

**Health literacy and
healthcare system navigation for
people who have had,
or are at risk of, a cardiac event**

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ABSTRACT

As the first study looking at health literacy and healthcare system navigation in Tasmania, the findings make a significant contribution to Australian-based health literacy research. Derived from a mixed methods survey of 18 mostly senior, regional participants with cardiac ill health, the data revealed a group for whom the abilities to access, understand and apply health information were largely inadequate. Yet remarkably, in light of that finding, most participants' experiences of healthcare system navigation were positive and most spoke with confidence about being able to perform the task. Participants' recollections were examined for factors that contributed to their experiences.

Analysis of the individual, service and system level themes that emerged from participants' recollections produced a complex picture of factors understood to impact their navigational experiences. In seeking to interpret and explain that complexity a framework was developed which highlights the role of health literacy at the individual level. The cogwheels depicted in the framework represent the interrelated nature of the factors impacting navigation at the various levels; the dynamic nature of healthcare navigation; and the influence health literacy may have on it.

That said, the contribution participants' health literacy made towards understanding the complexities of their navigational experiences were both conclusive and inconclusive. Conclusively, the data revealed a positive association between participants' health literacy and their depth of cardiac knowledge and subsequent ability to respond appropriately when symptomatic; their understanding of treatment protocols; and their self efficacy with filling out forms, reading hospital materials and learning about their cardiac conditions. However, data analysis revealed that in many ways the contribution participants' health literacy made towards understanding their navigational experiences was inconclusive. Self

management motivation; advice and support with navigational decision making; and service accessibility, for example, were also shown to assist participants who achieved across the range of possible health literacy proficiencies.

Collectively, those findings evidenced the vulnerability of participants with limited health literacy whilst demonstrating health literacy was one of a number of factors impacting the healthcare navigation experience. Thus, although limited health literacy risked making navigation more difficult it could be offset by other factors such as motivation, advice, support and service accessibility to make the overall experience a positive and manageable one. From the findings of this study it is recommended health literacy is addressed as part of a multifactorial intervention strategy to improve individuals' successful navigation of healthcare systems, whilst also advocating further research in the area.

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LIST OF ABBREVIATIONS AND ACRONYMS

ABS	-	Australian Bureau of Statistics
ACS	-	American Cancer Society
AIHW	-	Australian Institute of Health and Welfare
ALLS	-	Adult Literacy and Lifeskills Survey
ARIA+	-	Accessibility/Remoteness Index of Australia
ASGC	-	Australian Standard Geographical Classification
ASGS	-	Australian Statistical Geography Standard
AUROC	-	Area Under the Receiver-Operating Characteristics
COB	-	Country of birth
DoHA	-	Department of Health and Ageing, Australia
DHHS	-	Department of Health and Human Services, Tasmania
eHEALS	-	eHealth Literacy Scale
ED	-	Emergency Department
GP	-	General practitioner
HA	-	Heart attack
IALS	-	International Adult literacy Survey
MM	-	Mixed methods
NAAL	-	US National Assessment of Adult Literacy
NHPAC	-	National Health Priority Action Council
NVS	-	Newest Vital Sign
OECD	-	Organisation for Economic Co-operation and Development
OHS	-	Open heart surgery
PIAT	-	Peabody Individual Achievement Test
QUAL	-	Qualitative research
QUAN	-	Quantitative research
REALM	-	Rapid Estimate of Adult Literacy in Medicine
RDI	-	Recommended dietary intake
SAL	-	Survey of Aspects of Literacy
SBSQ	-	Set of brief screening questions
SORT	-	Slosson Oral Reading Test
TasCOSS	-	Tasmanian Council of Social Service
TOFHLA	-	Test of Functional Health Literacy in Adults
TSI	-	Torres Strait Islander
USA	-	United States of America
USDHHS	-	US Department of Health and Human Services
WRAT	-	Wide Range Achievement Test

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CHAPTER 1 – INTRODUCTION

1.1 OVERVIEW

This chapter presents a précis of the thesis. It begins with a brief summary of the background to the research followed by the problem the research sought to address and the key concepts in that process. Also central to the presentation is the aim and importance of the research together with the questions that guided it. The methodology and methods used to conduct the research are alluded to in the design section followed by an overview of its scope and limitations. The structure of the remaining thesis is outlined in the final section.

1.2 BACKGROUND

Healthcare navigation is the process by which people move into and through the multiple parts of a healthcare system to gain access to and use the services it provides (Sofaer, 2009). No person should spend more time and energy engaged in that process than otherwise necessary. Yet for those with low health literacy the challenge of navigation may prove as great a burden as the task of staying well, especially given the navigational demands made on those skills by complex healthcare systems and the requirements of chronic disease management.

Varyingly defined as the ability to access, understand and apply health information, the skills of health literacy are inextricably linked to the process of navigation. Data from the most recent Australian survey of health literacy, the 2006 Adult Literacy and Lifeskills Survey (ALLS), reveal 60 percent of people aged 15 to 74 years do not have adequate health literacy; the proportion is 63 percent in Tasmania (ABS, 2007a). The reality of those data is stark given the well documented implications of low health literacy and the fact Australia's healthcare system is

characterised by its complexity and rates of chronic disease are burgeoning among its population. Whilst in the United States of America (USA) a similar reality promulgated healthcare navigation programs aimed at addressing patient barriers to care such as low health literacy, in Australia's states and territories the responsibility for healthcare navigation devolves to the individual.

1.3 PROBLEM DEFINITION AND KEY CONCEPTS

There is minimal published research on the process of navigating healthcare in Australia from the perspective of patients with chronic disease. Moreover, Australian research focusing on health literacy in the context of healthcare system navigation seems yet to be realised. That represents a gap in Australian health literacy data pertaining to navigation and knowledge of relevance to those (eg. governments) seeking to better equip people with the skills and abilities to effectively access and use health services.

Four concepts are central to deriving understanding from the present research: health literacy; healthcare system navigation; chronic disease; and mixed methods (MM) research. The first three concepts are embedded in the problem definition whilst the fourth is the methodology chosen to conduct the research. Necessarily, each concept is defined and discussed in later chapters.

1.4 AIM

The aim of the present research was to determine the viability of health literacy as a focus for intervention to better equip people with the skills and abilities needed for healthcare navigation in the context of managing a chronic cardiac disease.

1.5 THE RESEARCH QUESTIONS

Three questions supported the research aim. Principally, do participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their chronic cardiac disease? In order to answer that question the responses to two precursory questions were necessary. Firstly, how do participants score on health literacy? Secondly, what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event?

1.6 IMPORTANCE OF THIS RESEARCH

Research largely emanating from the USA suggests health literacy plays an imperative role in healthcare navigation, with inadequate health literacy posing a barrier to accessing care and a significant reason for the patient navigation programs designed to overcome it. Research has yet to reveal the role health literacy may play in healthcare navigation for patients in Australia, especially those needing to deal with chronic disease. The importance of such data cannot be overstated given the Australian healthcare system places an expectation on patients across the country to use increasingly complex information and processes to inform their navigational decision making, moreover in the absence of programs offering relevant assistance. As a state of Australia and locale for the present study, Tasmania also has a record of inadequate health literacy among the majority of its adult population as well as higher than national average rates of chronic cardiac disease. The present research was therefore warranted to determine, in light of those collective data, if health literacy may be a focus for intervention to better equip people with the skills and abilities needed for healthcare navigation in the context of managing a chronic cardiac disease and in doing so, go some way towards filling that gap in the knowledge base on health literacy in Australia.

1.7 DESIGN

Based on a MM approach, the study used a concurrent embedded design whereby the quantitative (QUAN) component supplemented the predominantly qualitative (QUAL) focus. The utility of mixed methods as a research approach favoured its selection as did the fact both QUAN and QUAL methods were required to answer the questions. More specifically, the QUAN strand employed a numerical, objective measure of participants' health literacy using the Newest Vital Sign (NVS) tool whilst the QUAL strand used principles of phenomenology to explore and understand participants' experiences of navigating a healthcare system for the purpose of managing their cardiac ill health. The principal question combined the results of those analyses to explore the contribution health literacy made to healthcare navigation.

The study was not driven by a particular mixed methods paradigm or researcher bias regarding a school of thought within the field of health literacy enquiry. Rather, it was driven solely by the researcher's interest in health literacy and its pertinence to healthcare system navigation and purposely remained unencumbered by the unresolved paradigmatic and theoretical debates that continue to the present day regarding MM research and health literacy, respectively.

1.8 SCOPE AND LIMITATIONS

The present research had a volunteer sample population of 12 adult males and 6 adult females, all of whom lived in regional towns across the North West Coast of Tasmania. They participated in a cardiac rehabilitation program as a result of being at risk of, or having had, a cardiac event. Whilst the sample was a source of rich and valuable data it had a number of limitations to do with size, setting, gender mix and method of selection. Similarly, the oral presentation of the health literacy

measure may have been problematic for those participants with limited health literacy just as the retrospective focus of the research may have compromised the accuracy of the data because it relied on participants' memory of past events. A further limitation was the predominant subjectivity of the research findings. To that end, the processes leading to their production have been made transparent and provide a basis upon which to judge their merit.

1.9 STRUCTURE OF THE THESIS

Beyond this introduction, the thesis comprises five chapters that follow a logical sequence in presenting the research:-

Chapter 2: The *literature review* establishes the argument for the present research based on a knowledge and understanding of health literacy and healthcare system navigation gleaned from relevant publications. At the forefront of that argument is the most current Australian health literacy data from the 2006 ALLS and the relevance of those data to Tasmania given it is the setting for the present research. The significance of those data in the national healthcare context is highlighted by the dual demands placed on health literacy skills by Australia's complex healthcare system and burgeoning rates of chronic disease. Confronted by similar realities, the USA developed patient navigation programs to address the subsequent health outcome disparities being observed in its population. In the absence of such programs in Australia the individual is ultimately responsible for navigating the Australian healthcare system. The literature reveals little about that experience from the patient perspective, particularly those managing a chronic disease. Moreover, no Australian research has focused on health literacy in the context of the healthcare navigation experience. The chapter concludes by arguing the present research goes some way towards addressing that gap in Australian health literacy data by investigating whether health literacy contributes to an understanding of participants' experience of navigating a healthcare system to manage their chronic

cardiac disease. The pertinence of such new knowledge to aspects of the Australian and Tasmanian Governments' healthcare agendas is highlighted to further demonstrate the need for the present research given the role governments play in facilitating access to, and use of, health services.

Chapter 3: The *design* chapter describes the methodology underpinning the research process together with the specific methods used to conduct it. A MM approach was chosen to answer the research questions which had a QUAN as well as QUAL focus. A concurrent embedded MM design supported the dominance of the QUAL strand (ie. participants' healthcare navigation experience) and supplementary function of the QUAN strand (ie. participants' health literacy scores) in achieving the aim of the research. The subsequent implementation of that design involved approaches which were congruent with the collection and analysis of QUAN and QUAL data: postpositivism and phenomenology, respectively. The QUAN data consisted of participants' demographic details together with a numerical, objective measure of their health literacy using the NVS tool. The QUAL data comprised narratives collected through interview and focus group methods as well as documentation (eg. details of medical events) sourced from participants' paper-based Medical Record. The chapter provides an in-depth account of those methods and the pilot study which partly informed them. An in-depth account of the sampling and recruitment and consent process similarly reveal how decisions were made and implemented to uphold the quality of the research despite some inevitable limitations.

Chapter 4: The *results* chapter presents and discusses the raw data specifically pertaining to the two precursory questions. It begins with the QUAN data that sought to address the question: how do participants score on health literacy? The QUAL data that follows sought to address the question: what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event? Intentionally, scant comment is made in the chapter on participants'

health literacy levels relative to those data given it is the focus of the proceeding discussion chapter. The QUAL data are presented in sub-sections corresponding to the review of participants' Medical Record and to the several themes that encapsulated participants' experiences of healthcare system navigation, or more specifically, factors impacting those experiences at the individual, service and system levels. Remarkable perhaps, in light of participants' largely inadequate health literacy levels and the associated implications reported in the relevant literature, their experiences navigating the Tasmanian healthcare system were, for the majority, positive and reflected a sense of ease with the task. Exploration of the themes that emerged from participants' recollections of those experiences however, revealed a complex picture about which eleven summary statements were generated.

Chapter 5: The *discussion* chapter draws on the inferences of the results chapter to address, in the context of the relevant literature, the principal question of the research: do participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their chronic cardiac disease? The discussion deals in turn with each of the eleven statements made in the summary of the previous chapter to demonstrate the complexity of the thematic data to have emerged from participants' recollections of their navigation experiences. Necessarily, the focus of the discussion is whether participants' health literacy scores made sense of those statements. By way of summary and to conclude the chapter, a visual framework is presented. It depicts the interrelatedness of the factors impacting navigation at the individual, service and system levels; the dynamic nature of healthcare system navigation; and the pervasive impact of health literacy on such navigation. Indeed, the contribution participants' health literacy made towards understanding the complexities of their navigation experiences were at once conclusive and inconclusive.

