactions on the multiple levels of information, collaboration, judgment, and decision making. These behaviours will at times conflict with each other as evidenced by the tensions expressed by the PHCP participants. Finally, within their managed empowerment behaviours, PHCPs’ expectations and perceptions of patient roles, needs, motivation, and expectations are key to effective co-production of health literacy.

The PHCPs adopt managed empowerment as an expedient means to enable the patient to make ‘any kind’ of choice as long as it aligns with (or is pre-sanctioned

by) the PHCP and, typically, their evidence-based medicine practices. They are seen to provide the patient with informed choice in many areas but there are continuing power imbalances and conflicting authority concerns among PHCPs. Managed empowerment implies a negotiated balance between PHCP expert control and professional expertise with patient-consumer autonomy and expertise. The PHCPs can still exercise insider-information that is typically denied patient-consumers, including where to get information, what is available in the healthcare system, how to evaluate options. Managed empowerment enables the PHCPs to re-negotiate their professional authority, re-negotiate role and relationship expectations, and re-define their expertise in the health decision-making interaction. This interpretation finds support in Pilnick and Dingwall's (2011, p. 1374) argument that "asymmetry lies at the heart of the medical enterprise", suggesting that the role and nature of medicine is not compatible with consumerist trends and patient-centredness.

Figure 6.1 PHCPs' construction of health literacy



The current context of healthcare is a postmodern one characterised by individualism and a questioning of authority where baby boomers have lost faith in solutions offered by scientists or experts. These patient-consumers, who seek increased responsibility for their own health-related decisions, are relying less on trust in their primary healthcare professional and more on their own decision-making. However, tensions arise between patient autonomy and healthcare

professional paternalism, even challenging the profession in terms of what is considered good medicine and good practice. The managed empowerment that PHCPs enact will need to be responsive to health literacy being both *changed* and *ever-changing*. Today's patient-consumers, of which baby boomers are the influential leading edge, are involved in distributed practices of health using multiple resources - their own self-generated cognitive abilities, peers, friends, family, other patient-consumers, and multiple healthcare professionals - to achieve health outcomes. PHCPs' enactment of managed empowerment does not deny the healthcare professional role in health literacy. It represents an attempt to respond to individual patient preferences for information, choice, and autonomy. At times, patients may want to preserve differences in roles, information, and power, and at others they may want them reversed or re-negotiated. The challenge for PHCPs' health literacy practices is to correctly identify these preferences in order to minimise any expectation-enactment gap in health literacy behaviours.

6.4 Summary

Healthcare professionals enact multiple health literacy behaviours where they solicit information, evaluate information, shape choices, and foster health literacy among their patients, for themselves, and for their colleagues. PHCPs do not solely respond to the health literacy that patients present with and mobilise, but they contribute to patients' capabilities to be health literate as well as adding to their [PHCPs'] own health literacy. Therefore, by better understanding PHCP behaviours, health literacy can be better understood as a variable and collective achievement since PHCPs and patient-consumers act within networks of health literacy [re]sources and relationships.

Despite considerable research regarding traditional understandings of health literacy and subsequent public health information initiatives, such health literacy has not consistently delivered better health outcomes. The presumption that the more exposure a questioning patient-consumer has to expert medical evidence, the more the patient-consumer will be health literate, choosing between competing knowledge claims and achieving better health outcomes, is not always confirmed. Health literacy initiatives typically focus on better communication yet how

individuals make good health decisions is not fully understood. This thesis addresses research questions that will provide insights into the phenomenon of health literacy as interactional, influenced by behaviours, role expectations, relationships, and contextual pressures that maintain power asymmetries, information control, and professional status. In particular, this research contributes to the understanding of healthcare professionals' roles and construction of health literacy, which have been under-represented in health literacy research to date.

Health literacy as knowing how to act on health information and knowing how to engage with the demands of different health contexts is generally interpreted in a pragmatic manner as knowing how to be healthy and how to self-manage. However, knowing how to act within healthcare networks and relationships, including with a healthcare professional, is equally critical in health literacy as shown in this chapter. This 'knowing how to act' encompasses the complex phenomena of knowing how to [re]negotiate relationships, redefine professional identities, and bring to the surface fluctuating responsibilities in the healthcare interaction. Furthermore, these complex relational and interactional phenomena are likely to vary over: time, health event, context, and even within a single healthcare encounter. Tensions over relationships and responsibilities, rather than solely communication failures, need to be the focus for health literacy for it to be an asset that allows the active patient-consumer to bridge the information and empowerment gaps to overcome asymmetric healthcare relationships.

The thesis argument is briefly recapped before proceeding to the final chapter, Chapter 7: Extending the Conceptualisation of Health Literacy. Health literacy, one of the means to bridge gaps in health-related language, understandings, and discourse, is considered critical to patient-consumer involvement and shared decision-making in health. Shared decision-making in health, linked to higher patient satisfaction, is expected to be linked to better health and health outcomes. Traditionally, health literacy was approached from a predominantly functional bias using education as the mantra for improved compliance and health-improving choices by consumers. This research extends the understanding of health literacy by focussing on the processes between patient-consumers and PHCPs. In addition, this research acknowledges the contextual influences and the socio-cultural

characteristics of the baby boomer population. While the absence of health literacy places the patient-consumer entirely dependent on the healthcare professionals and the healthcare system, health literacy does not necessarily confer involvement, empowerment, or healthy choices. This chapter concludes that PHCPs enact important behaviours in health literacy that take into account competing forms of knowledge, distributed health decision making, and [de]professionalisation. These issues are at the core of the expectation-enactment gap in health literacy behaviours revealed by the baby boomer interview data. Since baby boomers are the leading, influential edge of changing patient-consumer roles and democratisation of health, detailing this gap in expectations of health literacy and understanding how both patients and practitioners construct this can help to develop ways of closing the gap for more effective health decisions and outcomes.

Chapter 7

Conclusion: Extending the Conceptualisation of Health Literacy

7.1 Introduction

This thesis provides an understanding of health literacy (with regard to primary healthcare) as a socially constructed phenomenon. The purpose is achieved by the overarching research question:

How are the roles and practices of health literacy perceived/constructed and performed in primary healthcare?

The research provides key insights into how individuals construct and understand health literacy as a social and contextual practice. Although health literacy is a socially constructed phenomenon this research is one of the few studies to investigate the phenomenon from a social and contextual practice perspective, thus addressing a research gap (Barton & Hamilton, 2000; Papen, 2009). Second, to the best of the researcher's knowledge, this is the first empirical investigation of health literacy among New Zealand baby boomers. It is also the first empirical investigation of health literacy in New Zealand to include the perspectives of primary healthcare professionals. Third, the study extends the conceptualisation of health literacy from being based on individuals described by health-risk or illness, to one based on individuals described by age and socio-cultural context.

This chapter summarises the conclusions regarding the research objectives which are then integrated into an extended conceptualisation of the phenomenon of health literacy. The chapter also discusses the contributions this research makes to knowledge, implications for practice and policy, limitations, and finally offers suggestions for future research.

7.2 Conclusions about the research objectives

The two supporting research questions focussed the research on firstly an age-defined group of individuals - NZ baby boomers – and secondly on primary healthcare professionals’ health literacy practices, behaviours, and expectations with regard to this particular population group.

Interpreting the results of this research through a hermeneutic lens, health literacy is conceptualised as a complex, negotiated, contextual, and interactional phenomenon. It is much more than just a competence for wellbeing, echoing the assertion that literacy is “situated, mediated, and dispersed” and indeed “literate activity...is not located *in* acts [of reading and writing], but *as* cultural forms of life saturated with textuality” (Prior, 1997, p. 280). This thesis makes several major conclusions regarding the phenomenon of health literacy which are briefly summarised in sections 7.2.1 and 7.2.2.

7.2.1 *Baby boomers’ constructions of health literacy*

Healthcare consumers are not simplistically literate/or not literate (reading and writing) in a health context. The research interpretation (Chapter 5) highlights how baby boomers actively integrate multiple resources at different levels (informal, institutionalised), at varying levels of intensity and complexity, and draw on different informational media in their health literacy. Health literacy behaviours are collectively described according to five major categories of description - seeker, decider, networker, sensemaker, and manager. Specific health literacy practices and behaviours may be temporary, may be organised by the individual, or may be largely influenced by other network/relational actors (professional or nonprofessional).

The baby boomer participants provided evidence of complex modes of enacting health literacy. They were neither wholly compliant nor entirely consumerist, moving along and between the self and interactivity horizons that helped describe their five health literacy categories of description.

From the hermeneutic analysis, asymmetries of information, power, and health literacy intentions often frustrated baby boomers in their health literacy expectations, practices, and relationships. Baby boomers understood health literacy to be integral to their health relationships and networks, both informal and institutionalised. Within their dynamic and multiple healthcare-related roles and relationships, participants sought to share and negotiate health literacy. Their understandings of health literacy challenge PHCPs to flexibly and compassionately respond in order to improve the dialogic interaction in healthcare encounters and consequent healthcare outcomes. By implication, health literacy can be more effectively negotiated and co-created when there is improved congruence between key actors' health literacy expectations.

These baby boomers understand health as an everyday practice shaped by diverse socio-cultural, educational, relational, and informational dimensions of living. These participants accept health literacy as integral to this connectedness of health.

7.2.2 PHCPs' constructions of baby boomers' health literacy

The primary healthcare professionals' constructions of health literacy are interpreted according to three major categories of description – knowledge broker, ethical agent, and enabler (Chapter 6). Although PHCPs provide their patients with informed choice in many areas, there are often underlying power and information imbalances, conflicting authority concerns, and [de-]professionalisation issues among PHCPs' experiences and practices of health literacy. Consequently, a conclusion of this research is that their health literacy behaviours are collectively interpreted as managed empowerment. These PHCP participants typically adopt managed empowerment as an expedient means to enable the patient to make 'any kind' of choice as long as it aligns with (or is pre-sanctioned by) the PHCP and their disposition toward particular, often evidence-based, healthcare practices.

7.3 Conceptual framework for health literacy

7.3.1 Overview

This section presents the conceptual framework as illustrated in Figure 7.1. This conceptual framework emerges from the hermeneutic interpretation process combined with the researcher's engagement in the processes of "...abstracting, generalizing, relating, selecting, explaining, synthesizing, and idealizing..." (Weick, 1995, p. 389) the data regarding the phenomenon of health literacy. The emergent conceptual framework presents the interlinked components of health literacy "laying out key factors, constructs or variables and presumes relationship among them" (Miles & Huberman, 1994, p. 440) that together provide a deeper understanding of the phenomenon.

Health literacy is conceptualised as a negotiated and social phenomenon that emerges from the interactions between and among individual skills and competences, contextual factors, relational processes and networks. According to the research conclusions, health literacy is co-created. This conclusion warrants a conceptualisation that accounts for individual patient-consumers in their healthcare contexts and diverse relational networks. The framework is presented as a schematic model representing the interrelationships of the key concepts comprising the participants' construction and experiences of health literacy (Figure 7.1).