Chapter 6: The final chapter, the *conclusion*, summarises the findings as they pertain to the research questions. Highlighting the significance of those findings is the framework illustrating the factors impacting participants' navigation of the Tasmanian healthcare system; the regional geography of the sample population; and the high number of participants with inadequate health literacy, as measured by the NVS. Proposed implications of the research include the need to improve health literacy in the community and develop a standardised measure of healthcare system navigation which would have the potential to contribute to health service planning and evaluation as well as provide a better appreciation of the healthcare experience from the patient perspective. The chapter incorporates a list of topics for future investigation generated from the present research and concludes with reference to the onus of responsibility that comes with being a patient in Australia.

Each chapter begins with an overview and concludes with a summary that provides the link to the proceeding chapter. The chapters are thus interlinked to reflect the research process and provide the reader with a logical progression of thoughts and ideas driven by the aim of the study.

CHAPTER 2 – LITERATURE REVIEW

2.1 OVERVIEW

This chapter presents a review of relevant literature and data obtained through the search strategy outlined in Appendix 1. It builds a knowledge and understanding of health literacy and healthcare system navigation and in doing so, creates an argument for the present research. It begins with an exploration of health literacy in terms of how it is defined and related to, but distinct from, general literacy. The implications of low health literacy that follow are put into an Australian context with a review of the most current national health literacy data from the Adult Literacy and Lifeskills Survey (ALLS) conducted in 2006. Highlighted is the relevance of those data to Tasmania given it is the setting of the present research. The significance of the ALLS health literacy data in the national healthcare context is established by documenting the demands made on health literacy skills by complex health care systems and chronic disease management. When combined with the implications of low health literacy, those dual demands are said to lead to potential health outcome disparities.

Recognising that potential the United States of America (USA) responded by developing patient navigation services which are further discussed to help build a knowledge and understanding of the healthcare navigation concept. It is then stated that because similar services are not provided in Australia the individual is ultimately responsible for navigating the Australian healthcare system, yet little is known about the process from the patient's perspective, particularly those needing to manage a chronic disease. Moreover, it is pointed out that there is a dearth of published Australian research focusing on health literacy in the context of healthcare system navigation providing sound argument for the present research as a means of addressing that gap in the knowledge base on health literacy in Australia. The literature review concludes with reference to an appendix highlighting the relevance

of the present research to aspects of the Australian and Tasmanian Government healthcare agendas, further supporting that argument given the role governments play in facilitating access to, and use of, health services.

2.2 UNDERSTANDING HEALTH LITERACY

2.2.1 WHAT IS HEALTH LITERACY?

Health literacy could be defined as little more than an understanding of health information and instructions. However, that somewhat simplistic definition understates the current literature on the subject. Indeed, being a “relatively new construct” (Berkman, Davis, & McCormack, 2010, p. 12) much effort has been made to clarify its meaning.

In her undertaking of a concept analysis of health literacy, Speros (2005) claims the first recorded use of the term was in 1974 in a paper calling for baseline health education standards for all school grades in the USA. Speros noted that until the early 1990’s the few references made to health literacy were in the context of, and defined by, the traditional measures of literacy, namely, reading and comprehension. Health literacy was not regarded as a distinct concept until 1992 when physicians affiliated with the American Emory University in Atlanta and the UCLA Medical Centre in Los Angeles undertook a two year study focusing on the measurement of health literacy in English and Spanish speaking adult outpatients of two public teaching hospitals (Parker, Baker, Williams et al., 1995). This seminal work described health literacy as “being able to apply literacy skills to health related materials such as prescriptions, appointment cards, medicine labels, and directions for home health care” (Parker et al., 1995, p. 537).

Definitions of health literacy have since reflected a conceptual evolution of ideas and understanding derived from a growing body of research (Bankson, 2009; Green, 2007; Peerson & Saunders, 2009; Wolf, Wilson, Rapp et al., 2009). Three definitions in particular stand out for their repeated use in the relevant literature and are provided by the American Medical Association's (AMA) Ad Hoc Committee on Health Literacy, The US Department of Health and Human Service (USDHHS) and the World Health Organisation (WHO). According to the AMA, health literacy is:

A constellation of skills including the ability to perform basic reading and numerical tasks required to function in the health care environment (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999, p. 553).

A broader perspective of that skill set is evident in the definition adopted by the US DHHS which states health literacy is:

The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (USDHHS, 2010, p. 1).

Whilst seemingly comprehensive, both definitions fail to account for contexts beyond health care settings, such as work and the community, and limit their scope to individual abilities. The WHO definition of health literacy, despite its earlier genesis, seems to address those 'failings' by encompassing notions of empowerment, health promotion, education and social benefit:

Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity

to use it effectively, health literacy is critical to empowerment
(WHO, 1998, p. 10)

According to Baker (2006), those often-cited definitions suggest “a lack of shared meaning” of health literacy which is “obviously problematic” to its study (p. 878). On the contrary, it could be argued any perceived differences between the definitions necessarily reflect the complex construct that is health literacy. For example, Fleming (2007) writes of health literacy in terms of a continuum from ‘below basic’ through to ‘proficient’ depending on skill level; Zarcadoolas, Pleasant, and Greer (2005) write of it being a dynamic entity that can change with experience; and Gong, Lee, Rozier et al. (2007) discuss the content specificity of health literacy whereby an individual who is able to apply information from materials with familiar content may struggle to comprehend and use information from materials written at the same level of complexity but involving unfamiliar content such as those encountered in healthcare settings.

In the report commissioned by the US Institute of Medicine (IOM), *Health literacy: A prescription to end confusion* (Nielsen-Bohland, Panzer, & Kindig, 2004), regarded by Rudd (2007) to be seminal because, at the time, it offered the most detailed analysis of the subject, health literacy is said to emerge when the expectations of those seeking information meet the expectations of those providing information. In this instance not only is a dual responsibility evident, but it also “draws attention to the communication skills and exchange of information between two parties: a lay public and health professionals” (Green, 2007, p. 12). Foulk, Carroll, and Nelson Wood (2001) suggest literacy can also be thought of as a form of “currency” (p. 8) whereby those with limited literacy skills have difficulty achieving health goals in much the same way people with limited finance have difficulty meeting their basic needs. It follows; improving one (health literacy) will improve the other (positive health outcomes).

Nutbeam (2000) writes of health literacy as one class of literacy among many, and as such, applies a broad brush to literacy classification with the aim of underscoring “the deeper meaning and purpose of literacy for people” (p. 263), be it health or otherwise. Citing the work of Freebody and Luke (1990), Nutbeam goes on to describe three classes of literacy: functional, communicative/interactive and critical. In that order, each classification is said to afford greater autonomy and personal empowerment which, in turn, is dependent on cognitive development, self-efficacy and personal and social skills mediating responses to communication in its various forms. Eight years later Nutbeam (2008) conceptualises health literacy as a dichotomy: a ‘risk’ whereby it influences health outcomes and an ‘asset’ whereby it is the health outcome. Both are described as important given one (health literacy as a risk) recognises the implications of low health literacy and the other (health literacy as an asset) recognises the complex nature of health-based decisions. Whilst not dissimilar in essence to his earlier work, Nutbeam’s more recent conceptualisation provides yet another way of defining health literacy. Moreover, it is indicative of a discourse on defining health literacy that continues in the literature to the present day (Berkman et al., 2010; Jordan, Buchbinder, & Osborne, 2010; Kickbusch, 2009; Mancuso, 2008; Nutbeam, 2009; Pleasant & McKinney, 2011; Wills, 2009).

The present study draws on the WHO definition of health literacy for its broad application and relevancy to healthcare navigation.

2.2.2 THE DISTINCTION BETWEEN LITERACY AND HEALTH LITERACY

Carolan, Steele, and Margetts (2010), among many others, use the terms ‘literacy’ and ‘health literacy’ interchangeably. This can be confusing for people new to the field of health literacy, particularly when reference is made in the general sense with either term seemingly applicable. It begs the question as to whether it is

necessary to make the distinction between literacy and health literacy in the context of health outcomes. Certainly, there is an undeniable and well documented relationship between both, the essence of which suggests good literacy equates to good health literacy (Chiovetti, 2006; DeWalt, Berkman, Sheridan et al., 2004; Fleming, 2007; Gillis & Quigley, 2004; Hemming & Langille, 2006; Joyner, 2011; Keleher, 2009; Rudd, 2007; White, 2008). Moreover, the reverse order of that relationship (ie. good health literacy equates to good literacy) is not evident in the reviewed literature suggesting literacy provides the foundation upon which health literacy is acquired (Ishikawa & Yano, 2008).

Baker (2006) nevertheless claims the relationship between literacy and health literacy is difficult to quantify. He instead draws attention to the importance of distinguishing between the two, particularly in the context of research “because a measure of an individual’s ability to read and understand health-related materials is likely to be more closely related to health outcomes than a measure of general literacy” (p. 879). Likewise, Villiare and Mayer (2007) acknowledge literacy and health literacy share “some overlapping meaning” (p. 213) but seem equally emphatic of the need to regard them as distinctly different terms. Chiarelli and Edwards (2006) echo that sentiment but also add, “from a public policy perspective, literacy is a cross-cutting issue” (p.537). Indeed, the authors regard both literacy and health literacy as integral to numerous government portfolios including health, education, social welfare and employment.

2.2.3 THE IMPLICATIONS OF LOW HEALTH LITERACY

A recurrent theme emerging from the reviewed literature is the shame people may feel about their low health literacy skills and the impact that has on their interactions and communication within the healthcare setting (Agre, Stieglitz, & Milstein, 2006; Brown, Ludwig, Buck et al., 2004; Cornett, 2009; Mika, Kelly, Price

et al., 2005; Villiare & Mayer, 2007; Wolf, Williams, Parker et al., 2007). A “culture of silence” (Foult et al., 2001, p. 12) is said to develop out of a sense of such shame given people typically wish to hide their literacy difficulties (Baker, Parker, Williams et al., 1996; Brown et al., 2004). Even in the absence of shame, Flinter (2007) reports “anxiety and fear [associated with low health literacy in the context of the health care experience] are pretty effective at shutting down [a person’s] ability to listen, hear and understand” (p. 5).

Compounding those experiences, and evidenced in an expanding body of literature, is an unequivocal relationship between low health literacy levels and adverse health-related outcomes (eg. Cavanaugh, Wingard, Hakim et al., 2010; Cho, Lee, Arozullah et al., 2008; Keleher & Hagger, 2007; Kollipara, Jaffer, Amin et al., 2008; Paasche-Orlow & Wolf, 2007; Rootman & Gordon-El-Bihbety, 2008; Schwartzberg, VanGeest, & Wang, 2005; Scudder, 2006; Shieh & Halstead, 2009; Tokuda, Doba, Butler et al., 2009; Yin, Mendelsohn, Wolf et al., 2010). Specific examples include poorer chronic illness management, physical and mental functioning (Baker, Parker, Williams et al., 1997; Schillinger, Barton, Karter et al., 2006; Wolf, Gazmararian, & Baker, 2005); a greater propensity for on-going health problems and deterioration in health (Baker, Parker, Williams et al., 1998); an increased risk of hospitalization (Baker, Gazmararian, Williams et al., 2002; Baker et al., 1998; Murray, Tu, Wu et al., 2009); and increased mortality (Baker, Wolf, Feinglass et al., 2007; Cavanaugh et al., 2010; Peterson, Shetterly, Clarke et al., 2011; Sudore, Yaffe, Satterfield et al., 2006). Indeed, people with low health literacy are 1.5 to 3 times more likely to experience adverse health-related outcomes than those with adequate health literacy (De Walt et al., 2004), depending on the outcome under examination (Wolf, Feinglass, Thompson et al., 2010).

The relationship between literacy and health outcomes can be direct (eg. when a person is unable to comply with prescribed treatment because he/she

cannot read the instructions) or indirect (eg. as a ramification of poverty, minimal formal education or unemployment) (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999; Chiarelli & Edwards, 2006; Chiovetti, 2006; Gillis & Quigley, 2004; Nutbeam, 2008). The significance of the relationship is underscored by its prevalence in “every patient interaction in every clinical situation” where low health literacy prevails (Brown et al., 2004, p. 152). That is assuming people with low health literacy even make it to the clinical setting given the degree of engagement they have with health services and interventions is, according to Keleher and Hagger (2007), minimal. In other words, their low health literacy puts them “outside a societal flow of information that...brings people to health care” (Foulk et al., 2001, p. 8) because they simply cannot access, understand and/or apply that predominantly written text which may in turn compromise the timeliness, appropriateness and quality of care they receive (Hasnain-Wynia & Wolf, 2010).

2.3 HEALTH LITERACY IN AUSTRALIA

2.3.1 THE ADULT LITERACY AND LIFESKILLS SURVEY

The implications of low health literacy are compelling and even more so when considered along with current national data. It represented the second survey of its type with its predecessor, the International Adult literacy Survey (IALS), conducted in Australia in 1996 as the Survey of Aspects of Literacy (SAL). Significantly, the health literacy domain was an addition to the 2006 ALLS (as was the domain of problem solving) and hence no time series national health literacy data exists up to, and beyond 2006 given a survey like the ALLS has not since been repeated (ABS, 2007a).

The health literacy data of the ALLS were derived as a by-product from the four skill domains of the survey: prose literacy, document literacy, numeracy and

problem-solving (Appendix 2). This was on account of the 191 health-related items embedded across the domains pertaining to the following activities: health promotion, health protection, disease prevention, healthcare maintenance and system navigation (Appendix 3). Proficiency was conceptualised along a continuum of five skill levels with Level 1 being the lowest and Level 5 the highest (Appendix 4). Across all domains, including that of health literacy, skills denoting Level 3 were judged by the survey developers to be the minimum required by individuals to adequately function in daily life (Statistics Canada and OECD, 2005).

2.3.2 RESULTS OF THE ALLS AND THEIR RELEVANCE TO TASMANIA

Two systematic reviews of American studies examining health literacy found in common a set of demographic and socio-economic markers reported to be associated with health literacy. Namely, age, education, income and ethnicity (Crane Cutilli, 2007; Paasche-Orlow, Parker, Gazmararian et al., 2005). Regarding age, results of the Australian ALLS show health literacy increased up to the age of 40 and then gradually decreased with age, representing an inverse relationship. DeWalt et al. (2004) note the decline in health literacy with age is occurring at a time in life when the burden of chronic disease and ill health is likely to be increasing. That trend is of particular concern in Tasmania because of its rapidly ageing population, with data from the Tasmania Department of Health and Human Services (DHHS) suggesting the percentage of the state's population aged 65 years and over is likely to double by 2050 (DHHS, 2008). That projection is on top of current demographic data showing Tasmanian already has the oldest population within Australia (ABS, 2010a).

Paasche-Orlow et al. (2005) report a significant relationship ($P = 0.02$) between education and health literacy levels found in their review of American studies suggesting the higher the level of education the higher the level of health

literacy. Hemming and Langille (2006) quantify that relationship claiming educational level accounts for as much as 60 per cent of a person's health literacy proficiency. The Australian ALLS data not only support those findings, it does so across three educational categories: attainment, participation and parental education. For example, of those who undertook an educational qualification in the year prior to the survey, 54 per cent achieved health literacy scores at Level 3 or above. In contrast, of those who did not undertake any formal education in that period only 30 per cent achieved similar levels of health literacy. In terms of parental education it was found 68 per cent of adults whose parents had as a minimum a Bachelor degree achieved a health literacy level of 3 or above. This is in contrast to the 58 per cent of adults whose parents attained a qualification below that of a Bachelor degree.

The results of Crane Cutilli's (2007) integrative review of research on health literacy and the geriatric patient population largely support the positive relationship between education and health literacy. However, the author did note a "slightly divergent trend" (p. 44) in those data. Namely, that health literacy levels have been shown to bear little correlation to a person's level of education, as found in studies by Wilson and McLemore (1997) and DeWalt et al. (2004). Crane Cutilli uses those findings to bolster her argument that simply knowing the highest grade level of education completed is, on its own, insufficient when determining a person's level of health literacy. That said, the otherwise positive relationship between education and health literacy should not be discounted, especially given "Tasmanian's educational outcomes are among the nation's worst with retention rates to Year 11 and 12 the lowest in the country by a significant margin" (TasCOSS, 2007, p. 5). Moreover, they look not to be improving based on recent data from the ABS showing the rates remain well below the National average (ABS, 2011).

The similarities between the findings of the Australian ALLS and those documented in the literature extend also to income. Research indicates a positive relationship between health literacy and income (Baker et al., 2002; Chew, Bradley, Flum et al., 2004; Eichler, Weiser, & Brugger, 2009) with the ALLS specifying a \$34,400 difference in equivalised income between those achieving a health literacy skill Level 1 and those achieving the more functional Level 3. For Tasmania the implications of those data are significant given Tasmanians have the lowest disposable income in the nation together with the highest number of people whose primary source of income is government pensions and allowances (ABS, 2009a).

Regarding ethnicity, the Australian ALLS recovered data on country of birth and more specifically, whether that country was English-speaking. Negligible difference was found between the people born in Australia whose health literacy score was at Level 3 or above (44%) and those with similar scores born overseas in mainly English-speaking countries (46%). A greater difference in health literacy proficiency was found for those born overseas in mainly non-English-speaking countries of whom only 26 per cent achieved Level 3 or above. The paucity of information on Tasmania's migrant population is perhaps not surprising given the state attracts less than one percent of Australia's overseas net migrant population (eg. 1,500 in the year to June 2008 - ABS, 2010b). So whilst the implications for Tasmania of the ALLS data regarding ethnicity and health literacy are difficult to quantify, their prominence in the context of the state's health matters comparative to other demographics such as age, education and income would likely be less.

The remaining findings of the Australian ALLS represent some interesting, but less remarkable data in the context of the present research and are outlined in Appendix 5.

Aggregated, the data produced by the Australian ALLS provide two stark realities. Firstly, health literacy (60%) was second only to problem solving (70%) as the domain with the greatest percentage of people aged 15 to 74 years who achieved *below* the functional skill Level 3. Secondly, Tasmania, along with the Northern Territory, had the highest representation (63% of the respective populations) among that cohort.

2.4 THE SIGNIFICANCE OF THE ALLS HEALTH LITERACY DATA

The realities of the Australian ALLS health literacy data are stark, particularly for Tasmania, but are they significant in the healthcare context? Quite conceivably, given the documented demands made on health literacy skills by complex health care systems and chronic disease management.

2.4.1 HEALTH LITERACY AND COMPLEX HEALTHCARE SYSTEMS

The Australian Institute of Health and Welfare (AIHW, 2010a) and others (Jeon, Essue, Jan et al., 2009; Newman, 2008) are blunt in their appraisal of the Australian healthcare system suggesting that whilst it is regarded as world-class for its effectiveness and efficiency, it is undeniably complex. Adequate health literacy is imperative to navigate such systems as they place an expectation on people to use increasingly complex information and processes to make informed health care decisions (Chen, Yehle, Plake et al., 2011; Crane Cutilli, 2007; Hibbard, Peters, Dixon et al., 2007; Kickbusch, Wait, Maag et al., 2005; Scudder, 2006; Villaire & Mayer, 2007; Westin, Bustillos, Gano et al., 2008). Indeed, people needing to access healthcare must first know about the services available to them; how to organise appointments; fill out forms; understand and report their medical history; give informed consent; follow instructions for taking medications; find their way to healthcare facilities and rooms within those facilities and so the list of tasks

continues. Even in light of the inevitable variation in peoples' abilities to perform such tasks, Sofaer (2009) contends "the field [of healthcare] has severely underestimated what patients have to navigate" (p. 77S). Possibly so too the importance of the health literacy skills needed to navigate because "a person's life may well depend on [them]" (Fleming, 2007, p. 54).

Such underestimations corroborate reported mismatches between the demands of complex healthcare systems and the health literacy skills of its consumers (Green, 2007; Paasche-Orlow et al., 2005; Sofaer, 2009; Wallace, 2006). For example, the reading grade levels of written materials used in healthcare settings and given to healthcare consumers have been found in several studies to far exceed the reading capabilities of the average consumer (Ache & Wallace, 2009; Chiovetti, 2006; Fleming, 2007; Green, 2007; Paasche-Orlow et al., 2005; Paz, Liu, Fongwa et al., 2009). The ramification of that mismatch for consumers may be misunderstanding medication dosages; being unable to make informed decisions about major procedures; or not being able to engage in preventative health measures. The ramification for healthcare systems of any such mismatch ultimately translates to one of cost (Eichler et al., 2009), estimated in the US¹ to be between \$US106 and \$US238 billion of annual healthcare expenditure (between 7 and 17 per cent of all healthcare expenditure) *directly* attributable to low health literacy skills (Vernon, Trujillo, Rosenbaum et al., 2007).

2.4.2 HEALTH LITERACY AND CHRONIC DISEASE MANAGEMENT

Just as complex health care systems place demands on health literacy skills so too does the management of chronic diseases. Whilst difficult to define because of their complexity and variability, most chronic diseases have in common the following features:

¹ A comparative cost estimate for Australia was not found.

- multifactorial causality
- a long development period
- a prolonged course of illness which may lead to other health complications
- associated functional impairment or disability (AIHW, 2006).

Examples include cardiac diseases, cancer, asthma, diabetes, depression and arthritis. Notwithstanding lifestyle issues brought about by such factors as better standards of living and associated changes to diet and activity levels, longevity has also improved through advances in successful medical treatments. Such advances have simultaneously increased the number of people needing to manage chronic diseases who may not have otherwise survived in previous years (Gazmararian, Williams, Peel et al., 2003; Lawn & Schoo, 2010; NHPAC, 2006; Schillinger, Piette, Grumbach et al., 2003). Indeed, chronic diseases are responsible for an estimated 80 percent of the total burden of disease for Australians with prevalence rates expected to escalate in line with global trends (AIHW, 2010a). In Tasmania for example, cardiac diseases represent the greatest threat to life and a disease burden that is 40 percent higher than the national average burden of 16.4 percent (ABS, 2009b). Collectively, those data reflect a significant impost on the healthcare system and one the Australian Government is treating with high priority to ensure an appropriate and cost effective response (NHPAC, 2006).

Yet clearly, the impost of chronic disease management is not just at the system level. Individuals also face a challenge because those encumbered with a chronic disease need to understand how to manage their condition (Barrett & Puryear, 2006; Chen et al., 2011; Gallagher, Donoghue, Chenoweth et al., 2008; Rudd, 2010). That challenge starts even before health services are called upon given people need to understand the link between changes in their body, how they feel, and when to seek intervention (Villiarre & Mayer, 2007). Self-management subsequently becomes an exercise in effective participation, in collaboration with

key health providers and services, to maintain health and ensure symptom control (Evangelista, Rasmusson, Laramée et al., 2010).

For people with cardiac disease for example, self-management may involve monitoring their weight and sodium intake, exercising regularly, taking prescribed medication and having regular blood pressure tests. For those with diabetes the tasks are likely to revolve around the monitoring of their blood glucose, whilst self management for those with arthritis may focus on joint preservation and pain control (AIHW, 2006). Importantly, all activities associated with the self-management of chronic diseases have as requisite skills the ability to access, understand and apply health information. In other words, health literacy (Campbell & Duddle, 2010; Chen et al., 2011; Devraj & Gordon, 2009; Evangelista et al., 2010; Macabasco-O’Connell, DeWalt, Broucksou et al., 2011; Mbaezue, Mayberry, Gazmararian et al., 2010). Moreover, utilisation of those skills is an on-going proposition given people with a chronic disease need to be able to *continually* access, understand and apply information vital to the self-management of their condition (Chiovetti, 2006; Foulk et al., 2001; Levy, 2007). As such, Fleming (2007) suggests health literacy skills provide the “strongest link” (p. 50) for people with chronic disease to their knowledge and understanding of how to care for themselves.

In summary, and according to the relevant literature, the dual demands made on health literacy skills by complex healthcare systems and chronic disease management are substantial. Moreover, both are inextricably linked given the latter necessitates access to the former. Add to that the implications of low health literacy discussed earlier, most notably the minimal engagement people with low health literacy are reported to have with health services and interventions, and the potential for health outcome disparities emerges. In the USA that potential was

realised in its cancer population during the 1990's and gave rise to a "buzzword in [American] health care" (Darnell, 2007, p. 81): patient navigation.

2.5 UNDERSTANDING HEALTHCARE SYSTEM NAVIGATION

2.5.1 WHAT IS HEALTHCARE SYSTEM NAVIGATION?

Not unlike the on-going discourse in the literature dealing with the definition of health literacy, 'navigation' in the healthcare context is also a concept lacking a standard definition (Anderson & Turner, 2007; Fowler, Steakley, Garcia et al., 2006; Freund, Battaglia, Calhoun et al., 2008; Nguyen & Kagawa-Singer, 2008; Wells, Battaglia, Dudley et al., 2008). Perhaps most elucidating is Sofaer's (2009) use of the term to denote the process by which people move into and through the multiple parts of a healthcare system to gain access to and use the services it provides. In their review of the predominantly American literature on the subject, Dohan and Scrag (2005) found definitions of navigation to be either service-focused or more commonly, barriers-focused. That is, the provision of a service or set of services to connect individuals to healthcare and direct them through their course of treatment or conversely, someone (ie. a 'navigator') specifically tasked with addressing patient barriers to care (eg. assisting patients with low health literacy to read and understand the health information they receive). The authors argue in favour of the latter "because it offers practical and conceptual advantages over a service-focused definition" (p. 850) which is said to do little to distinguish navigation from customary healthcare. Moreover, the 'practical' nature of the barriers-focused definition of navigation underscores the intention of the patient navigation programs through which navigation services are provided in the USA, arguably the pioneer of such endeavour.