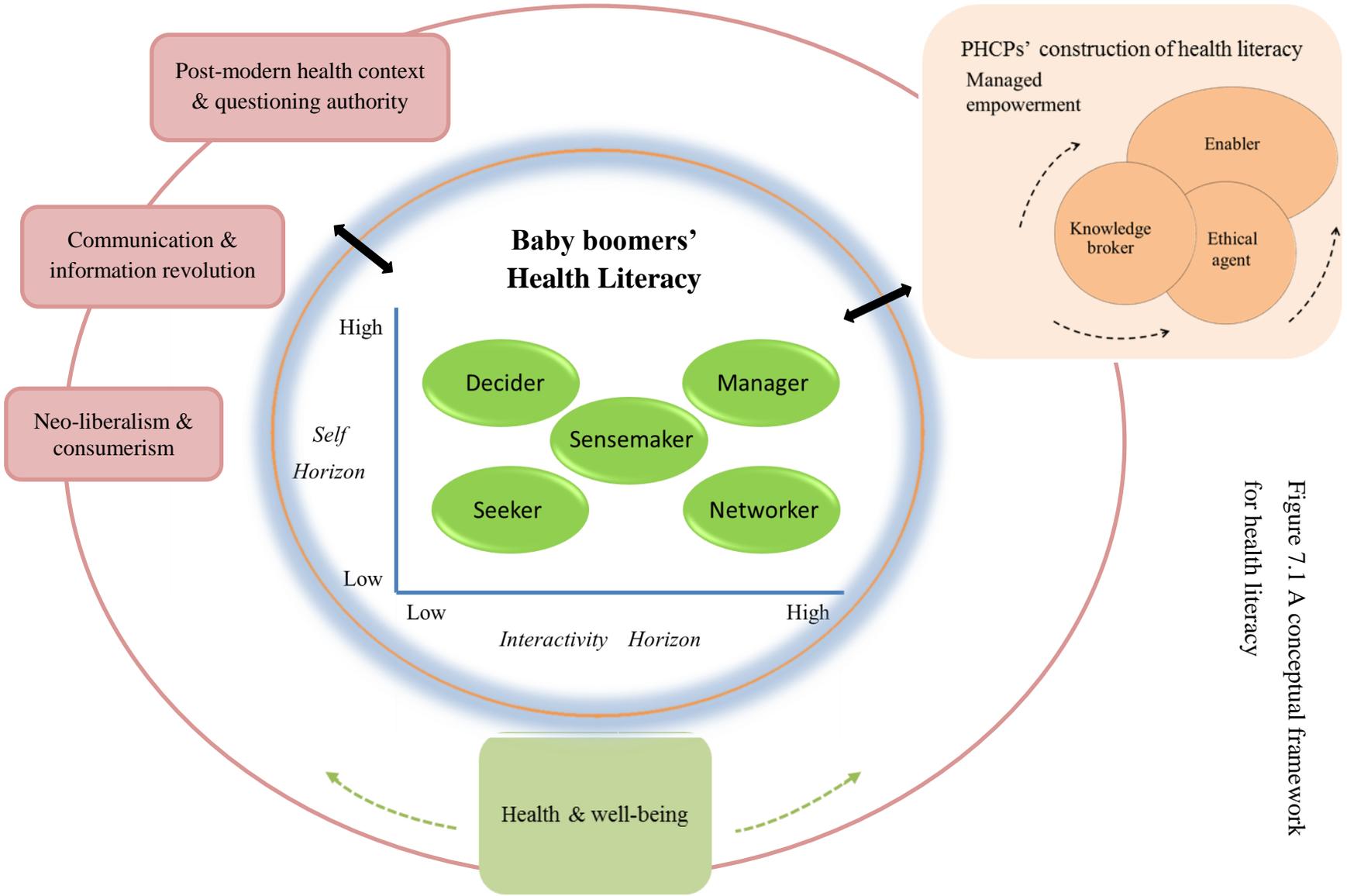


Figure 7.1 A conceptual framework for health literacy

7.3.2 *Conceptual framework explanation*

The central element of this conceptual framework is the active, purposeful, and contextual process of health literacy as interpreted from the baby boomers' experiences. In addition, the two large concentric circles illustrate that health literacy is negotiated and contextualised by each individual according to his/her multiple health contexts. According to this framework, health literacy is not necessarily dialogic as it typically involves multiple actors across multiple contexts. Health literacy behaviours, intentions, beliefs, and practices are influenced by these contexts and relationships (as depicted by the solid arrows between the concentric circles on the conceptual framework diagram, Figure 7.1), operating across multiple levels, relationships, and networks.

This framework conceptualises baby boomers' health literacy according to the seeker, decider, networker, sensemaker, and manager categories of behaviours and competences. These categories are defined along the two horizons of self and interactivity, providing spaces for multiple behaviours, expectations, and networks. The participants' texts described complex and dynamic health literacy roles, responsibilities, and intentions. This conceptual framework does not separately identify functional, communicative, or critical health literacy – although these are evident in the participants' interview data. For the research participants, health literacy was action-oriented and goal-directed.

The categories of baby boomers' health literacy are not mutually exclusive; for any individual there is a range of potential health literacy experiences and behaviours that lie within and across these categories. For instance, health literacy constructed as patient-as-decider does not preclude a construction of health literacy as patient-as-manager or networker, or vice versa. Importantly, this conceptualisation acknowledges that individuals can move between and within categories. As a negotiated, dynamic practice an individual's health literacy may shift from seeking or sensemaking-dominant health literacy roles and behaviours to one that is network-dominant or managing. These interpretations suggest that understanding health literacy at the detailed interactional level is crucial to understanding patient involvement and participation in healthcare, and thence to

the improvement of healthcare service delivery processes and ways of balancing potentially contradictory health literacy perspectives/expectations.

Dimensions of the individual's primary health event, his/her healthcare contexts, networks, and patient-practitioner(s) relationship(s) all influence an individual's particular understanding and practices of health literacy. Hence, the framework situates baby boomers' health literacy within the larger concentric circle labelled health literacy context. Individuals create, receive, translate, put into action, circulate, and transform their own (and interact with others') health literacy behaviours and practices distributed between and within these contexts. The conceptual framework illustrates these temporal, distributed, and dynamic aspects via the two horizons and the arrows between the inner and outer concentric circles (Figure 7.1).

The conceptual framework specifically identifies primary healthcare professionals as influential actors in shaping and being shaped by individuals' health literacy. The notion of managed empowerment is the collective theme reflecting the PHCPs constructions and practices of health literacy (Chapter 6). Managed empowerment explains the variability of health literacy behaviours enacted by these PHCPs and the fluctuating symmetry and asymmetry in healthcare interactions on the multiple levels of information, collaboration, judgment, and decision making. These behaviours will at times conflict with each other as evidenced by the tensions expressed by the PHCP participants. Managed empowerment implies a negotiated balance between PHCP expert control and professional expertise with patient-consumer autonomy and expertise. This construct of health literacy acknowledges that PHCPs still exercise an insider-information role typically denied patient-consumers, including where to get information, what is available in the healthcare system, and how to evaluate options. PHCPs conditionally adopt the notion of 'informed choice' and the 'active health consumer' constructing these concepts on their own terms. Managed empowerment enables the PHCPs to re-negotiate their professional authority, re-negotiate role and relationship expectations, and re-define their expertise in the health decision-making interaction.

Both baby boomers and PHCPs demonstrate “socially structured resources and competencies” (see Bourdieu, 1991 and *habitus*) that serve to position them as individuals having certain health literacy attitudes, intentions, and actions, and as enacting certain roles and social status (Dubbin, Chang, & Shim, 2013). Overlapping these *habitus* are role perceptions that individuals hold regarding behaviours, knowledge, and responsibilities; in the healthcare context, particular skills and attributes are considered valuable resources, for example, PHCPs’ perception of a ‘good patient’ and the baby boomers’ perception of a ‘good healthcare professional’ (refer Chapters 5 and 6). Roles are increasingly considered as sets of practices that link, for instance, PHCPs to patient-consumers (Akaka & Chandler, 2011); in this consideration then roles can change and recombine depending on the context. Enacting certain practices (as in the five baby boomer categories of description and the three PHCP categories of description) helps develop relationships and/or [re]establishes power and authority structures that contribute to role definitions. The sets of practices thus contribute to the context. The tensions evidenced by the PHCPs can be understood as patient-consumers enacting roles and acquiring [health] knowledge that were traditionally PHCP roles and knowledge.

Roles, as resources, are part of the encounter and can be used to effect change in the value that is created in the healthcare encounter. Thus, in this thesis’ conceptualisation, different actors (patient-consumers, PHCPs, network members) may enact similar roles while having different positions in the network of relationships and services that frame each interaction. Configuring and reconfiguring the dimensions of power, information, and/or autonomy occurs so that in some instances the patient may be the expert, at other times a passive ‘patient’, dynamically separating and re-integrating different roles – what may be valuable in one context may not be so in another. Health literacy is both a resource and one of the multiple outcomes from the patient-consumers’ network of health-related relationships, including the relationship with their PHCPs. PHCP and patient-consumer roles switch in the process of decision making - and can be likened to an iterative bundling and unbundling of sets of practices. This implies that a further set of practices is knowing how “to act” (not just knowing how to apply factual knowledge and use health information in a particular context, see Schulz &

Nakamoto, 2005), that is, knowing how to act in this process and relationship of changing health literacy roles. Knowing how to act requires PHCPs and patient-consumers to examine their respective perceived and enacted health literacy practices, combined with evaluating their personal knowledge (limits), skill sets, and health literacy expectations not as the exceptional case but as typical components of primary healthcare interactions. The self-reflexive primary healthcare professional and individual is an area for development with implications for patient development as well as PHCP education and training.

Finally, the categories of description are positioned within three predominant contextual factors of: the postmodern health context and questioning authority; communication and information revolution; and, neo-liberalism and consumerism. These are discussed in turn.

First, the postmodern health context and questioning authority. The current context of healthcare is a postmodern one characterised by fragmentation, diversity, a questioning of authority, shifting power relationships, and contested perspectives; science no longer enjoys a place of privilege with regard to knowledge claims (Giddens, 1990; Lyotard, 1979) where the “medical consultation has become a contested interaction” (Elwyn, 2005, p. 290). The proliferation of choice and fragmentation of expertise are characteristics of this postmodern context, linked to decreasing trust in the authority of healthcare professionals and the blurring of boundaries between expert and lay knowledge (Bury, 1998; Light, 2010; Madison, 2010; Mechanic, 1996; McKinley & Marceau, 2002; Popay, Williams, Thomas, & Gatrell, 1998). In this context, individuals typically seek increased responsibility for their own health-related decisions, questioning biomedical science, and exploring alternative health treatments (Hughner & Kleine, 2004). Patients increasingly self-diagnose and engage in online health information seeking; they are often better informed and more active in making choices regarding their healthcare.

Second, the communication and information revolution. The internet, Web 2.0, and increasingly sophisticated search engines have changed the context for health

information, health communication, and the ways in which people seek and find health information (Eysenbach, 2008). Consequently, the information age has diminished the traditional information imbalances that existed between healthcare professionals and patients (Blumenthal, 2002). Information is now easily and increasingly shared within networks (Castells, 2001; Spinuzzi, 2008); this network society, as a form of social organisation, is characterised by “networking, collaborating, and distributing [as] part of a broader cultural condition that accompanies our growing collective reliance on the Internet and other technologies of connectivity” (Castells, 1996, p. 508). These characteristics are matched by the circulation of information that is rapidly changing – the ‘metaculture of modernity’ where knowledge and information is constantly on the move (Swartz, 2011; Urban, 2001). For example, people have more access to health-related information via the internet and direct-to-consumer advertising, electronic health records are being digitised and automated, people are demanding easily accessible portals through which they can track their own medical records, and people are joining or developing online health communities (Dutta & Bodie, 2008; Eysenbach, 2000).