2.5.2 PATIENT NAVIGATION PROGRAMS IN THE USA

The concept behind patient navigation programs in the USA is to reduce health outcome disparities experienced by the medically underserved or disadvantaged by addressing the barriers (eg. low health literacy) that must be overcome to access care (Dohan & Scrag, 2005). In 1989 a series of nationwide hearings were conducted by the American Cancer Society (ACS) to better understand the barriers faced by disadvantaged populations in using the complex processes required for the prevention, diagnosis and treatment of cancer (Wells et al., 2008). The subsequent report by the ACS revealed financial barriers (eg. being unable to afford health insurance), logistical barriers (eg. no means of transportation to clinics), and sociocultural barriers (eg. low health literacy). In response to those findings a physician – Harold Freeman – formed an alliance with the ACS to establish the first patient navigation program in Harlem, New York in 1990. It targeted low income women, a population with “historically poor breast cancer outcomes” (Wells et al., 2008, p. 2000), by assisting them to overcome barriers to breast screening and follow-up care. The assistance was provided by ‘patient navigators’, people “of the community who [knew] the [health care] system and [were] highly wired to help the patients through it” (Freeman, 2004, p. 45-46). The nature of the assistance was patient-centred and as such, varied from organising transportation to, and childcare during, scheduled appointments through to providing emotional support and health education. Studies of the program revealed remarkable results with patient survival rate over five years going from 39 percent (pre-program) to 70 percent (Freeman, 2004).

Based on the pioneering work of Doctor Freeman, the patient navigation concept has proliferated across the USA with support from both the private sector and local, state and federal governments (Darnell, 2007; Nguyen & Kagawa-Singer, 2008). One example is the Patient Navigator, Outreach and Chronic Disease

Prevention Act of 2005 which was signed in to law to allow federal, million-dollar grants to employ and train patient navigators to assist Americans with varying chronic diseases obtain timely and appropriate healthcare. Likewise, the US National Cancer Institute and the ACS have jointly sponsored the Patient Navigation Research Program in order to undertake an in-depth examination of the role and benefits of patient navigation (Freund et al., 2008; Hendren, Griggs, Epstein et al., 2010; Steinberg, Fremont, Khan et al., 2006).

That is not to suggest, however, Doctor Freeman's innovative patient navigation model has provided the inspiration for all such practices in the USA. Indeed, Anderson and Turner (2007) point out, "another group of health workers who fill the navigator role is known by various names. Community health advisors, lay health workers, and promotoras (the Spanish term for health advocate) are a few of the names given to patient navigators in programs that have been offered through health centers and in outreach programs for several decades" (p. 5). More recent examples of such programs include the Project Access Dallas (Gimpel, Marcee, Kennedy et al., 2009), the Multidisciplinary Lung Cancer Clinic in Maryland (Seek & Hogle, 2007), and the PrimaCare Community Family Health Team in Ontario, Canada (Bertoni, 2009) all of which incorporate the patient navigation concept in the services they provide and are reportedly derived from analyses of local health care issues with no explicit reference to Freeman's work.

2.5.3 HEALTHCARE SYSTEM NAVIGATION IN AUSTRALIA

...many Australians do not really know a lot about the health system. There is no systematic education about it and most learn what they know by piecing together information from different sources...whether they can put the information together in the right way can be a matter of luck. (Horey, 2006, p. 29)

Despite Horey's observations, Australia's healthcare system does not explicitly identify the USA equivalent of patient navigator roles or associated programs within its current service delivery structure. Therefore, healthcare system navigation in Australia principally devolves to the patient, a point highlighted in Australia's National Primary Health Care Strategy (DoHA, 2009) and supported notionally in an Australian study that looked at the strategies people with Type I diabetes used to access healthcare services (Rasmussen, Wellard, & Nankervis, 2001). It found strategies pertaining to navigation were articulated as the key to developing a better healthcare system for that group of people living with a chronic disease. Yet, beyond Rasmussen et al's. (2001) study, a dearth of published literature exists about the process of navigating Australian healthcare systems from the perspective of patients with a chronic disease.

2.6 AUSTRALIAN RESEARCH ON HEALTH LITERACY AND HEALTHCARE SYSTEM NAVIGATION

Rasmussen et al. (2001) did not report health literacy as one of their study variables and whilst American findings on health literacy and its impact on healthcare system navigation for people with chronic diseases (evidenced through its navigation programs) could be extrapolated as pertaining to Australia, they are clearly no substitute for country-specific research. Keleher and Hagger's (2007) scoping review of published studies to do with health literacy in Australia found a lack of breadth and subsequent patchy knowledge base. Australian health literacy research published in the intervening years has focused on its conceptualisation (Jordan et al., 2010); state-based population surveys (Adams, Appleton, Hill et al., 2009; Barber, Staples, Osborne et al., 2009; Gillespie, 2009); reviewing patient education materials (Owen, Kohne, Douglas et al., 2009); dentistry (Parker & Jamieson, 2010); and patient involvement in healthcare decision making (Smith, Trevena, Nutbeam et al., 2009). Still other examples of current Australian research

can be found where the focus on health literacy has been more implicit (eg. Carolan et al., 2010; Considine, Smith, Hill et al., 2010; Gill, Hill, Adams et al., 2010; Hoffman & Cochrane, 2009).

Yet, despite a growing interest in the area, there is no published Australian research focusing on health literacy in the context of healthcare system navigation. The present research will therefore go some way towards addressing that gap in Australian health literacy data by asking the principal question: do participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their chronic cardiac disease? The new knowledge gained from seeking to answer that question will also go some way towards addressing an identified need, in Tasmania at least, to look beyond current health data used as a basis for comparison with the other Australian states and territories (eg. birth rates, death rates, life expectancy) to "the causes behind any observed differences that matter most in terms of [revealing] what Tasmania needs to do to improve [the] health status [of its population]" (DHHS, 2008, p. 5). Moreover, the Tasmanian Stronger Communities Taskforce's² *State of Our Community Report 2007* identified "the biggest single gap in [their] data [was] the availability of information [health or otherwise] at the local level" (p. 24), understood to include the North West region of the State. Data from the present research will not only contribute local health information but do so with pertinence to the broader health agendas of the State and Federal Governments outlined in Appendix 6, underscoring their role in facilitating access and use of health services.

² The Tasmanian Stronger Community Taskforce is an initiative of the State Government's Department of Premier and Cabinet that was convened to advise the Minister for Community Development on: the state of Tasmanian communities; strategies to make Tasmania more inclusive; and the promotion of community development goals.
(www.dpac.tas.gov.au/divisions/SIU/reports_research_and_data/state_of_our_community_2007)

2.7 SUMMARY

It was the intention of the literature review to build a knowledge and understanding of health literacy and healthcare system navigation, thereby creating an argument for the present research. It posits the Australian ALLS health literacy data at the forefront of that argument with strong support coming in the guise of a complex healthcare system and burgeoning rates of chronic disease. Confronted by similar realities, it was noted the USA established patient navigation programs to stem the tide of the resultant health outcome disparities being observed in its population. In the absence of such programs in Australia the individual was proclaimed as ultimately responsible for navigating the healthcare system. Whilst Australian research was able to reveal a little about that experience and an emerging body of Australian health literacy research was identified, no research was found to date that purposefully combined the two topics. It is therefore argued the present research adds new knowledge to the field of health literacy in Australia at the same time as being pertinent to government health agendas, by investigating whether health literacy contributes to an understanding of patients' experience of healthcare system navigation to manage their chronic cardiac disease. The design of that investigation will be discussed in the proceeding chapter.

CHAPTER 3 – RESEARCH DESIGN

3.1 OVERVIEW

This chapter details how the research was designed to address the three questions supporting its aim. That is: do participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their chronic cardiac disease; and precursory to that, how do participants score on health literacy and what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event? Details of the design include the methodology underpinning the research process together with the specific strategies or methods used to conduct it. The first section of the chapter provides an overview of the mixed methods (MM) approach used to preference its design components. As a distinct approach in the social and human sciences MM research is relatively new and as such warrants a descriptive introduction, including mention of the paradigmatic foundation of such enquiry as one example of its unresolved issues. The second section of the chapter describes how, with ethical approval, the research design was implemented. It begins with the pilot study that informed aspects of that process and then proceeds with coverage of sampling, recruitment and consent, and data collection and analysis derived from 18 participants. The chapter concludes with the measures of quality and limitations of the present research design.

3.2 RESEARCH METHODOLOGY

3.2.1 MIXED METHODS OVERVIEW

The overall methodological orientation of the present research was MM. At its simplest level, MM research is defined by the use of both quantitative (QUAN)

and qualitative (QUAL) methods in the same study (Creswell, Plano Clark, Gutmann et al., 2003) and has previously been used in the field of health literacy research (eg. Arthur, Geiser, Arriola et al., 2009; Johnson, Jacobson, Gazmararian et al., 2010; Jones, Devers, Kuzel et al., 2010; Reigel, Vaughan Dickson, Goldberg et al., 2007). Philosophically it has been varyingly described as a third research movement alongside the monomethods of the QUAN and QUAL traditions (Johnson & Onwuegbuzie, 2004; Onwuegbuzie, Johnson, & Collins, 2009; Teddlie & Tashikkori, 2010).

The field of MM research commands recognition as the third major research movement not least of all because of its expanding list of pertinent handbooks, textbooks, journals and websites (Onwuegbuzie et al., 2009; Leech & Onwuegbuzie, 2009) coupled with exponential growth in its application across the health sciences (Forthofer, 2003), among many other disciplines (Leech & Onwuegbuzie, 2009). All of which is underscored by the proclaimed utility of MM over monomethods.

3.2.1.1 THE UTILITY OF MIXED METHODS RESEARCH

The fundamental goal of any research method is to answer research questions well. According to Johnson and Onwuegbuzie (2004), MM research affords the best opportunity to achieve that goal by allowing design components to be strategically mixed and matched to need, not paradigm as seen in the QUAN and QUAL traditions. In MM's infancy it was Howe's (1988) contention that the one-way paradigm-method linkages of QUAN and QUAL purists was indefensible and that the requirements of the investigation should determine the choice of methods. Such flexibility has since become a hallmark of MM research, allowing not only QUAN and QUAL questions to be answered simultaneously in the same study (Greene & Hall, 2010; Teddlie & Tashikkori, 2003) but also allowing access to a broader array of

types of research data than would be possible through a single method design (Creswell et al., 2003).

Likewise, stronger and more diverse findings are possible when MM researchers apply Johnson and Turners' (2003) *fundamental principle of mixed methods research* that states "methods should be mixed in a way that has complementary strengths and nonoverlapping weaknesses" (p. 299). In other words, MM research, unlike monomethods, allows the strategic selection of QUAN and QUAL methods based on their combined strengths and different limitations which in turn generates the aforementioned stronger inferences and more divergent findings (Creswell et al., 2003; Teddlie & Tashikkori, 2003). MM research is thus advocated as a superior way to "get more out of the data" (Onwuegbuzie & Teddlie, 2003, p. 353) and better reveal the complexities of the phenomena under investigation (Creswell et al., 2003; Johnson & Onwuegbuzie, 2004; Johnson & Turner, 2003; Morse, 2003)

3.2.1.2 THE CHALLENGES OF MIXED METHODS RESEARCH

Of course, MM research is not without its challenges. It invariably demands extensive data collection which has time and cost implications (Teddlie & Tashikkori, 2010). There is a need for investigators to be familiar with both QUAN and QUAL forms of research and understand how and why they are being mixed (Creswell, 2009). Moreover, it is a field that continues to evolve with many areas of procedural uncertainty (Teddlie & Tashikkori, 2009) and unresolved issues (Teddlie & Tashikkori, 2010), as will be discussed shortly. It is therefore ultimately incumbent on researchers to weigh up the challenges against the benefits of MM research when selecting a methodology that best meets the needs of their particular investigation.

3.2.1.3 WHY A MIXED METHODS APPROACH WAS CHOSEN

It follows, the benefits of MM outweighed its challenges to become the methodology of choice for the present research and because both QUAN and QUAL approaches were necessary to answer the three questions underpinning its aim. The two precursory questions: how do participants score on health literacy? and what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event? required a QUAN and QUAL approach, respectively. The principal question, as an amalgam of those questions, necessarily required both a QUAN and QUAL focus. Indeed, either approach by itself would have been inadequate in so much as it would have provided data on participants' health literacy but not their experience of navigation (ie. QUAN only) or conversely, their experience of navigation but not their health literacy (ie. QUAL only). Finally, MM research in the present instance made possible the convergence and corroboration, or triangulation, of the QUAN and QUAL data as well as the elaboration, enhancement, illustration and clarification, or complementarity, of the two data sets (Green, Caracelli, & Graham, 1989)

3.2.1.4 THE UNRESOLVED ISSUE OF PARADIGMATIC FOUNDATION

As a formally recognised methodology MM research has a history spanning only the past few decades (Onwuegbuzie et al., 2009). Thus, unlike the two older QUAN and QUAL research traditions, the procedural guidelines for MM research continue to evolve with the synthesis of visual models, a notation system and design specifications evidence of such development (Creswell et al., 2003). Moreover, the evolution of MM research is reflected in the amount of text dedicated to addressing its unresolved issues including, but not limited to, the use of paradigms (Teddle & Tashakkori, 2010). Defined as socially constructed worldviews that are neither inviolate nor immutable (Greene & Caracelli, 2003; Mertens, 2003) the 'paradigm

war' of last century set the stage for the emergence of MM research and the subsequent articulation of a pragmatic worldview that made it permissible to combine QUAN and QUAL methods in the same study. Thus, in rejecting the incompatibility thesis, pragmatists espoused its antithesis: "the compatibility thesis" (Teddlie & Tashikkori, 2009, p. 84). As a philosophy, pragmatism originates largely from the work of Peirce, James and Dewey (Greene & Hall, 2010), all of whom were interested in understanding real-world phenomena in terms of their empirical and practical consequences (Johnson & Onwuegbuzie, 2004). Whilst there are multiple versions of pragmatism (Cresswell, 2009), its characterization in the MM literature focuses attention on the research problem with a subsequent needs-based approach to method selection for the purpose of deriving knowledge about the problem (Teddlie & Tashikkori, 2009). In other words, selecting a combination or mixture of methods (QUAL *and* QUAN) that "works best" (Johnson & Onwuegbuzie, 2004, p. 17) to understand phenomena.