Third, neo-liberalism and consumerism. A set of social changes has also resulted in the notion of the actively responsible individual in the age of neoliberalism (Lupton, 1997; Rose, 2001). The greater role of market mechanisms has extended neoliberal reforms into health and healthcare, positioning the patient-consumer as someone who actively seeks biomedical information, who is responsible for his/her health by his/her own choices, and who has a moral obligation to maximise one’s own health. In this neoliberal context the patient-consumer exercises choice, expresses satisfaction or dissatisfaction over their healthcare consumption, and makes rational choices to allow them to stay or become healthy (Henderson & Petersen, 2002; Schneider & Hall, 2009; Timmermans & Oh, 2010). The neoliberal model of consumer choice indicates abundant information but also considerable pressures to make responsible, ‘compliant’ health consumption decisions (Briggs & Hallin, 2007, 2010; Petersen et al., 2010); however, “despite the language of empowerment this often entails compulsion, added responsibilities, and pressures to conform” (Petersen et al., 2010, p. 392).

Consumerism has challenged the once-dominant biomedical authority model, where the production of knowledge and expertise was located within the medical profession. In response to consumerism, patient-centred care is predicated on an understanding of the patient and their biopsychosocial context, a sharing of responsibility and power, and mutual understanding of both the condition and the goals for care (e.g., Epstein et al., 2005; Epstein, Fiscella, Lesser & Stange, 2010). Although consumerism, as a manifestation of neoliberalism, seeks to empower patients by nullifying traditional power and information imbalances in health, it also brings new responsibilities and uncertainties for the patient-consumer.

7.3.3 Conceptual framework: Concluding comments

Within the baby boomers' health literacy categories of description (the large central circle) an individual can be situated in different categories of description in this conceptualisation over their life, health events, and healthcare relationships. At this level, individuals link together actors and information within their negotiated contexts to enable and enhance their health, health knowledge, and health decision-making as active, purposive agents. Collaboration, interpretation, and agency are fundamental aspects of these processes. Health literacy circulates, is [re]constructed, and put to work by individuals (e.g., Luke, 2005, p. 661) as they exercise choice and take action related to health.

The five categories of description along the horizons of self and interactivity provide a new way of understanding the phenomenon of health literacy, “reconstitute[ing] from these materials [interview texts] new domains of perception and new languages of thought” (Brown, 1976, p. 185) for representing the phenomenon of health literacy. Incorporating these categories, this conceptualisation addresses the complexities inherent in the [re]negotiation of health literacy as a social practice.

Health literacy cannot be reduced to an individual's set of skills nor is it simply the provision of information. Skill, competences, and information provision are necessary but not sufficient resources in health literacy [behaviours]. This

conceptual framework extends the understanding of health literacy by embodying the key findings of this research, specifically,

- health literacy is about behaviours and skills to make meaning of health;
- health literacy has multiple, dynamic relationships that can be bundled and unbundled as the individual constructs and reconstructs health understandings;
- baby boomers manage and integrate multiple resources and actors in their health literacy, and;
- diverse beliefs and knowledge bases are implicit in health literacy behaviours and intentions.⁴⁰

Complex dimensions of power, expectations, autonomy, and roles (institutional, formal, and informal) are some of the background to the conclusion of this research that health literacy is a negotiated, social, and distributed practice.

This conceptual framework finds support in the notion of literate activity by Prior and Schipka as “ways of being in the world” (2003, p. 182). This literate activity of being in the world echoes how baby boomers experienced health literacy behaviours and practices as they constructed and modified their health literacy understandings through interaction (see above). At the same time they contributed to their networks, building collective health literacy ‘capital’/infrastructure. Therefore, health literacy in this perspective has a capacity building function aligning with the Ottawa Charter of Health Promotion that “health is a resource for life, not the object of living” (WHO, 1986). PHCPs perceived fundamental roles for themselves in health literacy from brokers of information and treatments, through acting as professional ethical agents, to being enablers and co-learners, within the contexts of distributed health decision-making and competing forms of knowledge.

⁴⁰ Although the participants were selected according to age, ethnicity, and gender (Chapter 4), investigation of gender and ethnicity differences is outside the scope of this research. The stratified sampling was for the purpose of exploring commonality of understandings.

Importantly, this conceptual framework provides a nuanced understanding of the health literacy dimensions Sørensen et al. (2012) label as “accessing, understanding, appraising and applying” health information for health decisions (refer Chapter 3). A deeper understanding of how baby boomers not only acquired information but also how they processed, transformed, and acted on health information and services has emerged from describing participants’ key health literacy roles, relationships, and practices. Furthermore, by including PHCPs’ constructions of health literacy, the dimensions of the interdependence of health literacy-in-context can be better understood. In this framework, the PHCP responds to the health literacy behaviours and dispositions that patients mobilise, contributes to the patients’ diverse resources and networks, and enhances health literacy as a collaborative achievement towards improved health-related outcomes.

Therefore, health literacy is not an individual responsibility but a phenomenon co-produced through, and by, the relationship with [in this research] PHCPs, the health system, and the health environment. Health literacy is a negotiated practice. In this respect, the conceptualisation acknowledges baby boomers’ health literacy partially disrupts and discounts the neoliberal construction of individual responsibility for health as being the whole picture. The wholly neoliberal view of individual responsibility for health is disrupted by understanding health literacy as dynamic and distributed with changing roles and practices. Such a conclusion finds support in the notion that empowerment (an ideal of neoliberalism) when differentiated into informational empowerment and decisional empowerment nevertheless has counterintuitive and differential effects on individuals’ health choices and behaviours, possibly attributable to varying cognitive and emotional burdens (Camacho, De Jong, & Stremersch, 2014).

Finally, this conceptual framework is focussed at the individual level emphasising the distributed and interactional dimensions of health literacy; it does not extend into the macro or population level regarding disease prevention or large-scale health promotion interventions. However, an appreciation of health literacy as described in this research reveals the dimensions for more effective congruence between health literacy behaviours, intentions, and expectations among multiple

actors in diverse contexts; consequently, healthcare communication and interventions can be better orchestrated.

7.3.4 *Definition of health literacy*

This thesis began with the definition of health literacy as “the individual’s capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions” (IOM, 2004, p. 1). During the course of this research the European Health Literacy consortium (adapting Sørensen et al.’s 2012 framework and definition) defined health literacy as “...linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course” (Kickbusch Pelikan, Apfel, & Tsouros, 2013, p. 4). Growing appreciation of the widening ambit of health literacy is reflected in the Australian Commission on Safety and Quality in Healthcare recent definition of health literacy as “the way in which consumers make decisions and take action about health and health care...influenced by their own skills, capacities and knowledge; *and by the environments in which these actions are taken*” (ACSQHC, 2013, p. 6, emphasis added).

Using the hermeneutic interpretation of this research data the conceptual framework of Figure 7.1 has at its core an extended definition of health literacy. This definition identifies individuals’ health literacy competences, skills, intentions, beliefs, and behaviours according to self and interactivity dimensions. This part of the definition makes a contribution by adding nuanced layers and interactivity/interdependency to Nutbeam’s (2000) three dimensions of functional health literacy, interactive health literacy, and critical health literacy. Secondly, health literacy is defined as a process and outcome of interdependent contextual and interactional factors of: firstly, primary healthcare professionals’ health literacy behaviours and expectations in three key categories, and secondly, the socio-cultural context described according to three major themes. This embedded approach to a definition of health literacy provides a diffuse and complicated

array of elements acknowledging that literacy is both an interdependent competence and a skill in action embodying choice (Hermann, 2008), as well as action and competence. Therefore, this definition also builds on the third aspect of Schulz & Nakamoto's (2005) three-tiered conceptualisation of health literacy, judgment skills or practical wisdom by identifying baby boomers' practices and expectations concerning the exercise of health choices. Finally, this definition of health literacy cannot be extricated from a shared social world, a body of knowledge (both lay and expert), and structures of power that exist within and around the phenomenon of health literacy.

The definition of health literacy emerging from this study is,

Health literacy is an interactive, negotiated, distributed, dynamic, and social practice that involves individuals acquiring, processing, and choosing health information and behaviours as they interact within and are interdependent on their social worlds.

7.4 Research contribution and implications

This thesis contributes to health literacy knowledge through the hermeneutic process of interpreting individuals' dynamic and nuanced health literacy practices and behaviours. Second, insights into individuals' and PHCPs' dynamic and nuanced health literacy practices have implications for primary healthcare encounters and delivery of services. Third, the thesis' conclusions implicate health literacy as fundamental in the co-production of primary healthcare services and policies that seek to increase citizen involvement.

Finally, a contribution this thesis makes is to encourage the health literacy of both the researcher and others this research touches. Therefore, from the participants' own voices a further research contribution is,

Now that I've talked to you I might bite the bullet and just go there and say, 'Look I'd like some peace of mind, can you just check over a few things?' EFT#9

and

*...it [the interaction with the PHCP] should be me [the patient] saying, 'Actually I would like to go on the list to have a scan.' I think **I'll be doing more of that** [after participating in this research]. EFL#3*

Thus, the relationships and networks that contribute to the social, distributed practice of health literacy are varied, extending to encounters such as this research itself.

7.4.1 Contribution to health literacy knowledge

The World Health Organisation considers health literacy “...a compelling and timely topic...[a] fundamental component of pursuing health and well-being in modern society...as societies grow more complex and people are increasingly bombarded with health information and misinformation and confront complex health care systems...” (Kickbusch et al., 2013, p. iv). This research makes a contribution to health literacy knowledge by empirically investigating the phenomenon among individuals who are defined according to age, and not according to health risk or ill-health. Furthermore, by studying health literacy among a population of baby boomers, this study provides timely insights into the phenomenon according to socio-cultural dimensions for which baby boomers may well be the influential leading edge.

Another contribution relates to the view of health literacy as an individual asset (refer Chapter 3). The hermeneutic interpretation of the study data is that this perspective overlooks the complex interactional dimensions of the phenomenon. The thesis introduces the concept of health literacy as a negotiated and distributed practice, synthesising baby boomers' health literacy as “It's not my health literacy, it's ours”. The research concludes that the baby boomer participants are typically not individual patient-consumers of healthcare. At varying levels of intensity and complexity they experience and practice health literacy as being shaped by multiple interactions, actors, and information sources.

The baby boomer participants are typically ‘tuned in’ to health, they are respectful of expertise, and they expect to be central to health decisions in their relationships

with primary healthcare professionals. Equally, they hold (at varying levels) well-defined expectations of the health literacy of their PHCP. As a social and distributed practice, health literacy is about effort, risk, authority, and power. These conclusions also contribute to a better understanding of the changing meanings of ‘healthcare professional’ with implications for health literacy literature to accommodate and appreciate diverse health beliefs.

In general terms, this thesis concludes with a definition of health literacy that includes individual skills and competences, contextual factors, and relational and network characteristics. From this perspective and as a final contribution to health literacy knowledge, this research extends the conceptualisation of health literacy (refer section 7.3) to include understanding multiple actors, multiple modes of information seeking and processing, as well as acknowledging dynamic behaviours, intentions, and expectations regarding health literacy practices. While information is implicated in the participants’ constructions of health literacy, individual dispositions, competences along with interactional processes, networks and relationships are equally emphasised. These dimensions have been typically under-researched in health literacy literature.

7.4.2 Implications for health literacy practices and healthcare services

The conceptualisation of health literacy as a process with multiple contextual and dynamic dimensions has implications for health literacy practices and primary healthcare service delivery. The organisation of the primary healthcare system and workflows often hinder health literacy practices; for example, limited time for consultations, lack of continuity in PHCPs, and multiple healthcare professionals. However, strategies and systems for effective health literacy practices will differ according to individuals’ and PHCPs’ health literacy roles, responsibilities, and expectations, as well as diverse contextual dimensions.

Despite health literacy being a multi-disciplinary field, many health literacy interventions come from a functional approach to health literacy, often with disappointing results. Better information and better communication are important, but this thesis concludes that roles, relationships, expectations, and contexts of

health literacy are profound factors in baby boomers' and primary healthcare professionals' understanding and practices of the phenomenon of health literacy. While there are contextual pressures shaping health literacy, it will be more effectively negotiated and co-created when there is congruence between health literacy understandings, needs, and expectations among the 'actors'. Health literacy congruence could provide the framework for improved healthcare communication, interaction, service type/timing, decision-making and engagement that allows the consumer to make reasoned choices regarding health.

In other words, healthcare encounters require a depth of interactivity so that individuals and healthcare professionals are responsive to the negotiated and distributed practices of health literacy. This is challenging because it also means that undifferentiated health communications and information are likely to be ineffective. The patient-as-manager or networker will enact different health literacy roles with different needs and expectations than the patient-as-seeker. It is likely to be difficult to implement health literacy practices that address these dynamic factors alongside institutional and cost constraints that are embedded in primary healthcare systems. Equally challenging will be improving the degree of shared views/attitudes around *expected* and *accepted* health literacy roles and practices of PHCPs and patient-consumers.

7.4.3 Implications for primary healthcare management and health promotion

The multiple actors, resources, and networks that shape health literacy understandings and practices in the conceptual framework (section 7.3) suggest several managerial and health promotion implications.

The management of health system workflows is a complex process. However, grounding the relationships and processes in health literacy congruence can help healthcare managers accommodate and adapt to the changing roles and responsibilities of patient-consumers and primary healthcare professionals. For example, this could include: managing healthcare consultations to be flexible to health literacy needs and expectations; healthcare consultations that incorporate how healthcare consumers use and prioritise multiple information sources, such as

the internet and relational networks; and, making health literacy discussions a priority in healthcare consultations.

The thesis concludes that baby boomers as healthcare consumers understand health literacy to be a shared practice. This has implications for the education and training of primary healthcare professionals, to enable them to evaluate what individuals bring to healthcare encounters and how health literacy actions can be co-created. It is important to encourage self-reflexivity training for primary healthcare professionals, examining their perceived and enacted health literacy practices and developing responses appropriate for patient-consumers' negotiated and dynamic health literacy practices. Integrating this learning with, for example, clinical reasoning and examination, would help PHCPs tailor their interactions to the health literacy of their patients.

The thesis conclusions also suggest areas for development in health promotion and health communication. For example, health literacy initiatives and communication campaigns are likely to be most effective when they are customised according to an understanding of the distributed and negotiated practices that underpin health literacy as experienced by New Zealand baby boomers. Similarly, there are implications for marketing - such as direct-to-consumer advertising, packaging, and promotion – around building health literacy supportive environments starting with reliable health information through to social marketing and environmental design that enhances health literacy (for example, nudging approaches where the shaping of environments cue in certain behaviours, Marteau, Ogilvie, Roland, Suhrcke, & Kelly, 2011; Thaler & Sunstein, 2008). Workplace networks and organisational strategies (not just organisations that deliver healthcare services) for health literacy (refer, for example, CSR Europe, 2013) also deserve closer on-going attention by managers and healthcare professionals given the underpinning of baby boomers' health literacy on shared knowledge and distributed practices.

7.4.4 *Implications for primary healthcare policy*

Figure 7.2 illustrates the policy implications of this thesis' findings regarding health literacy by adapting Pestoff's framework of the three pillars of social order - the community, the market, and the state. Health sector reforms in New Zealand can be interpreted as typically moving along the points depicted by the solid blue arrow of Figure 7.2 between the state and the market (refer Chapter 2). The broken black arrows in Figure 7.2 depict the potential for involving citizens in decision-making and broadening the conception of healthcare services, processes and interactions. It is in these areas where health literacy can enable improved patient-consumer agency and authentic involvement of the community pillar in healthcare policy.

Ways to increase citizen and third sector involvement in the provision and governance of social services (depicted by the broken black arrows, Figure 7.2) are attracting considerable attention for reasons that are evident in New Zealand - namely, the ageing population, a deficit of citizen involvement in democratic government at all levels, and severely limited financial budgets (Gauld, 2000, 2009a, 2009b). The extended conceptualisation of health literacy provided by this thesis offers support for the co-production of health services where health literacy permeates all three pillars of social order. Primary healthcare policy that is cognisant of health literacy can empower users of primary healthcare services, and "...could revolutionize relationships between communities and providers by positioning users of services in the centre of service delivery moving beyond the 'provider-centric' model..." (Fotaki, 2011, p. 950).

7.5 Limitations

The interpretations presented in this research occur within the hermeneutic process where there is an account and understanding at a particular point in time and context, of participants' health literacy behaviours from the participants' interview texts. These interpretations do not solely rely on uncovering author intended meanings but uncover non-authorial meanings – in that the researcher's interpretation brings with it her pre-understandings, distanciation, and appropriation; in this way "...[hermeneutic] understanding of [the interview texts] is not merely a reproductive but always a productive activity as well" (Gadamer, 2004, p. 296). Furthermore, it is important to note that the hermeneutic process is not finite and there is no definite point at which understanding becomes complete. In this way this thesis and its interpretations are both contextual and historical.

While this research fills an important gap in health literacy research it is important to note some limitations. The research design used participant (baby boomers and PHCPs) in-depth interviews. The baby boomer research participants were recruited according to a convenience sample and in agreeing to participate may indicate that they are a group of the population with particular health literacy characteristics. PHCPs were selected according to Patton's (2002) intensity sampling. Given that this selects individuals having an already-expressed interest and expertise in health literacy, the advantages of such participants providing rich description and understandings may be offset by presenting particular health literacy understandings. The research does not include observations of the individual-PHCP interactions nor individual-other network actor interactions, relying on participants' verbal accounts of their health literacy roles and behaviours. Observations and pairing individuals with their PHCPs would have triangulated the interpretation of the textual interview data, potentially providing additional insights to the negotiated and distributed practice(s) of health literacy. However, this would have presented ethical and privacy issues. This research does not include longitudinal investigation of changing health literacy roles, practices, and expectations; to do so, was deemed unmanageable within the time frame and scope of the study.

A question may be raised regarding the diverse selection of PHCPs. The 11 PHCPs are from a range of primary healthcare specialisations engaged in different forms of primary healthcare treatment. While this does not enable the research findings to focus on one treatment modality (for instance, general practitioners), this heterogeneity ensured a rich body of data.

Finally, it should be noted that this research is specifically situated within the New Zealand socio-cultural context.

7.6 Suggestions for future research

The thesis' conclusion that baby boomers understand health literacy as a social, negotiated, and distributed practice affirms the changing role of citizens in the neoliberal society. Just as the reflexive and flexible self (Giddens, 1991) is displacing the earlier notion of acquiescent patient-consumers, "the command society is being displaced by the society of reflexivity" (Cope & Kalantzis, 2009, p. 172). Therefore, it would be beneficial for future research to further explore these reflexive roles among patients and practitioners regarding health literacy. Part of this future research agenda could focus on the development of different forms of health knowledge (lay and expert knowledge), the implications of these for the professional identity of primary healthcare professionals, and how changing consumer roles in health literacy can encourage collaboration in primary healthcare. With these further understandings, health literacy may become more of a responsive partnership between individuals, healthcare professionals, and relational networks.

The significance of the ageing population worldwide and the growing concerns over healthcare costs provide the justification for several areas of future health literacy research. This thesis concludes with a conceptualisation of health literacy from the hermeneutic interpretation of the participants' data. This conceptualisation is acknowledged as being constituted from the specific socio-cultural context of New Zealand baby boomers with regard to primary healthcare. This context may have influenced how health literacy is experienced and constructed. Furthermore, while the research selected a stratified sample

according to ethnicity and gender no differences in these sub-groups were identified as the research purpose was to identify commonality of understandings of the concept of health literacy rather than differences. However, future research could extend the present study by refining the examination of health literacy among the baby boomer cohort with the purpose of exploring differences according to ethnicity, cultural beliefs, and values. Further research could also extend this study in contexts other than New Zealand and different age cohorts.

Research investigating gender differences in the health literacy categories of description could deepen the understanding of men's health literacy and their roles and behaviours as agents in their healthcare. Research to explore health literacy congruence, by recruiting individuals in association with their PHCPs in order to better understand their health literacy interactions, could offer potential directions for improved efficiency in healthcare service delivery. This research has interpreted participants' constructions of health literacy at one particular point in time. Earlier in this thesis, the conceptual framework of baby boomers' health literacy noted the important temporal dimension of the phenomenon; therefore, a future research project could usefully adopt a longitudinal design exploring individuals' experience of the phenomenon over time. In this way the shifts and patterns in the categories of individuals' health literacy could be better understood.

Finally, the term health literacy is increasingly used in an extended way, being more than a set of outcomes from health promotion campaigns. Similarly, health literacy as 'something more than' cognitive and communicative skills is "...a rather imperfect analogy to the notion of literacy" (Engstrom, 2011, p. 24). Indeed, the term itself may be restricting the understanding, implementation, and implications of health literacy behaviours. The findings from this thesis confirm that further research is needed from this extended perspective to refine and clarify the term health literacy.

7.7 Conclusion

This thesis investigates the baby boomers' and PHCPs' constructions and experiences of health literacy. In answering the research question it purposefully adopts a micro-level investigation of health literacy, resulting in a nuanced understanding of health literacy that encompasses the complex dimensions of interactional roles, responsibilities, and expectations in primary healthcare. Chapter 5 presents the baby boomers' understanding of the phenomenon of health literacy according to the categories of seeker, decider, networker, sensemaker and manager that have temporal, interactional, and contextual influences. These categories of description lead to the interpretation that baby boomers understand health literacy as a negotiated, distributed, and social practice. Chapter 6 presents the understanding of health literacy interpreted from the PHCPs' data according to the categories of knowledge broker, ethical agent, and enabler. Collectively, these three categories are interpreted as PHCPs understanding the phenomenon as managed empowerment. The thesis then concludes in this chapter with a conceptual framework of health literacy highlighting these key factors and their interrelationships. Several original contributions to the field of health literacy through the empirical investigation of this thesis are discussed and implications of the research outlined.