Many advocates of the pragmatist paradigm can be found in the MM literature (Bazeley, 2003; Biesta, 2010; Forthofer, 2003; Howe, 1988; Johnson & Onwuegbuzie, 2004; Maxcy, 2003; Rallis & Rossman, 2003; Teddlie & Tashikkori, 2003). However, it does not receive wholesale acceptance as the paradigm of choice for all MM researchers. For example, Mertens (2003) questions the usefulness of pragmatism, instead preferring the transformative-emancipatory paradigm that focuses on social inequalities experienced by marginalised groups such as women, the poor, ethnic/racial minorities, those with disabilities and members of gay and lesbian communities where the goal of MM research is explicit: creating a more equal and democratic society. In response, Teddlie and Tashikkori (2003) take a 'horses for courses' stand, suggesting either paradigm can be applied to MM research depending on the nature of the investigation. More recently Onwuegbuzie et al. (2009) continued the dialogue regarding MM's paradigmatic foundation by presenting an additional nine paradigms that provide philosophical justification for

conducting MM research, thereby leaving unresolved the issue of a paradigmatic foundation for such inquiry.

3.2.2 THE MIXED METHODS DESIGN

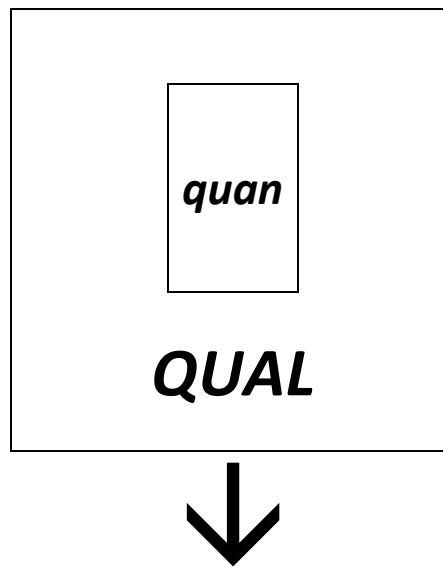
The variants of design for MM research can be overwhelming. In Tashakkori and Teddlie's (2003) handbook alone, 35 such designs are cited. The subsequent challenge of selecting an optimal MM research design has been aided by the typologies developed by scholars in the field (eg. Creswell, 2009; Johnson & Onwuegbuzie, 2004; Leech & Onwuegbuzie, 2009; Tashakkori & Teddlie, 2003). Whilst valued for their provision of foundational design options upon which to consolidate the practice and language of MM research (Teddlie & Tashakkori, 2010), Teddlie and Tashakkori (2009) stress the typologies are infinite because "the actual diversity in mixed methods studies is far greater than any typology can adequately encompass" (Maxwell & Loomis, 2003, p. 244). Not surprisingly, the many typologies that have, with time, come to occupy the literature on MM research reveal overlapping and divergent features together with varying levels of complexity (Leech and Onwuegbuzie, 2009; Teddlie & Tashakkori, 2010). As a tenet of MM research it is therefore recommended the features differentiating the typologies be mindfully selected for their salience to the investigation at hand and subsequently used to guide the final design selection (Creswell, 2009; Creswell et al., 2003; Johnson & Onwuegbuzie, 2004; Teddlie & Tashakkori, 2009, 2010).

The following design features were deemed salient to the present MM research: the number of strands; the timing of those strands; when the data were mixed; and the weighting of methods. Figure 3.1 provides two illustrations (one notational, one visual) of the derivative of those design decisions which has varyingly been described as a concurrent embedded design (Creswell, 2009), a concurrent nested design (Creswell et al., 2003) and a concurrent dominant status design (Leech

Figure 3.1

A notational (a) and visual (b) illustration of the concurrent embedded MM design used in the present research

a) QUAL + quan → Interpretation of data



b) Interpretation of Data

Adapted from a) Morse (2003) b) Creswell (2009)

& Onwuegbuzie, 2009). The notation used in the Figure was developed by Morse (2003) and is widely used in MM research (Creswell et al., 2003; Teddlie & Tashakkori, 2009). The uppercase QUAL represents the dominant aspect of the design whilst the lowercase quan is the less dominant aspect. That is, the QUAN methods are a smaller part of what is primarily a QUAL design. Both the '+' and the boxes indicate the methods are employed concurrently whilst the '→' indicates the direction of the sequential research process.

The strands of a research design encompass all the stages of the study from conceptualisation through to inference (Teddlie & Tashakkori, 2009). The present

design typified a multistrand design because it had both a QUAN strand and a QUAL strand, each being driven by its own question. Respectively, how do participants score on health literacy and what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event? Given the time constraints to do with completing the research the stages of both strands were undertaken at the same time, or concurrently (Creswell, 2009; Johnson & Onwuegbuzie, 2004; Tashakkori & Teddlie, 2003). By design the strands were methodologically independent (Morse, 2003) with the QUAN and QUAL data being mixed only at the inference or interpretation stage in order to answer the question of whether participants' health literacy scores contributed to an understanding of their experiences of navigating the healthcare system to manage their chronic cardiac disease? In practice however, the mixing of methods was more suffuse. For example, the interview schedule incorporated both open and closed-ended questions (more details available at 3.3.5.2.2), or intramethod mixing (Johnson & Turner, 2003) and the identifiers used alongside quotes from participants were alpha-numeric (eg. K2, G5). Likewise, the data were allowed to 'talk to each other' in a semi-iterative manner during the data, or cross tracks, analysis (Greene, 2007; Teddlie & Tashakkori, 2009). More specifically, knowledge gained from the analysis of the QUAN data to do with participants' health literacy informed the analysis of the QUAL data to do with their experiences of healthcare system navigation, evidence of which can be found in the reporting of the QUAL results.

The last feature deemed salient to the present MM design was the weighting of methods, or assigning priority to the QUAN and QUAL strands, as a function of the overall research process (Creswell, 2009). Whilst a number of authors also view that feature to be an important consideration in the design of MM research (Creswell, 2009; Creswell et al., 2003; Morse, 2003), others such as Teddlie and Tashakkori (2009) do not. They argue the priority of methodological approach cannot be determined in advance of the research being conducted and as such can only ever

be an expected or unexpected outcome. Seemingly less arguable is the difficulty of translating the decision to assign one approach priority over the other given it is essentially a subjective interpretation that may differ from one researcher to the next (Creswell et al., 2003). The present research for example, had a QUAL or inductive orientation that dedicated much text to exploring participants' experience of healthcare system navigation. The QUAN data, that had as their focus participants' health literacy, provided different explanations and ideas about those experiences but were interpretable only in relation to the QUAL data. The QUAN data thus served a supplemental, but no less important role in providing a more complete understanding of the navigational phenomenon as opposed to being the basis for statistical inferences (Morse, 2003; Sandelowski, 1995).

3.2.3 THE QUANTITATIVE AND QUALITATIVE STRANDS

Whilst the MM design provides an overall methodology for the present research, Morse (2003) stresses the need to maintain the "methodological congruence" (p. 191) of the strands within that design. That is, the assumptions and components of the selected QUAN and QUAL approaches need to be upheld. In the context of MM research however, the caveat to such adherence appears to be 'as far as practicable'. Regarding sampling for example, the QUAN approach often entails randomisation so that each participant has an equal probability of being selected whereas the QUAL approach tends to be a more purposeful selection of participants who have experience of the phenomena under investigation (Creswell, 2009). According to Teddlie and Tashakkori (2009), sampling for MM research involves a degree of compromise between the two methodologies which they suggest depends on many factors, not least of which is practicality. How the issue of sampling was addressed in the context of the present research is discussed in the proceeding section on methods.

The QUAN strand of the present MM design observed the postpositivist approach to research in so much as it employed a numerical, objective measure of participants' health literacy using a standardised test. Moreover, the collection and descriptive analysis of those data endeavoured to uphold the methodology of such scientific enquiry and is discussed in the proceeding section on methods. The QUAL strand had as its objective to explore and understand participants' experience of navigating a healthcare system. The methodology chosen for that purpose was phenomenology. With a long history in QUAL research (Andrews, Sullivan & Minichiello, 2004), phenomenology is primarily concerned with uncovering the meaning and essence of human experience (Higginbottom, 2004; Walton & Madjar, 1999). It was first described in the early twentieth century by European philosophers, most notably Edmund Husserl, and has since been associated with the work of Heidegger, Gadamer, Arendt, Levinas, Sartre, Merleau-Ponty and Derrida (Moran, 2000). Despite the many schools of phenomenology (eg. transcendental, existential, hermeneutical), they have in common a focus on the subjective reality of human experience (Higginbottom, 2004). Moreover, Walton and Madjar (1999) proclaim its utility in health research given it affords a way of grasping "the ordinary, the unexpected, and the ineffable elements of human experience in health" (p. 1). Yet, phenomenology, as it was originally conceived, was a philosophy not a research methodology (Dowling, 2007). Psychologists such as Amedeo Giorgi and Barbro Giorgi (2008) have since been credited with establishing reliable methods for conducting phenomenological research and in their simplest form were applied in the present context, the details of which can be found in the proceeding section.

3.3 RESEARCH METHODS

3.3.1 ETHICAL CONSIDERATIONS

The present research was approved by the Health and Medical Human Research Ethics Committee (Tasmania) Network (H&M HREC) (Ref. No. H0010893), a partnership between the University of Tasmania and the Department of Health and Human Services of the Tasmanian Government. The research was therefore conducted in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007)³ ensuring, among other things, participant's privacy and confidentiality was respected throughout the research process.

3.3.2 THE PILOT STUDY

Whilst pilot studies have been recommended for informing decisions regarding sampling (Byrne, 2001; Mason, 2004), in the present context a pilot study was undertaken to inform the choice of health literacy measure and suitability of the interview questions. Six enrollees of a local cardiac rehabilitation program (CRP) (more details available at 3.3.3) were recruited to participate in the pilot study which was conducted in February, 2010. They were advised the data they contributed to the study would not be reported and that they would be excluded from the ensuing doctoral research. The specific objectives of the pilot study were to establish the utility of the shortened version of the Rapid Estimate of Adult Literacy in Medicine (REALM-S), a health literacy measure, and the interview questions intended for use in the ensuing research.

³

<http://www.nhmrc.gov.au/publications/synopses/e72syn.htm>

As one of the earliest assessments of health literacy, the REALM is a pioneering achievement for Terry Davis and her co-developers based in the USA. It assesses the pronunciation of common medical and lay words for body parts and illnesses derived from patient education materials used in American primary care clinics (Davis, Crouch, Long et al., 1991). Its underlying premise is that difficulties reading and pronouncing words may foretell problems with comprehension (Brez & Taylor, 1997; Murphy, Davis, Long et al., 1993; McKenna & Dougherty Stahl, 2009) and was thus designed to assist medical professionals to broadly assess their patients' literacy so they could then use an appropriate level of instruction and materials for patient education purposes (Davis et al., 1991). In its original form the REALM comprises 125 words across four columns and in ascending order of difficulty according to the number of syllables they contain. Following three years of field testing, feedback from physicians suggested a shortened version would be more practical in the busy medical setting which gave rise to the 66-item version of the REALM (REALM-S), a copy of which can be found in Appendix 7.

The REALM-S has an administration time of between 1 to 2 minutes (Davis, Long, Jackson et al., 1993) compared to the 3 to 5 minutes of the REALM (Davis et al., 1991). Both use the dictionary pronunciation as the scoring standard and calculate the total number of correctly pronounced words as the raw score which is subsequently converted to a American school grade range estimate of reading ability (Davis et al., 1993). Table 3.1 presents the conversions for the raw scores on the REALM-S, together with their interpretation relevant to a healthcare setting. Psychometric analyses revealed the REALM-S has high correlation with standardised general reading tests such as the SORT (Pearsons correlation $r = 0.96$); the reading recognition component of the PIAT-R (Pearson correlation $r = 0.97$); and the reading component of the WRAT (Pearson correlation $r = 0.88$) as well as a test-retest reliability coefficient of 0.99 (Davis et al., 1993).