This research presents participants' health literacy constructions within the highly contextualised and distributed experiences that occur both within and outside of an individual's formalised primary healthcare encounters. Individuals understand health literacy as encompassing dynamic multiple roles and behaviours, at varying levels within these roles. Although the research participants' (baby boomers and PHCPs) data reflect the neoliberal emphasis on individual responsibility for health (refer Chapter 1, and see Petersen, Davis, Fraser, & Lindsay, 2010), health literacy is equally understood as being inextricably embedded in distributed and social practices. Health literacy practices, behaviours, and processes are negotiated and distributed through individuals' social and professional networks. The significance of others (a range of network actors and healthcare professionals) in multiple health contexts (health events, healthcare systems, and sociocultural contexts) is emphasised in the construction of health literacy.

In conclusion, this study provides evidence of the interactional and dynamic aspects of health literacy and the diverse experiences of this phenomenon. In doing so, it is hoped that better appreciating this diversity and the negotiated practices in health literacy can improve healthcare communications and healthcare outcomes.

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Appendix 1: New Zealand health funding

Type of funding	Proportion	Proportion
Public funding		81%
- general taxes	88%	
- employment based ACC	11%	
- local government	1%	
(Source: Gauld, 2012)		
Private funding		
- out-of-pocket		13%
- private insurance		5%
- other		<1%
(Source: OECD, 2011a)		
<hr/>		
2011 NZ health expenditure per capita		US\$3,182
(Source: Davis et al., 2014)		

Appendix 2: Summary of New Zealand social policy perspectives 1800s-2000s

(Adapted from Belgrave, 2012 with reference to Sinclair, 1988 and Gauld, 2009b)

	New Zealand context	Prevailing social policy perspective
1800s	Establishment of the colony Treaty of Waitangi	Liberalism - autonomy of the individual - laissez-faire capitalism
1870s/1880s	Depression - challenges to liberalism	State-centred socialism - focus on interests of egalitarian majority - goal of rational & efficient society
Early 1900s	Concern for population sustainability - health camps, family allowance, pensions	State regulation - state intervention to influence behaviour
1930s-1960s/1970s	1930s - economic stabilisation through full employment - social security as national security - 1938 Social Security Act - universal access to healthcare By 1970s, citizenship-based welfare principles	Citizenship welfare state - reforms due to failure of the marketplace
1980s/1990s	Welfare state unsustainable & too expensive Elimination of trade protection Reduction in size of the state activities	Neoliberalism - reforms due to failure of the state - state activities subject to market pressure - consumer economy emphasising individual choice
2000s	‘Third way’ policies - services rationed by need - removal of market rents for State Housing tenants - improved patient information & involvement in healthcare	Social democratic goals - softening market-based policies - limited state intervention e.g., income redistribution - emphasis on individual responsibility

Appendix 3: Overview of NZ health system integration and reforms, 1980s-2010s

(Adapted from Cumming, 2011; Gauld, 2009a, 2009b, 2012; Ryall, 2008; Sheridan et al., 2011)

	1980s	1990s	2000s	2010s
<i>Health policy dominated by...</i>	Concern to achieve cost containment at the macro level	Measures to increase efficiency and enhance responsiveness at the micro level	Focussing on patients and public health goals	Measures to improve productivity, quality, service access - especially to electives and cancer treatments
	New Public Management tools	Concerns for cost effectiveness	Localising decision-making	Improved clinical governance
		Quasi-market model for health governance	Democratising service governance, including multiple modes of governance	Aim to build public confidence
				Central planning
<i>Integration & reforms with regard to</i>	Area Health Boards - public health, primary and secondary care	Regional Health Authorities: all health & support services –	21 District Health Boards - to plan, manage, provide and fund services for the population of their districts, under the 2000 NZ Public Health & disability Act (NZPHDA)	Stronger regional alliances - planning/funding for some services
...Planning and funding functions	Bulk funding of hospitals	Hospitals as State owned firms – principal providers		District Health Boards - most services; annual plans;
		‘Managerialist’ perspective	Reintegration of purchasing and provision - HFA abolished	Whānauora contracts - high needs populations
		Health Funding Authority (HFA) - all health and support services		National Health Board - oversee and assess regional & district level planning; no statutory powers.
...Service budgets	Area Health Boards - Public health, primary and	Some capitation	Capitation for 80 Primary Health Organisations - first contact	Capitation for Primary Health Organisations (first contact

	secondary care	Some pharmaceutical and laboratory budget contracts Global budget (for one Independent Practitioner Association)	services to work with local communities - 2008, 80 PHOs covered 95% of population	services)
...Service planning and support	Area Health Boards - public health and secondary care	Independent Practitioner Associations -1999, >80% GPs members of over 30 IPAs (Starke, 2010)	Primary Health Organisations District Health Boards - public health and secondary care	Primary Health Organisations (amalgamations) District Health Boards – public health & secondary care
...Services	Area Health Boards - public health and secondary care		Local initiatives District Health Boards - public health and secondary care services to be provided themselves or purchased from non-government providers. Health promotion services	Local initiatives Integrated family health centres and clusters District Health Boards – public health and secondary care
...Services for a single condition		Integrated care pilots Local initiatives	Local initiatives	Local initiatives
...Services for a specific population		Integrated care pilots	Māori & Pacific Primary Health Organisations	Māori & Pacific Primary Health Organisations Whānauora organisations - Provision for high needs population

Appendix 4: Summary of Baby Boomer characteristics

(Source: Davey & FitzPatrick, November, 2013)

Appendix Table 4.1 Baby boomer (BB) characteristics – Empirical

Psychological Values					
Characteristic	Authors	Research details	Respondents	Findings	Context
<i>Freedom</i>	Braun-LaTour, LaTour, & Zinkhan (2007)	Qualitative: Short qualitative questionnaire + in-depth interviews USA	N=60 Gen X = 20 BBs = 20 Silent Generation (pre BBs) = 20	Prevalent BBs' defining memories related to the need to break from parental control and putting off responsibility; associated with feelings of freedom at "letting one's hair down."	Retail - Automobile
<i>Youthful bias</i>	Sudbury (2004)	Quantitative: 1. Questionnaire Self-administered UK 2. UK data compared with 4 USA studies	N=356 50-79, mean 60.2 Convenience sample	1. 10+ year difference between chronological & cognitive age. 2. UK → younger cognitive age than USA	Gerontology
<i>Cognitive age</i>	Reisenwitz & Iyer (2007)	Quantitative: questionnaire USA	Convenience sample N= 295 40-58	No significant differences between younger (1956-65) and older BBs (1946-55) on behavioural variables except for cognitive age.	Generational comparison
<i>Youthful image + mature identity + de-emphasise age signification</i>	Biggs, Phillipson, Leach, & Money (2007)	Qualitative: 150 semi-structured interview quest' res and 30 interviews UK	150 first wave BBs (1945-1954)	Consumption used by BBs to manipulate age-identity and relations with younger generations. Age not important to BBs' sense of identity. Fitness and health-conscious; maintenance of health in order to enjoy retirement.	Social gerontology

<i>Self-respect, Security, Warm relationships, Sense of accomplishment</i>	Sudbury & Simcock (2009)	Quantitative: Questionnaire (List of Values) Self-administered	N=626 50-79yrs, mean 62.4yrs Quota sample	1. UK and US “older” consumers similar in 4 primary values 2. “Fun & enjoyment of life” more important to UK respondents 3. Importance of values differ by cognitive age.	Older consumers
		UK UK research data compared USA studies			
<i>Distinguishing characteristics confirmed</i>	Gibson, Greenwood, & Murphy (2009)	Quantitative: Rokeach Value Survey	N=5057 1464 BBs (1946-1964) 1440 Gen Y 2153 Millennials	BBs ‘live to work’ <u>Terminal values</u> : Health; Family security; A comfortable life; Freedom; Wisdom; True friendship; Salvation; Inner harmony; A sense of accomplishment <u>Instrumental values</u> : Honest; Responsible; Loyal; Capable; Independent; Loving; Ambitious; Logical; Forgiving; Self-controlled	HR management
<i>Diverse Ageing differently Collective power</i>	Glasgow (2013)	Qualitative: 11 focus groups	N=70 (1946-1965) Urban & semi-urban	Generational identity Values: work/life balance, decision-making autonomy, self-reliance, change agents, collective responsibility	Social policy
<i>Ageing differently</i>	Buckland (2009)	Quantitative: Online survey.	1162 BBs (1946-1964)	NZ BBs: different meaning of work, leisure and ageing. NZ BBs are more physically vital than US counterparts, have a more outwardly focussed social conscience, greater resilient optimism, more adventurous than US counterparts.	Attitudinal study
		NZ Comparison US Boomer Dreams study (Smith & Clurman, 2007)			

<i>'Health' & 'wellness' constructed socially</i>	Murray, Pullman, & Rodgers (2003)	Qualitative: Group discussions (20) + individual interviews (28)	N=154 BBs = 1945-1965	Importance of lifestyle, self-care	Health psychology
Canada					

Social Values					
Characteristic	Authors	Research details	Respondents	Findings	Context
<i>Connectedness</i>	Wood (2002)	Qualitative: Open ended story-telling questionnaire USA	43 BBs 90 'boomlets'	Boomers focussed on convenience as the primary benefit of online shopping, discussed product customization in terms of being consumer-driven. Boomers found technology efficient, but disengaging, isolating, and enslaving.	Retail
<i>Caring & connectedness</i>	Arsenault (2004)	Qualitative + Quant: Survey 5 open-ended questions USA	N=790 190 veterans 203 BBs, 243 Xers 154 Nexters.	Boomers identify important leadership factors: honesty, expertise, employees as friends.	Leadership
<i>Collectivism</i>	Sirias, Karp, & Brotherton (2007)	Quantitative: Survey Individualism/collectivism measure USA	N=434 BBs=228 (1945-1962) Gen X=206 (1963-82)	Gen Xers more individualistic than BBs	Management

Environmental Values					
Characteristic	Authors	Research details	Respondents	Findings	Context
<i>Pro-environmentalism</i>	Sudbury-Riley, Kohlbacher, & Hofmeister (2012)	Quantitative: Questionnaire (self-admin'd + F2F) UK, Germany, Japan, Hungary	N=1275 'Seniors' 50+ (mean 64yrs) Random sample	Higher Ecologically Conscious Consumer Behaviour connected to taking part in demos, blogging, using Internet forums, donating to charities	Ethical purchase behaviour
<i>Moderate Environmental attitudes</i>	Barber, Taylor, & Strick (2010)	Quantitative - online questionnaire USA	N=850 responses	Millennials stronger environmental attitudes than BBs and Gen Xers	Environmental attitudes
<i>Socially-conscious + Green Boomers</i>	Focalyst (2007) from AARP Services and Milward Brown	Quantitative: Survey USA	N=30,000 BBs (1946-1964) + Matures (born before 1946)	'Green Boomers' = more loyal, more knowledgeable, more attuned to advertising, seek authenticity, relevance, consume more media	Attitudes and behaviours related to shopping
Work values					
Characteristics	Authors	Research details	Respondents	Findings	Context
<i>Work values</i>	Chen & Choi (2008)	Quantitative: Questionnaire Self-completion USA	N=398 hospitality managers and supervisors BBs=92 (1946-64) Gen X = 144 Millennials = 112	Generational differences in work values. <u>BB Work values:</u> Way of life Achievement Supervisory relationships Altruism Intellectual stimulation Personal growth	Management

<i>Work values</i>	Wong, Gardiner, Lang, & Coulon (2008)	Quantitative: 2 questionnaires Self-completion Australia	N=3535 managers & professionals BBs = 1945-1964 Gen X Gen Y	De-bunks some generational stereotypes	Managerial psychology
<i>Relationships</i>	Westerman & Yamamura (2007)	Quantitative: Mail survey USA	N=234 Accountants	Relationship fit primary determinant of employee satisfaction for BBs.	HR management
<i>Hard workers</i>	Cogin (2012)	Quantitative Cross-cultural: USA, Australian, China, Singapore, Germany	N= 407 Traditionalists (1926-1944), BBs (1947-1963), Gen X (1966-1976) Gen Y (1979-94)	BBs' most important work value = 'hard work' Lowest work value = 'independence'	HR management
<i>Loyal</i>	Yu & Miller (2005)	Quantitative: Questionnaire Taiwan	N=437 Gen X (under 35) BBs (over 35)	BBs more loyal, accept a task-oriented leadership style	Large manufacturing SMEs.
<i>Loyal</i>	Smola & Sutton (2002)	Quantitative: questionnaire + existing 1974 data USA	N=350	BBs work = one of the most important parts of a person's life BBs more loyal than Gen Xers	Managerial psychology

<i>Hard work</i>	Cennamo & Gardner (2008)	Quantitative: Online questionnaire +self-report NZ	N=504 BBs 1946-61 (23%) Gen X 1962-79 (57%) Gen Y 1980+ (17%)	BB workers place more importance on extrinsic values & status values	Managerial psychology
<i>Work rewards</i>	Hewlett, Sherbin, & Sumberg (2009)	Quantitative + Qualitative: Surveys, FGs, interviews USA	N=3782 “employed college graduates”	7 other types of rewards rated as important as \$	Management
<i>Working life</i>	Quine, Bernard, & Kendig (2006)	Qualitative: Focus groups Australia	N=78 BBs 1946-1955	Enjoyment + purpose = incentive to work Stress= disincentive to work	Retirement planning
Consumer Behaviour					
Characteristics	Authors	Research details	Respondents	Findings	Context
<i>“Older” consumer market not homogeneous</i>	Sudbury & Simcock (2009)	Quantitative: Questionnaire Self-administered UK	N=650 50-79, mean 62.4 Age-quota sample	5 segments: Solitary sceptics; Bargain-hunting belongsers; Self-assured sociables; Positive pioneers; Cautious comfortables	Market segments
<i>Wealthier (than their parents)</i>	Keister & Deeb-Sossa (2001)	Quantitative: Comparison existing census data. Micro-simulation model	BBs 1945-1965	Speculation about BBs shocking the superannuation system may be overstated.	Sociology

<i>Questioning</i>	Noble, Schewe, & Kuhr (2004)	Quantitative: Survey USA	N=184 BBs = 83 Matures= 101	BBs seek additional information from sources other than their doctor, question their doctors, prefer more informality, try alternative treatments.	Healthcare
<i>Sceptical consumers</i>	Roberts & Manolis (2000)	Quantitative: 2 Surveys=marketing & advertising; compulsive buying. Mall-intercept=quota USA	1. N=476 57 BBs 1946-64 419 Gen X 65-76 2. N=917 380 BBs 537 Gen X	BBs less positive about marketing than Gen Xers 7% BBs compulsive shoppers vs 11% Gen Xers	Marketing
<i>Pragmatic</i>	Littrell, Ma, & Halapete (2005)	Quantitative: Survey - mail and mall intercept. USA	Gen X (29-40yrs, n=200) BB (41-59yrs, n=589) Swing (60-75yrs, n=266)	BBs valued pragmatic clothing; close alliance with fair trade; environmental sustainability.	Retail
<i>Appearance + pragmatism</i>	Davey, King, & FitzPatrick (2012)	Qualitative: Exploratory interviews and focus group NZ	N= 13	Glasses perceived as making participants feel older; considered to make them appear older to others. Boomers valued a high quality of life and glasses helped improve this.	Retail
<i>Relate-ability</i>	FitzPatrick, King, & Davey (2013)	Qualitative: Exploratory interviews, FGs, and arts-based method NZ	N=13	BBs want ads that are relate-able, use real characters, engaging narrative, information intensity, humour and point of difference.	Advertising

<i>\$ value conscious</i>	Kumar & Lim (2008)	Quantitative: Questionnaire Gen Y: Convenience sample at uni BBs: online survey Probabilistic sample	N=298 BBs=139 1946-1964 Gen Y=159 1980-1994	Mobile service quality Economic value more important to BBs Emotional value more important to Gen Ys	Marketing
		USA			
<i>Economy of time & money</i>	Moore & Carpenter (2008)	Quantitative: Phone survey	N=342 Sil. Gen 1925-42, BBs 1943-1960, 13 th Gen 1961-81, Gen Y 1982-2004	BBs most price conscious and least prestige sensitive BBs less enthusiastic about shopping	Retail
		USA			
<i>Customised service</i>	Tassiopoulous & Haydam (2008)	Quantitative: Survey	N=324 Golf tourists	BB golf tourists expected customised service	Tourism
		South Africa			
<i>Wealthier</i>	Lusardi & Mitchell (2007)	Quantitative: National Health & Retirement Survey data	N=2635 Early BBs (1948-1953)	EBBs have higher levels of net worth than earlier cohorts.	Economics
		USA			
<i>Individuality</i>	Carpenter, Moore, Doherty, & Alexander (2012)	Quantitative: online survey	N=492 23% Silent Gen 31% BB 22% Gen Xers 24% Gen Yers	Gen Xers and Gen Yers have higher levels of identification than BBs.	Consumer behaviour
		USA			

<i>Not status conscious</i>	Eastman & Liu (2012)	Quantitative: online survey USA	N=220	Gen Yers significantly have higher levels of status consumption than BBs.	Retail
<i>Ecotourism</i>	Cleaver & Muller (2002)	Uses existing psychographic data	BBs = 1945-66	Socially aware lifestyle prime target for ecotourism	Tourism
<i>Technology</i>	Niemela-Nyrhinen (2007)	Quantitative: Mail survey Finland	N=620 BBs=1946-1955	Low levels of technology anxiety High levels of technology experience	Mobile technology
<i>Technology adopters</i>	Yang & Jolly (2008)	Quantitative: online survey USA	N= 153 67 Gen Xers 86 BBs	BBs found mobile services more difficult to use than Gen X BBs perceived mobile services more useful than Gen Xers	Mobile data services
<i>Bridging generation Modified materialism</i>	Leach, Phillipson, Biggs, & Money (2013)	1. Secondary English Longitudinal Study on Ageing (ELSA) 2. Qualitative: In-depth interviews UK	First-wave BBs 1.N=50 1945-1952 2. N=150; plus 30 1945-1954	Less materialistic than younger generations Invest in rational consumption	Consumer behaviour

Appendix Table 4.2: Baby boomer (BB) characteristics – Non-empirical

Characteristics	Author details	Article details	Population	Conclusions	Context
<i>Wealthy → high purchasing power</i>	McCreery (2000) (Cited in Sudbury-Riley et al., 2012)	Book	Japan 1947-1951 BBs	Highly active, energetic, consumption-oriented, curious about technology, shopping-related mentality	Consumer behaviour
<i>Propensity to consume</i>					
<i>Youthfulness Consumerism Individualistic Familial ideology Political activism</i>	Phillipson, Leach, Money, & Biggs (2008)	Literature review - thematic analysis	UK, US, Australia, Canada, France BBs	New inequalities: Cumulative advantages/disadvantages	Sociology
<i>Heterogeneity</i>	Macky, Gardner, & Forsyth (2008)	Editorial		Challenges premises underlying generational cohorts	Management psychology
<i>Dominant values: Tolerance Power/authority Achievement Stimulation</i>	Crumpacker, M. & Crumpacker, J. (2007)	Opinion piece		Challenges generational perspective	HR management
<i>Communication: Face time One-on-one In-person</i>	Crumpacker, M. & Crumpacker, J. (2007)	Opinion piece		Challenges generational perspective	HR management
<i>Individualism</i>	Huber & Skidmore (2003)	Book	BBs		Policy-making

Characteristics	Author details	Article details	Population	Conclusions	Context
<i>Social activism</i>	Huber & Skidmore (2003)	Book	BBs		Policy-making
<i>Identify with youthful activities</i>	Harkin & Huber (2004)	Book	BBs		Policy-making
<i>Healthier</i>	Dann (2007)	Opinion	BBs 1946-1964	May be healthier than similar aged earlier cohorts but decline is still inevitable.	Marketing
<i>Idealistic Driven</i>	Glass (2007)	Literature review	BBs 1941-1960 Gen X 1961-1976 Gen Y 1977-1992		HR management
<i>Changing/developing</i>	Coleman, Hladikova, & Savelyeva (2006)	Literature review	BBs 1946-1964	Risk=trying to read the BB market	Marketing
<i>Creative adaptors</i>	Yoon, Cole, & Lee (2009)	Literature review	US 'older' market BBs 1946-1964	CDM depends on degree of fit between the individual & the context (vs age-based decrements in cognition)	Marketing USA
<i>Self-actualisers</i>	Wolfe (2004-5)	Opinion	BBs 1946-1965	BBs looking to experiential sources of meaning	Marketing
<i>Wealthy Active consumers</i>	Nitta (2006)	Literature review	First gen BBs b. 1947-1949	BBs = huge business potential	Economics Japan
<i>BBs = Economic force</i>	Pak & Kambil (2006)	Literature review	BBs, "50+" (No birth yrs)	BBs → new opportunities for business	Marketing USA
<i>Health & health service needs</i>	Humpel, O'Loughlin, Wells, & Kendig (2010)	Literature review	BBs	Substantial scope for health improvement Strong associations between working and health	Healthcare Australia

Appendix 5: Health literacy definitions search procedure

Search terms:

“health literacy” definition

“health competence” definition

Sørensen et al. (2012) found 19 publications that explicitly dealt with the definition of health literacy yielding 17 explicit definitions.

Database results filtered for peer reviewed journal articles

PubMed - 37 articles

Web of Science - 58 articles

PsychINFO - 27 articles

Scopus - 56 articles

Other databases were reviewed (Proquest Social Sciences and Emerald via subject portals of psychology, social science research, strategic management and social policy) and no new search results occurred.

Dated June 20, 2013

Appendix 6: Email invite to Baby Boomer participants

Dear *[participant]*

I am currently a PhD student in the Waikato Management School, University of Waikato. My research is about the health literacy of Baby Boomers - those people born between 1946 and 1965 - and who are living in New Zealand.

Health literacy includes how you get health information and health advice, what you do if the health information you need is not available or is not suitable, and how these factors affect healthcare decisions and relationships with healthcare providers. I want to better understand New Zealand Baby Boomers' health literacy specifically concerning primary healthcare (including GPs). I have attached the Participant Information Sheet.

The people I interview need to be 48 to 67 years old, and either born in NZ or currently living in New Zealand.

During the interview we will discuss your opinions and experiences about your health literacy. The interview is likely to last around 45 minutes and with your consent will be audio-recorded.