Table 3.1.
Conversions and interpretations of the raw scores of the REALM-S

<u>Raw score</u>	<u>Grade range</u>	<u>Interpretation</u>
0 -18	<3 rd grade	May not be able to read most low literacy materials or at all. May need repeated oral instructions, materials composed primarily of illustrations, or audio- or video- tapes.
19 – 44	4 th to 6 th grade	May need low literacy materials. May not be able to read prescription labels.
45 - 60	7 th to 8 th grade	May struggle with most currently available patient education materials.
61 -66	9 th grade and above	Should be able to read most patient education materials.

Adapted from Davis et al. (1993)

The REALM-S was originally chosen for the present research because of its uncomplicated administration (Dani, Stobo, Capell, et al., 2007; Foltz & Sullivan, 1998; McCray, 2005; Mancuso, 2009); it has been well received by patients (Davis, Michiellute, Askov, et al., 1998); it has previously been used in Australian health literacy research (eg. Barber et al., 2009; Buchbinder, Hall, & Youd, 2006); and as the most commonly used health literacy assessment tool (Monachos, 2007) it is regarded by some as the ‘gold standard’ (Bennett, Robbins, Al-Shamali, et al., 2003). That said, the REALM-S was found through the pilot study to be unhelpful in providing a meaningful assessment of participants’ health literacy levels. All six participants were assessed at the 9th grade and above meaning they were likely to be able to read most patient education materials. Yet, invariably participants’ responses to the interview questions exposed a striking contrast between their ability to read health-related words and their ability to understand them. Moreover,

the pilot data suggested numeracy was an aspect of health literacy that needed to be incorporated into its assessment if it was to be meaningful. For example, participants spoke of not understanding dosages on the prescription labels of their medication and being confused by the daily recommended intake amounts pertaining to their dietary requirements. An alternative health literacy measure – the Newest Vital Sign (NVS) – was subsequently chosen to replace the REALM-S and is discussed in more detail in the proceeding section 3.3.5.1.2.

The pilot study was also undertaken to determine the suitability of the interview questions intended for use in the present research. They were positively received by all participants and answered appropriately. However, it emerged the relevance of some questions to the research topic was not always apparent to participants (eg. their level of participation in the self management of their health) and that brief, scripted introductions to the categories of navigation questions would be helpful.

3.3.3 SAMPLING

Given the dominant strand of the present research design was QUAL a purposive, or non-probability sampling technique was employed with the aim of generating information-rich data from a small number of cases (Kemper, Stringfield, & Teddlie, 2003; Llewellyn, Sullivan, & Minichiello, 2004). That was despite MM sampling techniques (eg. basic, parallel, sequential, multilevel and combined) being an option (Teddlie & Tashikkori, 2009). However, such techniques necessarily incorporate a level of probability sampling which was not a feature of the present design because of the supplementary nature of the QUAN strand and because the same sample was used to serve both strands of the research. Thus, sampling in the present instance became a methodological trade-off regarding the extensiveness of the data collection whereby the depth of information generated by participants took

precedence over the breadth of information that would have been possible had a larger, probability sampling technique been utilised. Nevertheless, in keeping with the intent of phenomenological research and the principal question driving the present research, depth of information was paramount to understanding participants' experiences of healthcare system navigation and as such, vindicated the trade-off regarding sample size.

A framework of variables (Marshall, 1996), or sampling frame (Mason, 2004) was conceived to guide the selection of a sample that would best answer the research questions under investigation. Essentially, participants needed to have had experience navigating the healthcare system in Tasmania and have had, or be at risk of, a cardiac event thereby denoting the likelihood of a chronic cardiac condition. Also important was the need for participants to be able to give informed consent regarding their participation. Enrollees of the Cardiac Rehabilitation Program (CRP), organised and conducted by staff of the North West Regional Hospital in Burnie Tasmania, represented a credible and accessible population from which to recruit participants to the present research. The community-based, nine week multidisciplinary program helps enrollees understand and adjust to their cardiac conditions through education, dietary advice, exercise, counseling and support, as recommended by the National Heart Foundation of Australia and the Australian Cardiac Rehabilitation Association. Consultation with the Program Co-ordinator confirmed the suitability of CRP enrollees to be involved in the present research.

It is customary for QUAL sampling techniques to result in data collection that is contingent on its progression and analysis, thus resulting in a continuous, iterative and evolving process (Llewellyn et al., 2004; Sobal, 2001). Moreover, it is a process that generally subscribes to the theory of data saturation in which the addition of more cases fails to generate new information, thereby establishing the extent of the data collection and subsequent sample size (Morse, 2000). In the present instance

however, the extensiveness of the data collection and resultant sample size was established at the outset of the investigation as opposed to being data driven. That is, over a data collection period of six months it was determined a total of eighteen participants would be interviewed and invited to join in one of three focus groups. Guiding the formation of those parameters were recommendations gleaned from the sampling literature pertaining to sample size for QUAL research as well as the practicalities of finite time and resources. The parameters were also congruent with the transcribing, coding and analytical abilities of the researcher. Indeed, the schedule of interviews meant one participant was interviewed each week for a period of six weeks after which a focus group was convened involving those six participants. That pattern was repeated twice more over the six month data collection period and ensured adequate time for transcribing, coding and analysing the data immediately following each interview and focus group. Unexpectedly, data saturation seemed⁴ to be reached before the data collection period had concluded suggesting the extensiveness of the fixed data collection schedule may have been appropriate for generating a thorough account of participants' experiences of healthcare system navigation with regard to the questions they were asked.

3.3.4 RECRUITMENT AND CONSENT PROCESS

It was tantamount to the ethical conduct of the present research that the recruitment of potential participants was undertaken in a way that did not impact their privacy. To that end, potential participants were approached individually on behalf of the researcher by the CPR Co-ordinator who explained the research project and what their participation would involve. Copies of a Participant Information Sheet outlining those details were provided to the Co-ordinator who then gave them to potential participants for their perusal and to reinforce what they had been told

⁴ Sandelowski (1995) cautions against claims of data saturation because they come from data analytical skills acquired only through experience. Given the relative inexperience of the present researcher it is not unreasonable to suppose reference made to data saturation in the present context may be premature.

verbally. The researcher was contacted by the Co-ordinator when a person she had approached expressed interest in participating in the research and willingly provided their name and contact telephone number. The names of those not willing to participate, or not approached by the Co-ordinator to participate, were not available to the researcher. The researcher subsequently made telephone contact with the willing participants to arrange a time and place, at their convenience, to conduct the interview as well as to answer any questions they may have had in relation to the research and/or their participation in it.

The CRP Co-ordinator was provided with a detailed briefing about the research and how it was going to be conducted together with suggestions on how to approach potential participants. Ultimately however, the researcher remained unaware of precisely how the Co-ordinator chose to enact her recruitment role. According to Llewellyn et al. (2004), such is the problem of recruiting through a third party. The authors also raise the associated problem of potential participants' willingness to participate in research being influenced by their relationship with the third party. The vast majority of participants in the present research enjoyed a good relationship with the CRP Co-ordinator which may have influenced their willingness to participate but failed to account for the willingness of at least one participant whose relationship with the Co-ordinator was reportedly not good. Certainly, recruitment did not seem hampered by the third party strategy.

Prior to commencing each interview potential participants were reminded of the details of the research outlined in their copy of the Information Sheet they had retained from when the Co-ordinator had approached them. They were provided with the opportunity to again ask any questions they may have had in relation to the research and then presented with the Participant Statement of Consent Form (Appendix 9). The details on the form were discussed with them after which they were directed to the area on the form requiring them to indicate their intention to

participate by signing the line adjacent to either the 'yes' or 'no' box. The researcher then signed the same form in declaration of having explained the research and the details concerning participation to the signatory whose consent was perceived as informed and understood. Throughout the data collection period the process of consent was uniformly smooth with each participant appearing to comprehend and willingly commit to their part in the research.

3.3.5 DATA COLLECTION AND ANALYSIS

As previously mentioned, the QUAN and QUAL strands of the present MM research design were methodologically independent with mixing only occurring (theoretically at least) at the data inference or interpretation stage. As such, the data collection and analyses processes subscribed to the QUAN and QUAL traditions. Using MM nomenclature those processes are referred to as 'MM data collection' and 'parallel mixed data analysis' respectively (Teddle & Tashakkori, 2009). The following description of the data collection and analyses is logically presented in terms of the QUAN and QUAL strands.

3.3.5.1 THE QUANTITATIVE STRAND

3.3.5.1.1 THE METHODS USED TO COLLECT THE DATA

The QUAN data consisted of participants' demographic details together with a numerical score of their likelihood of having limited health literacy. The demographic data included: age; gender; indigenous status; relational status; living arrangements; residential postcode; country of birth (and years living in Australia if applicable); language spoken at home; highest educational attainment; labour force status; income; and whether participants were privately insured for health

expenses⁵. Collection of those data was through self report in response to direct questioning. Participants' health literacy was determined using a standardised test: the Newest Vital Sign (NVS).

The rationale for assessing health literacy is based on the proposition a person with limited literacy will have different communication and learning needs in the health setting compared to a person who has adequate literacy (Paasche-Orlow & Wolf, 2007). Historically, health literacy was an assessment of a person's reading ability using tests (eg. SORT, WRAT and PIAT) borrowed from the field of education (Murphy et al., 1993). However, those tests were complex and had as their focus the nature and causes of limited reading skills so were neither practical nor relevant to the healthcare setting (Davis et al., 1998). Moreover, years of schooling, self reported reading ability and how a person presents themselves have been found to be inaccurate proxies for health literacy (Buchbinder et al., 2006; Chew, Bradley, & Boyko, 2004; Dani et al., 2007; Davis, Kennen, Gazmararian, et al., 2005; Davis, Mayeaux, Fredrickson, et al., 1994; Foltz & Sullivan, 1998; Jackson, Davis, Bairnsfather, et al., 1991; Pandit, Tang, Bailey, et al., 2009; Shohet, 2004; Williams, Parker, Baker, et al., 1995). Thus, a mandate exists for a specific measure of health literacy and many scholars have risen to that challenge.

No less than nineteen original and derivative measures of health literacy have been developed to date (Jordan, Osborne, & Buchbinder, 2011). They take the form of direct assessment of a person's ability (eg. REALM, Test of Functional Health Literacy in Adults - TOFHLA); self-report of those abilities (eg. eHEALS, SSBQ); and broader, population-based measures (eg. NAAL, ALLS). Yet, a recent online discussion about the measurement of health literacy involving "the largest known international group of health literacy professionals" (Pleasant & McKinney, 2011, p. 95) revealed that despite such endeavour, existing measures are inadequate.

⁵ Participants' medical histories were recorded at the same time as they reported their demographic details but was narrative and thus treated as QUAL, not QUAN, data.

Reasons given for such inadequacy were many and varied but examples included the lack of a theoretical foundation; the use of limited population samples for validation; and incomparability across contexts such as culture and life course. Pertinent to the present research was the criticism leveled at the existing measures of health literacy of focusing solely on the individual at the expense of the healthcare system and the professionals working within it.

The consensus of the online discussion group of health literacy professionals was not altogether novel given the many previous references in the literature to the inadequacy of health literacy measures (eg. Andrulis & Brach, 2007; Barber et al., 2009; Boswell, Canon, Aung et al., 2004; Friedman, Corwin, Dominick et al., 2009; Griffin, Partin, Noorbaloochi et al., 2010; Hanson-Divers, 1997; Hartley & Horne, 2006; Ishikawa & Yano, 2008; Jordan et al., 2011; Marvin Jeppesen, Coyle, & Miser, 2009; Mancuso, 2009; Morris, MacLean, Chew et al., 2006; Nielsen-Bohlman et al., 2004; Nutbeam, 2008, 2009; Pleasant, 2008; Rootman & Ronson, 2005; Rudd, Kirsch, & Yamamoto, 2004; White, 2008). Notably, those references appear well intentioned with the imperative for a more comprehensive health literacy measure implicit in all of them. As the field of health literacy evolves so too, it would seem, will the measures used in its assessment. The existing measures meanwhile continue to be used by researchers as useful estimates of health literacy.

3.3.5.1.2 THE TOOLS USED TO COLLECT THE DATA

Collection of participants' demographic data was by questions incorporated into the interview protocol. Following the pilot study, the NVS became the health literacy assessment tool of choice for the present research because it assesses participants' abilities to use and understand numbers and text, both of which are skills deemed requisite to successfully navigate the healthcare environment (Monachos, 2007; Weiss, Mays, Martz et al., 2005). Goldbeck, Paschal, Jones et al.