I would really appreciate your participation. If you are happy to help, please get back to me and we can arrange a time and place to suit you. You can contact me on

0272687864

or 07 8384466 ext 7909

or by email, janetd@waikato.ac.nz

I look forward to hearing from you. Many thanks,

Janet Davey

Appendix 7: Participant Information Sheet

Participant Information Sheet

Waikato Management School
Te Raupapa



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Health literacy and New Zealand Baby Boomers

My name is Janet Davey and I am a doctoral student in the Department of Strategy and Human Resource Management, Waikato Management School of The University of Waikato. My supervisors for the interview phase of the research are Associate Professor Kathryn Pavlovich and Professor Stewart Lawrence. This research will be completed using my personal resources and the support of The University of Waikato. The results of this study will be publicly available in the form of my PhD thesis, conference papers and journal articles.

Brief outline of the research

Health literacy is an individual's capacity to make sound health decisions in the context of everyday life and the capability to participate in such decisions. The primary objective of my PhD is understanding the health literacy of NZ Baby Boomers and how this affects their relationships with healthcare practitioners and their healthcare decisions.

Participant's role and consent

You are invited to take part in an interview conducted by me. In the interview, that will take approximately 45 minutes, you will be asked for your views related to the study purpose. The interview will be conducted face-to-face or over Skype depending on circumstances and your preference. With your permission the interview will be recorded using a voice recorder. The recorded discussion will be transcribed and stored on a password-protected computer. The transcripts, thesis, or any publications will not include information or names that could identify you.

Confidentiality

You will be asked to sign a Consent Form before the interview commences. However, you are free to withdraw from the interview up to two weeks after the interview or refuse to answer any specific questions. You are also free to ask questions at any time before, during and after the interview. Once your interview is transcribed you will be given the opportunity to edit the transcript, and/or request that some sections not be used for publication. The voice recordings will be erased after they have been transcribed. Finally, if you would like to receive a summary of the research findings, please let me know during the interview.

Contact details of principal researcher:

Janet Davey

Phone: Office 078384466 Ext. 7909 Mobile 0272687864 Email:
janetd@waikato.ac.nz

Contact details of supervisors (July to December 2013):

Associate Professor Kathryn Pavlovich

Department of Strategy and Human Resource Management, Waikato
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Phone: 078384466 Ext. 4837 Email: kpav@waikato.ac.nz

Professor Stewart Lawrence

Department of Accounting, Waikato Management School.

Phone: 078384466 Ext. 8794 Email: stewartl@waikato.ac.nz

Appendix 8: Interview guide for Baby Boomer participants

Prior to the interview, each participant:

- a) Completed a brief biographical paragraph about themselves, including:
- self-reported health status on 5-point scale: poor, fair/ok, good, very good, excellent⁴¹
 - any disability or chronic disease
 - how long since their last visit to a GP: within last week, within last month, within last 6 months, within last year, more than 12 months
 - how long since their last visit to any other primary healthcare provider: within last week, within last month, within last 6 months, within last year, more than 12 months
 - age, highest educational qualification, and occupation
- b) Completed the following brief survey (Chinn & McCarthy, 2013):
1. How often do you need someone to help you when you are given information to read by your doctor, nurse or pharmacist?
 often sometimes rarely
 2. When you need help, can you easily get hold of someone to assist you?
 often sometimes rarely
 3. Do you need help to fill in official documents?
 often sometimes rarely
 4. When you talk to a doctor or nurse, do you give them all the information they need to help you?
 often sometimes rarely
 5. When you talk to a doctor or nurse, do you ask the questions you need to ask?
 often sometimes rarely
 6. When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?
 often sometimes rarely
 7. Are you someone who likes to find out lots of different information about your health?
 often sometimes rarely

⁴¹ Adapted from the following: Miilunpalo et al., 1997, 5-point scale good, fairly good, average, rather poor, and poor; Chinn & McCarthy, 2013, 4-point scale poor, fair/OK, good, very good/excellent; Ouschan, Sweeney, & Johnson, 2006, 7 point scale 1=very poor to 7=excellent.

8. How often do you think carefully about whether health information makes sense in your particular situation?
 often sometimes rarely
9. How often do you try to work out whether information about your health can be trusted?
 often sometimes rarely
10. Are you the sort of person who might question your doctor or nurse's advice based on your own research?
 yes, definitely sometimes not really/
rarely
11. Do you think that there are plenty of ways to have a say in what the government does about health?
 yes, definitely maybe/sometimes not really/
rarely
12. Within the last 12 months have you taken action to do something about a health issue?
 yes no
13. What do you think matters most for everyone's health? (*tick one answer only*)
 a) information and encouragement to lead healthy lifestyles b) good housing, education, decent jobs and good local facilities

Issues for discussion

This research is about you and your health. The purpose of my study is to understand how New Zealand Baby Boomers make health decisions in their day-to-day life. Important aspects of this include how you get health information and health advice, and what you do if the health information you need is not available or is not suitable. The specific focus of this research is on primary healthcare. Primary healthcare providers are the health professionals you can go to without a referral from a General Practitioner (GP) and they include GPs, chemists, optometrists, chiropractors, integrative medicine professionals, and osteopaths.

Topics I would like to discuss with you are:

1. Thinking about your experiences in trying to look after your health (or the health of your family),
 - How do you decide to get health advice?
 - Where do you go to get health advice and healthcare?
 - Do you usually get the help you need?
2. When you talk to your doctor (*or another primary healthcare provider*), what do you do when
 - (a) you are not satisfied with the information you get?

(b) you are not satisfied with the diagnosis/treatment options/medication you are offered?

What factors do you think contribute to this happening?

3. Thinking about your experiences in trying to look after your health (or the health of your family),

- tell me about one of your best experiences

and

- tell me about one of your worst experiences

For each of these

What made it so bad/good?

What do you think contributed to this happening?

What factors about the situation do you think contributed to this happening?

4. For most people, interaction with their GP is the most frequent encounter with the health system,

- tell me about how you relate to your doctor.

5. What abilities do you think you need in order to get and to use all of the health information you need?

6. In relation to your *primary* healthcare what helps you

- get enough information,

- understand it, and

- act on it?

7. What do you expect from your doctor (*or another primary healthcare provider*)?

8. In what ways do you question the advice from your doctor (*or another primary healthcare provider*)?

Appendix 9: Interview guide for Primary Healthcare Professionals

This research explores the health literacy of NZ Baby Boomers (aged between 48 and 67 years of age) and the factors that influence the crucial aspects of health literacy, including knowledge about health issues, interactions with health providers, and opportunities for participation in healthcare. The focus is on primary healthcare and a range of primary healthcare providers are invited to participate in interviews. In particular, the purpose of this part of my study is to gain an understanding of your perception of the health literacy of baby boomers, the factors influencing baby boomers' involvement with their primary healthcare, and the influence of health literacy on their relationship with you as a primary healthcare provider.

Prior to the topic guide below, each participant will be asked some questions about themselves, including:

- How long have you been here?
- What did you do before this job?
- Where did you study to become?

Topics I would like to discuss with you are:

1. What do you think are the important aspects of health literacy?
2. What about the more interactive and/or critical aspects of health literacy? What do these entail?

3. What do you think needs to be in place for health literacy to occur?

Some prompts for this question may include:

- *Communication skills*
- *Personnel Resources*
- *Personal skills*
- *Information resources*

4. What is your experience in approaching/interacting with baby boomer patients? What factors influence your interactions with baby boomers?

Some prompts following up on responses to this question may start with

- *What happens when ...*
- *What do you do when ...?*
- *Why do you think this happened?*
- *So what does this say about health literacy?*
- *Now what are the implications of this for your practice?*

5. How do you think you can influence the health literacy of baby boomers?

Appendix 10: AAHLS coding summary

Functional health literacy (Hi 9, Lo 3)				
FQ1	How often do you need someone to help you when you are given information to read by your doctor, nurse or pharmacist?*	<input type="checkbox"/> often 1	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 3
FQ2	When you need help, can you easily get hold of someone to assist you?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
FQ3	Do you need help to fill in official documents*	<input type="checkbox"/> often 1	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 3
Communicative health literacy (Hi 9, Lo 3)				
ComQ1	When you talk to a doctor or nurse, do you give them all the information they need to help you?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
ComQ2	When you talk to a doctor or nurse, do you ask the questions you need to ask?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
ComQ3	When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
Critical health literacy (Hi 12, Lo 4)				
Cr1	Are you someone who likes to find out lots of different information about your health?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
Cr2	How often do you think carefully about whether health information makes sense in your particular situation?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
Cr3	How often do you try to work out whether information about your health can be trusted?	<input type="checkbox"/> often 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> rarely 1
Cr4	Are you the sort of person who might question your doctor or nurse's advice based on your own research?	<input type="checkbox"/> yes, definitely 3	<input type="checkbox"/> sometimes 2	<input type="checkbox"/> not really/rarely 1

Empowerment health literacy (Hi 8, Lo 3)

Emp1	Do you think that there plenty of ways to have a say in what the government does about health?	<input type="checkbox"/> yes, definitely 3	<input type="checkbox"/> maybe/ sometimes 2	<input type="checkbox"/> not really/rarely 1
Emp2	Within the last 12 months have you taken action to do something about a health issue that affects your family or community?	<input type="checkbox"/> yes 2	<input type="checkbox"/> no 1	
Emp3	What do you think matters most for everyone's health? a) information and encouragement to lead healthy lifestyles b) good housing, education, decent jobs and good local facilities c) both	<input type="checkbox"/> a) 1	<input type="checkbox"/> b) 3	<input type="checkbox"/> c) both 2

Note. AAHLS coding:

1. Questions FQ1 and FQ3 were reverse coded for constructing the functional health literacy score for each participant.
2. Question Emp3 included participant responses of 'both'; coding emphasised recognition of social determinants of health literacy.
3. Don't know/Not sure/Not applicable were coded as zero and subsequently excluded from the summary statistics

Appendix 11: Participant profile data

	Poor	Fair/ok	Good	V. Good	Excellent
Self-reported health	1	4	14	21	6
	Last week	Last month	Last 6 mths	Last 12 mths	>12 mths ago
Last visit to GP	6	9	16	5	10
Last visit to other PHCP	2	9	10	5	20
Disability	Yes	15	No	31	
	No formal qualification		Secondary qualification		Tertiary qualification
Education qualifications	5		12		29
Occupations					
Manager		Nursery propagator			Process worker
Research officer		Project executive			Caregiver
Primary school teacher		Machine operator			Process worker
Newspaper editor		Student			Housekeeper
Semi-retired gardener		Minister of religion			Unemployed
House cleaner		Early childhood teacher			Teacher
Student adviser		Food bank manager			Retired
Farmer		Translation service provider			Student
Financial accountant		Transcriptionist/Manager			Teacher
Tutor		Student			Product controller
Garden designer		Accounts bookkeeping			Engineer
Teacher		Student			Teacher
Self-employed		MyThai trainer			Clothing wholesaler
Student		Builder			Road marker
Community worker		Laboratory manager			Store manager Bus driver
Health literacy (AAHLS)*	N	Av. score	Av. score %		S.D.
Functional health literacy (max=9, min=3)	46	8.413043	93.48		0.796080
Communicative health literacy (max=9, min=3)	46	8.456522	93.96		0.852274
Critical health literacy (max=12, min=4)	42	9.571429	79.76		1.965692
Empowerment health literacy (max=8, min=3)	41	5.365854	67.07		1.184372

*Don't know/Not sure/Not applicable responses were excluded from summary statistics

Appendix 12: Research memo excerpts

Research memo excerpt participant #1

- Health is very important in her life, even though she rarely goes to a GP, often uses own networks for health information.
- She is passionate about the need for healthcare that is available & appropriate - that treats the patient with respect & is responsive.
- Concern (ve: story about work colleague who had massive stroke & similar age to participant) about 'not knowing' a lot about "diabetes, low sugar" with regrets "I didn't know diabetes did that" etc (see recording). This event prompted a 'check-up' of non-normal visit to the doctor, otherwise the attitude was healthcare is something to be accessed only when really 'ill' (see flow example).
- Obviously uses networks for health - daughters ve: healthy eating, dad for good pills.
- Lot of discussion about "googling" - but only for an event. Apprehensive about using too much cos could get overwhelmed & think you had everything wrong with you. Didn't seem to use "online" health info in opposition to dr. but rather timely and definitely proactive in health.