(2010) are especially adamant about the inclusion of a numerical component in health literacy assessment tools after finding reading comprehension and numeracy skills, in the context of understanding health information, do not necessarily correlate and must therefore be regarded as integral, but assessed as distinct aspects of health literacy. As well as being freely available from the Internet⁶ the NVS has a short administration time of approximately three minutes which was important in the context of the present research because its use immediately preceded the considerably longer participant interview. Moreover, administration of the NVS did not require participants to complete a paper and pen task which has known inaccuracies associated with low health literacy levels (Al-Tayyib, Rogers, Gribble et al., 2002). The NVS also overcomes the limitations of the REALM (does not assess text comprehension or numeracy) and the TOFHLA (lengthy administration time), two of the more commonly used health literacy measures (Osborn, Paasche-Orlow, Davis et al., 2007). Finally, being based on a nutrition label the NVS had intuitive appeal because it was something participants were likely to have encountered in the on-going management of their cardiac health and would therefore, according to Baker (2006), be more acceptable. Research has since shown the NVS to be positively received by those to whom it was administered (eg. Ciccarelli Shah, West, Bremmeyr, et al., 2010; Ryan, Leguen, Weiss, et al., 2008; VanGeest, Welch, & Weiner, 2010)

Developed by Barry Weiss and his colleagues (Weiss et al., 2005) in America, the NVS is a six item test of a person's ability to read and apply text and numerical information derived from a nutrition label off a container of ice cream (Appendix 10a). It was chosen for its psychometric properties from a short list of five health-related scenarios developed by health literacy experts based on concepts and situations familiar to them. Namely:-

⁶ www.pfizerhealthliteracy.com/physicians-providers/newest-vital-sign.html

1. Instructions from a prescription for headache medicine
2. A consent form for coronary angiography
3. Heart failure self-care instructions
4. A nutrition label from an ice cream container
5. Instructions for asthma medication

Appendix 10b shows answers to each of the six items are either correct or incorrect with the tally of correct answers representing the final score (ie. 0 to 6). The scores are then interpreted as follows:

- 0 to 1 correct answers = a high likelihood of limited health literacy
- 2 to 3 correct answers = the possibility of limited health literacy
- 4 to 6 correct answers = almost always indicates adequate health literacy.

In the context of the present research however, the three score categories were collapsed to just two categories (ie. 0 to 3 and 4 to 6) to make the descriptive interpretation of the data more meaningful given the small sample population from which it was derived (Burns, 2000). The subsequent score interpretations of 'suggests inadequate literacy' (0 to 3) and 'suggests adequate literacy' (4 to 6) made intuitive sense by eliminating the ambiguity of 'the possibility of limited health literacy' without deviating from the intent of the original score interpretations (Saratakos, 1998). Whilst those scoring 2 to 3 were more often able to get the last two prose questions correct compared to those scoring 0 to 1, responses between the two lower-scoring groups were sufficiently similar to warrant collapsing the original categories. Indeed, scores from 0 to 3 seemed to reflect the sensitivity of the NVS in defining "suggests inadequate literacy" as a numeracy or prose issue.

Using the TOFHLA as the reference standard, the NVS was found by Weiss et al. (2005) to have good reliability (Cronbach alpha = 0.76) and criterion validity ($r =$

0.59, $P < .001$), although Mancuso (2009) referred to those psychometrics as acceptable and poor, respectively. The area under the receiver-operating characteristics (AUROC) for predicting TOFHLA scores was 0.88 which was “substantially higher” (Weiss et al., 2005 p. 518) than the 0.72 found for educational level and 0.71 found for age. To that end, Weiss et al. (2005) concluded the NVS could more accurately predict TOFHLA scores than education or age. The AUROC curve for the NVS revealed a score of ≤ 2 had a sensitivity of 72 percent and a specificity of 87 percent whilst for scores ≤ 4 the sensitivity was 100 percent and the specificity was 64 percent. Thus, the NVS was shown to have high sensitivity for detecting people with limited health literacy which was confirmed two years later in a study by Osborn, Weiss, Davis et al. (2007) aimed at extending its psychometric evaluation. That said, Mancuso (2009) cautioned that the high sensitivity of the NVS may result in misclassifying those with adequate health literacy just as its low specificity may result in overestimating those with limited health literacy.

3.3.5.1.3 THE MANNER OF DATA COLLECTION

Questions regarding participants’ demographic details were asked at the conclusion of the interview in accordance with a wording and sequence protocol. The NVS was administered to participants ahead of their interview and introduced as “just some questions in relation to a nutrition label you’d find on the side of a tub of ice cream”. That is was an assessment of health literacy was not specifically mentioned to allay any anxiety participants may have felt in response to an assessment situation. A laminated, A4 version of the nutrition label was given to participants to hold and to which they could refer, as needed, whilst being asked the questions out loud by the researcher. The score sheet was housed in a clipboard folder and marked by the researcher as participants gave their answers. Time was allowed for participants to read the nutrition label and consider their answers, with questions being repeated verbatim on request. The score was not tallied until after

the interview had been completed and the researcher was no longer in the presence of the participants to avoid any discussion of its interpretation and potential impact that knowledge may have had on participants' interview participation. For example, had participants been made aware their NVS score suggested limited health literacy that may have provoked in them feelings of shame which, in turn, may have altered how they responded to the interview questions. Instead, on completion of the NVS participants were simply thanked for their answers and their attention directed toward the ensuing interview.

3.3.5.1.4 THE DATA ANALYSIS

For each participant the total of their correct answers on the NVS was tallied and interpreted as either 'suggests inadequate literacy' (0 to 3 correct answers) or 'suggests adequate literacy' (4 to 6 correct answers). Those data were then summarised in bivariate contingency tables embedded in the following results chapter. The QUAN data pertaining to participants' health literacy were therefore not subject to analysis beyond frequency description for the purpose of answering the question of how participants scored on the NVS. Their demographic data were treated similarly but summarised in a univariate table.

3.3.5.2 THE QUALITATIVE STRAND

3.3.5.2.1 THE METHODS USED TO COLLECT THE DATA

The QUAL data comprised narratives collected through interview and focus group methods as well as documentation (eg. dates of medical events) sourced, with participants' approval, from their paper-based Medical Record. Teddlie and Tashakkori (2009) refer to the latter method as an "unobtrusive measure" (p. 223) of MM research that affords examination of a phenomenon without interfering with or

altering it. Such a method also has the potential to overcome the methodological weaknesses of self report associated with interviews and focus groups in which participants may react in a manner (eg. nervously or with increased anxiety) that compromises the accuracy of their responses (Johnson & Turner, 2003). Combined, the three chosen methods of QUAL data collection represented a triangulated or intermethod mixing strategy whereby each method made a unique contribution towards better understanding participants' experiences of healthcare system navigation than if only a single method had been used (Johnson & Turner, 2003; Morgan, 1997; St John, 2004).

3.3.5.2.2 THE TOOLS USED TO COLLECT THE DATA

The semi-structured interviews followed a wording and sequence protocol and incorporated both open and close ended items (Appendix 11). The categories of items concerning navigation were based on a review and understanding of the literature and thus, a priori. Authors whose work was particularly useful in that regard included: Barber et al., (2009), Bunn, Lange, Urrutia, et al., (2006), Gimpel et al., (2008), Rasmussen et al., (2001), Sobo, Seid, and Gelhard (2006), Vitry, Phillips, and Semple (2008), Wathen and Harris (2007), and Wells et al., (2008). The three items comprising the Set of Brief Screening Questions (SBSQ) (Chew et al., 2004), a health literacy measure, were embedded in the interview schedule (Q1.4.2, Q1.4.3 and Q1.4.4) primarily for their relevance to the research topic as a possible indication of participants' self-reported efficacy with nominated health literacy tasks, not as a measure of health literacy per se. That was because of their inability to predict limited literacy more accurately than a model based on demographic characteristics alone (Daniel, Greene, & Peters, 2010; Ohi, Harris, Nurudtinova, et al., 2010; Paasche-Orlow & Wolf, 2007). For consistency, the format of the SBSQ was replicated in the close ended questions to do with participants' ability to find out information (Q1.4.1), their ability to adhere to their prescribed health and

medication regimens (Q1.4.5), and how often they felt they could access services locally (Q5.3.2). To ensure a complete coverage of participants' navigational experiences they were asked towards the end of the interview for comments on any relevant issues they felt had not been covered by the previous questions (Q6.0). Few participants utilised that opportunity, perhaps suggesting the topic was otherwise well covered by the previous questions.

Adding to the narrative data collected through the individual interviews was that collected through the focus groups. The questions posed to the focus groups (Appendix 12), which comprised the same participants, covered some of the categories of items covered in the interviews. Selection of those categories was based on issues that emerged from the analysis of the interview data. For example, from the first six interviews it became apparent that perception of illness chronicity differed among participants when they responded to questions about their knowledge of the cardiac disease process. Thus, the meaning of chronic illness became a focus group question within the category of 'knowledge about the disease process'. The questions constructed for the first focus group were used in the second and third focus groups to build on those data with the additional questions in the latter two groups coming from the data analysis of interviews 7 to 12 (second focus group) and 13 to 18 (third focus group). Intentionally, the number of questions asked in the focus groups was less than the number asked in the interviews to afford more time for discussion and interaction among participants. In essence then, the focus groups were a structured follow-up to the interviews and served to strengthen the research data in terms of depth and detail.

The documentation sourced from participants' paper-based Medical Records pertained to the quantifiable elements of their self-reports about navigating the healthcare system (eg. diagnoses, dates of consultations, services used). Participants' interview transcripts were highlighted for quantifiable elements which

were then manually cross-checked with their Medical Record. The data collected indicated the elements, when present in participants' Medical Records, were either congruent or not congruent with their self-reports. The Medical Record was taken as a true and accurate record of events.

3.3.5.2.3 THE MANNER OF DATA COLLECTION

Both the interviews and focus groups were recorded on audiotape to enable verbatim transcriptions. Supplementary hand notes were made in an exercise book allocated to each of those sessions. All data were de-identified using randomly assigned letters A to R of the alphabet (ie. the first 18 letters) with the numeral alongside the letter indicating the NVS score of the associated participant. The resulting alpha-numeric de-identifier (eg. A6, K3) had the intended utility of allowing an immediate visual reference to participants' health literacy when reporting the results whilst simultaneously preserving their anonymity. Scripted preambles (Appendix 13) were used to commence the interviews and focus groups. Likewise, scripted sentences (seen in bold on the interview form in Appendix 11) were used in the interviews to introduce participants to the proceeding categories of navigation questions. In both instances the scripts established the relevance of the ensuing questions and data collection process.

The interviews on all but one occasion were conducted in the participant's home at a time of their convenience. Due to a prior commitment, one participant's interview was conducted at his workplace. Information contained in the Participant Information Sheet (Appendix 8) suggested a 1 to 2 hour timeframe for the interviews which was reiterated when arrangements were being made with participants to conduct them. The interviews lasted an average of 53 minutes. The focus groups were conducted in a meeting room of the Rural Clinical School in Burnie, Tasmania. Participants were thus required to travel to the School and were provided with

directions if the location was not known to them. Again, information contained in the Participant Information Sheet (Appendix 8) suggested a 1 to 2 hour timeframe for each group session. They lasted an average of 50 minutes. As a courtesy, refreshments were made available to those able to participate in the groups. Reasons precluding participants (n = 6) from attending one of the focus groups included travel, work and ill health. The review of participants' paper-based Medical Records was conducted within the Patient Information Management Services (PIMS) of the North West Regional Hospital in Burnie, Tasmania. Prior approval was obtained from the Hospital's Chief Executive Officer and a list of the required Medical Records was given to the PIMS Manager a week in advance of arriving to conduct the review. The review took approximately 150 minutes.

3.3.5.2.4 THE DATA ANALYSIS

In keeping with the tradition of phenomenology, the interview and focus group data were subject to a four step process of analysis described by Giorgi and Giorgi (2008). First, each transcript was read in its entirety to gain an overall sense of participants' descriptions of their navigational experiences. Using the QSR data management software NVivo⁷ the second step involved coding the transcript in to "meaning units" (Giorgi & Giorgi, 2008, p. 34), or parts that served to clarify both the explicit and implicit aspects of participants' navigational experiences, as interpreted by the researcher. The third step in the process of data analysis constituted the transformation of those meaning units into themes sensitive to the topic of navigation. The thematic analysis strategies employed to achieve that transformation included searching the meaning units for repetitions as well as similarities and differences (Ryan & Bernard, 2003). Whilst the process of developing themes proved a largely iterative process over the course of the data collection

⁷ <http://www.qrsinternational.com/>

period, they also arose in the a priori context based on an understanding of the relevant literature and research.

The next step in the process of analysis was somewhat of a departure from Giorgi and Giorgi's phenomenological approach and more in keeping with that of MM research. Namely, the creation of an "inter-respondent matrix" (Onwuegbuzie & Teddlie, 2003, p. 356) or Participant X Theme matrix. Developed for the purpose of legitimising MM research, the matrix applies the statistical concept of effect sizes to QUAL data by projecting the frequency of emergent themes within a sample as a percentage or prevalence rate (Onwuegbuzie & Teddlie, 2003). Thus, for each participant a score of 1 is given for a theme if evident in data pertaining to that participant; otherwise, a score of 0 is given. The authors go on to describe the computation of manifest and latent effect sizes based on the resultant matrix. Such computation however, was not a feature of the inter-respondent matrix in the present research because shading, not scores, were used to show that a theme pertained to a participant. The subsequent matrix therefore provided a purely visual rendering of the themes across the participant population to give a sense of their frequency (Appendix 14).