Research memo excerpt participant #12

- A "busy" attitude to health-
- Draw information from professionally trained family sources and family / cultural traditions
- Will try things as alternatives to traditional Western medicine first - based on informal professional advice.
- Even though health issue doesn't appear to give it a lot of "time" or thought - Doesn't vesicise except to verify - given time as scarce resource.

Research memo excerpt participants #14 and #15

- Notes on PP views #14, #15
- to people
- Do not identify as busy bodies
 - Importance of integration & understanding of different lifestyles, habits (good, exercise)
 - Emphasis on understanding N2 way for healthcare
 - ✓ " " pp individual "taking" responsibility
 - ✓ being accountable
 - More than just reading, writing.
 - Concern over "social isolation" as the group of people gets older in N2 with reduced social structures that used to be part of home - this is their "home" now.
 - Concern that "availability" is not enough.

Appendix 13: Summary of interview details

	No. of interviews	Total interview time (hours)	Average interview length
Baby boomers	43	31.0	43.25 mins
PHCPs	11	9.5	51.81 mins
Total interviews	54 [#]	40.5	
(Total participants	57)		

[#] Three interviews included two baby boomer participants at the same time.

Appendix 14: Ethics Approval

Research Office
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The University of Waikato
Private Bag 3105
Hamilton 3240
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THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

MANAGEMENT SCHOOL
Te Rauapa

MEMO

To	Janet Davey, Dean's Office, Waikato Management School
From	Amanda Sircombe, Research Manager
Date	24 th June 2013
Subject:	Waikato Management School Ethical Application

Dear Janet

*Ethics Application WMS 13/91
Towards an Integrated Model for the Provision of Healthcare Services to New Zealand Baby
Boomers: Key Stakeholders' Perceptions, Priorities and Plans #12/193*

The above project, as outlined in this ethics application, has been granted Ethical Approval with Recommendations for Research by the Waikato Management School Ethics Committee.

Please note: should you make changes to the project as outlined in the approved ethics application, you may need to reapply for ethics approval.

Best wishes for your research

Regards

Amanda Sircombe
Research Manager

Appendix 15: Consent Form

Consent Form for Participants

Waikato Management School

Te Raupapa



THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Health Literacy and New Zealand Baby Boomers

I have read the **Information Sheet for Participants** for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I am free to withdraw from the study up to 2 weeks after the interview, and/or to decline to answer any particular questions in the study. I agree to provide information to the researchers under the conditions of confidentiality set out on the **Information Sheet**.

I agree to participate in this study under the conditions set out in the **Information Sheet** form.

I agree to the interview being recorded using a voice recorder.

Signed: _____

Name: _____

Date: _____

Researcher's Name and contact information:

Janet Davey
Dean's Office,
Waikato Management School,
University of Waikato.
Ph: 078384466 ext 7909
janetd@waikato.ac.nz

Supervisors' Names and contact information (July to December 2013):

Associate Professor Kathryn Pavlovich
Department of Strategy and Human Resource Management, Waikato
Management School.

Email: kpav@waikato.ac.nz
Professor Stewart Lawrence
Department of Accounting, Waikato Management School.
Email: stewartl@waikato.ac.nz

**The Waikato Management School Ethics Committee, University of Waikato
has approved this research**

Appendix 16: Transcription confidentiality

Email confirmation, 14/08/2013

Privacy and Confidentiality

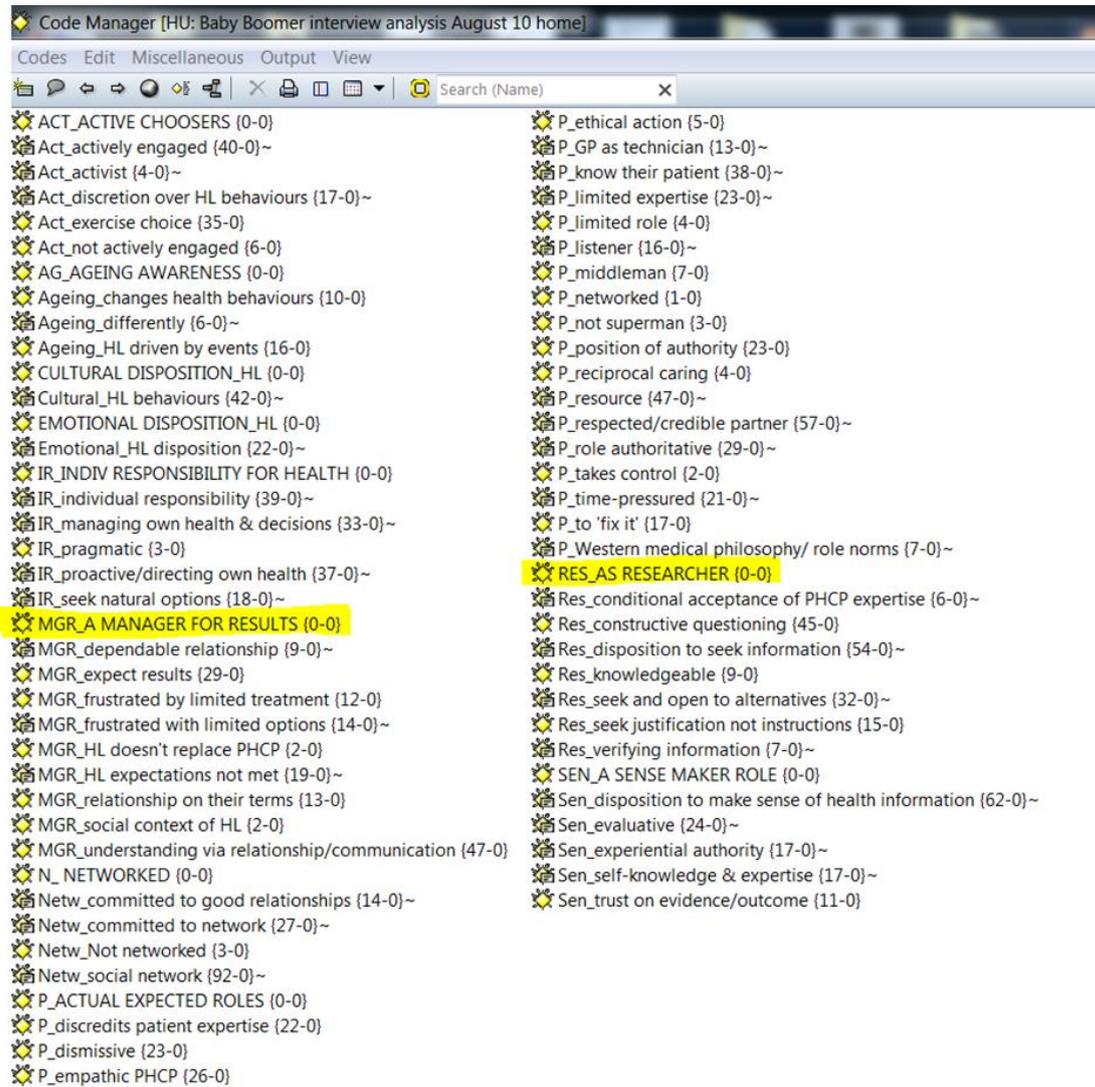
Audio Transcription Services provides confidential transcription services. We sign an NDA if requested. We believe in *HWC* - Handle with Care, all of our customer's projects. We delete all records at your request.

Kind Regards

Lenna K. Millar | Manager
Audio Transcription Services (ATS)
Connect on LinkedIn
Phone: 646-3444198 | Mobile: 027-7894928

"Striving for excellence and quality assurance"

Appendix 17: Screenshot ATLAS.ti code manager Baby Boomer interviews



Baby Boomer interview analysis August 30 home - ATLAS.ti

Project Edit Documents Quotations Codes Memos Networks Analysis Tools Views Windows Help

F-Docs P15: E F L #8.rtf (43) Quotes Codes ACT_ACTIVE CHOOSERS (0-0) Memos

P15: E F L #8.rtf

036
039 So, the one I go to now is very different. He's very open-minded. He is very much into nutritional approaches to healing that are fairly similar to my own ideas, and he's a lot more open and aware. I have taken him information on things which he has taken on board which I really admire him for. At the same time there's a limit to the extent of his knowledge and how far he's prepared to go, which we discovered when we went along for ██████'s check recently and he expressed great horror that ██████ wasn't taking a swarm of drugs... no, not horror, surprise... and then looked at the list of supplements that I'd spent about a thousand hours working out the programme for ██████, which was all based on extensive research, and he looked very briefly at that and said, "Oh no, I think that's far too much to put all those together. It's better to just have lots of baby spinach and lots of green vegetables and lots of bone broths and good diet. That's what I would do."

040
041 So I wasn't very satisfied with that response because a heart by-pass means that there's some serious stuff going on and I didn't really think that baby spinach leaves were going to do the ticket.

042
043 ': How did you then resolve that kind of disagreement or did that discussion just peter out?

044
045 ██████ We didn't need to really. He said that he told ██████ that in most instances of people in his situation, he would normally be putting them on statins and this and that. He said, "But I'm not going to do that with you because I know you won't take them." And I think he wouldn't have taken them himself either. So, he's responsive to us and he's perfectly aware and respectful of the fact that we'll make our own decisions, so I admire him for that.

046
047 ': That's really good. Can we go back to when you had to change your GP - what sorts of things did you look for in the GP and how did you go about choosing this other one, given the previous experience?

048
049 ██████ The reason I had gone to the previous GP - well, I hadn't actually gone to him, what had happened was I had a friend who was a doctor in that practice, a woman, and I had just started going to her and then she left and went to Christchurch and so I got the next guy in the practice. So, we kind of fell in to him. Then when I gleaned that he wasn't really on the same wavelength at all and that view was solidified by the vitamin D experience, then I made the decision to go.

050
051 That coincided with this other guy coming to town who I already knew about from a woman I know who does Bodywork, which is manipulations of muscles and things to sort out structural problems, and she had worked with him. They'd sort of done various things together and she had told me about him and how different he was and how he had similar nutritional ideas to me. He came

- █ P_empathic PHCP
- █ P_discredits patient expertise
- █ MGR_HL expectations not met~
- █ P_know their patient~
- █ Act_exercise choice
- █ Act_actively engaged~
- █ Netw_social network~