The utility of such a visual rendering of the themes was proven in the context of completing the fourth and final step of Giorgi and Giorgi's data analysis process. Indeed, the matrix provided a user-friendly basis upon which to develop a framework to account for participants' "typically essential" (Giorgi & Giorgi, 2008, p. 46) experiences of healthcare system navigation. Moreover, the alpha-numerical identifiers revealing participants' health literacy further informed the development of that framework. In effect then, the matrix provided a complete representation of the QUAL data and a useful reference point for their analysis.

3.3.6 MEASURES OF THE RESEARCH QUALITY

According to Yardley (2008), establishing the validity and reliability of MM research is problematic because of the incompatibility of the QUAN and QUAL methodologies and subsequent absence of a “common language” (p. 249) defining those measures of quality. For example, ‘validity’ and ‘reliability’ in QUAN research are referred to as ‘trustworthiness’ and ‘credibility’ in QUAL research (Creswell, 2009; Mertens, 2003). The task thus becomes establishing the quality of both the QUAN and QUAL strands of MM research using the respective standards of those traditions and then evaluating the quality of the meta-inferences made on the basis of the integrated data (Johnson & Onwuegbuzie, 2004). Perceiving an “ostensible obstacle” (p. 300) in the need to apply three sets of standards to assess the quality of MM research Teddlie and Tashakkori (2009) developed a framework that essentially integrates those standards using the two broad criterion of design quality and interpretive rigour. That is, the degree to which the most appropriate procedures have been selected and implemented for answering the research questions and the degree to which plausible interpretations have been made from the findings. With relevance to those criteria, several measures of quality were used in the present research.

Foremost among those measures was the use of a research journal to record the selection and implementation of the procedures and to serve as a reference for the write-up of the research. The use of a research journal is also proclaimed for the audit trail it provides in defense of the decisions made regarding the selection and implementation of the procedures (Byrne, 2001; Yardley, 2008; Yin, 2003). The NVS is a standardised assessment of health literacy and as such meets a criterion for quality in QUAN research in so much as it enables replication of findings across different contexts (Yardley, 2008). Measures of quality to do with the dominant QUAL strand included checking the transcripts for obvious mistakes and through

mail-outs, allowing participants the opportunity to do the same. There was a constant comparison of data with the Nvivo codes to check for definition anomalies or “drifts” (Creswell, 2009, p. 190) and other researchers were engaged to cross-check the codes to ensure “intercoder agreement” (Creswell, 2009, p.191) of the data they described.

The triangulation of data sourced from the interviews, focus groups and participants’ Medical Records also added to the quality of the QUAL strand (Creswell, 2009; Yardley, 2008). Similarly and at times, more than one perspective of a theme was presented in the context of rich, thick description, as was negative or discrepant information that countered the themes and demonstrated recognition of the complexities and variations in the data (Creswell, 2009). For example, reference was made to the ‘overwhelming majority’ who experienced few difficulties navigating themselves around the healthcare system but not to the exclusion of two participants whose experiences of navigation ran counter to that sentiment. There was also reflexive analysis of whether the researcher’s bias may have influenced the findings (Creswell, 2009; Yardley, 2008). With a background in health, the researcher was acquainted with the navigational processes involved in healthcare utilisation and conscious of the discrepancies in such knowledge when attempting to understand the experience from the perspective of the participants. Such bias may have influenced the interpretation of participants’ accounts of how easy or hard they found healthcare navigation and was mitigated through peer debriefing. Indeed, throughout the data analysis process others were involved in discussions to do with interpretation of the data which also ensured the research resonated with people other than the researcher (Lupton, 2004).

Whilst the criteria of Teddlie and Tashakkori’s (2009) integrative framework for assessing the quality of MM research apply equally to the QUAN and QUAL strands of any such design, one aspect of interpretive rigour applies only to MM

research. That is, integrative efficacy or the degree to which the inferences from each strand are effectively integrated into a meta-inference (Teddle & Tashakkori, 2009). The design of the present research demonstrates such integration by embedding the QUAN data (ie. participants' health literacy scores) with the QUAL data (ie. participants' experiences of healthcare system navigation) throughout the reporting process. Moreover, such integration culminates in the meta-inferences of the discussion and conclusion chapters on whether participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their chronic cardiac disease.

3.3.7 LIMITATIONS OF THE RESEARCH

The generalisability of the inferences drawn from the findings of the present research is limited by the small population sample which had more males than females and was recruited from a single setting. The sample was also self-selected which may reflect a selection bias in so much as people who volunteer to participate in research generally exhibit a greater interest in their healthcare activities than those who do not volunteer (Evangelista, Doering, Dracup, et al., 2003) and may misrepresent outcomes for the wider population (Woolf, Rothemich, Johnson, et al., 2000). Furthermore, the NVS was read to participants and whilst such presentation is often recommended as a non-print strategy for people with low literacy a potential drawback is in the association between low literacy and auditory information processing and verbal memory (Hill-Briggs & Smith, 2008). The NVS questions were thus repeated when necessary to help ameliorate that problem. Similarly, the research had a retrospective focus that relied on participants' memories of past events and as such may have compromised accuracy (McEntree, Cuoma, & Dennison, 2009). That said, the congruity between participants' self-reports and data found in their Medical Records was high and for that reason it is not expected the retrospective focus introduced an additional bias to the data

collection. Finally, a vulnerability more so than a limitation of the present research findings is that they are largely subjective (Giorgi & Giorgi, 2008). To that end, the processes leading to their production have been made transparent and whilst no guarantee, offer the critical observer a basis upon which to judge their merit.

3.4 SUMMARY

This chapter reported the methodology and methods underpinning the present research. With use of both QUAN and QUAL methods, a MM methodology was chosen. More specifically, a concurrent embedded design which accounted for the dominance of the QUAL strand and supplementary function of the QUAN strand. The importance of the pilot study to the design of the present research could not be overstated given it informed the choice of health literacy measure and confirmed the suitability of the interview questions. Coverage of the remaining design features revealed how decisions were made and implemented to uphold the quality of the research despite some inevitable limitations. The proceeding chapter will discuss the data that emerged as a direct consequence of that process.

CHAPTER 4 – RESULTS

4.1 OVERVIEW

This chapter presents and discusses the raw data. It begins with the quantitative (QUAN) data that, beyond obtaining participants' demographic information, sought to address the question: how do participants score on health literacy? The qualitative (QUAL) data that follows sought to address the question: what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event? Those data are presented in sub-sections corresponding firstly to the review of participants' Medical Records and secondly, to the themes that emerged from the QUAL data analyses which encapsulate participants' experiences of healthcare system navigation, or more specifically, the factors impacting those experiences. Scant comment is made on participants' health literacy relative to each theme given it is the focus of the proceeding discussion chapter of the thesis which addresses the question: do participants' health literacy scores contribute to an understanding of their experience of navigating a healthcare system to manage their chronic cardiac disease? Some QUAN data are subject to discussion in the context of relevant literature for the purpose of elaboration and/or explanation and because it was logical to include the references in conjunction with the raw data rather than in the proceeding discussion chapter given its aforementioned focus.

4.2 THE QUANTITATIVE DATA

The QUAN data was generated from the 18 interviews and covers participants' demographic details as well as their assessed health literacy in response to the question: how do participants' score on health literacy?

4.2.1 DEMOGRAPHICS

Demographic characteristics of the participants ($N=18$) are presented in Table 4.1. Those data show the mean age was 67.3 years (SD 10.0), accounting for a range in age from 45 to 83 years where the females were, on average, older than the males (Table 4.2). The majority of participants were male ($n=12$); not native to, but born in, Australia ($n=16$); spoke English as their first language ($n=18$); had undergone stenting⁸ ($n=10$); derived an income from a government funded pension ($n=13$); had left school at or before year 10 ($n=16$); were retired from the labour force ($n=12$); were married ($n=12$); lived with their partner ($n=13$); and did not have private health insurance ($n=15$).

The demographic data of the majority of participants were largely consistent with current data generated by the Australian Bureau of Statistics (ABS) on comparable population-based measures (ABS, 2007a, 2007b, 2009b, 2009c, 2010a). The single inconsistency between the present demographic dataset and those of the ABS concerned gender ratio. The majority of participants were male whereas the majority of Tasmanians are female (ABS, 2010a). Moreover, after adjusting for age, national estimates of cardiac disease are slightly higher among females than males (AIHW, 2011). Whilst it is difficult to attribute causality for the latter anomaly based on the present data and small sample size, one plausible explanation may be the lower participation rates in cardiac rehabilitation among women found in a number of studies reviewed by Daly, Sindone, Thompson, et al., 2002.

Geographically, the participants were spread across the North West Coast of Tasmania from Ulverstone through to Smithton (Appendix 15). The most recent

⁸ Describes a process whereby an expandable metal – the stent – is inserted into a narrowed or blocked coronary artery to keep it open thereby improving or restoring blood flow to the heart muscle.

Table 4.1
Participants' characteristics (N=18)

	<i>N</i>	(%)
Age, mean (<i>SD</i>)	67.3	(10.0)
Gender		
Female	6	(33.3)
Male	12	(66.7)
Aboriginal/Torres Strait Islander	0	(0)
COB		
Australia	16	(88.9)
UK	2	(11.1)
Language		
English	18	(100)
Diagnosis		
Angina	2	(11.1)
Angina with stenting	3	(16.7)
Heart attack with stenting	7	(38.9)
Pacemaker	1	(5.6)
Bypass	5	(27.8)
Income		
Aged Pension	10	(55.6)
Disability Pension	3	(16.7)
Employment	3	(16.7)
Self-Funded Pension	2	(11.1)
Highest Educational Attainment		
Year 10 or below	16	(88.9)
Tertiary	2	(11.1)
Labour Force Status		
Retired	12	(66.7)
Not working/Disability Pension	3	(16.7)
Working	3	(16.7)
Relational Status		
Married	12	(66.7)
Divorced	2	(11.1)
Defacto	1	(5.6)
Widowed	3	(16.7)
Living Arrangements		
With Partner	13	(72.2)
With Relation	1	(5.6)
Alone	4	(22.2)
Private Health Insurance		
Yes	3	(16.7)
No	15	(83.3)
Residential Postal Area		
Ulverstone	3	(16.7)
Penguin	4	(22.2)
Burnie	4	(22.2)
Boat Harbour	1	(5.6)
Somerset	3	(16.7)
Wynyard	2	(11.1)
Smithton	1	(5.6)

Socio-Economic Indexes for Areas (SEIFA) released by the ABS show the areas in which participants lived were in the lower deciles (Appendix 16), meaning they were in the bottom percentages of the Australian population for measures of relative socio-economic disadvantage, including income and education (ABS, 2008). That is important in so much as evidence suggests a person's health can be influenced by the socioeconomic characteristics of the neighbourhood in which he or she lives. (Gerber, Weston, Killian, et al., 2008; Luo, Wilkins, & Kramer, 2006; Savage, Bailey, Wellman, et al., 2005).

Table 4.2
Participants' age correlated with their gender

	Age (Mean)		Total No. (Mean)
	Under 65	65+	
Male	5 (57.4)	7 (72.4)	12 (66.2)
Female	2 (58.0)	4 (74.0)	6 (68.7)
TOTAL	7 (57.6)	11 (73.5)	18 (67.3)

Also noteworthy was that participants were all from regional areas, as defined by the Remoteness Structure of the Australian Standard Geographical Classification (ASGC) (ABS, 2006)⁹. Whilst recognized as not always corresponding with everyday perceptions (AIHW, 2010b), the Remoteness Structure of the ASGC – *Major cities, Inner regional, Outer regional, Remote and Very remote* – provides a basis for comparison of differentials, such as health, across geographic areas. It is based on the calculated road distances to the nearest service centres and is represented by a value range on the Accessibility/Remoteness Index of Australia

⁹ Whilst the ASGC was superseded by a new statistical geography, the Australian Statistical Geography Standard (ASGS), in July 2011 to address some of its shortcomings, the Remoteness Structure of the ASGC continued as part of the ASGS.
(www.abs.gov.au/websitedbs/D3310114.nsf/home/Frequently+Asked+Questions Accessed 23/7/11)

(ARIA+). Major cities for example, have a value range of 0 to 0.2 whilst regional areas have a range between 0.2 and 5.92 and remote areas a range between 5.92 and 10.93 thus showing the ARIA+ value increases with remoteness. However, analysis of Tasmanian-based research data in terms of the ASGC is not possible because the majority of the state is classified as regional and therefore lacks truly contrasting populations. The classification does nevertheless provide a broad statistical geography¹⁰ in which to contextualise Tasmanian-based research data such as in the present instance.

The two participants born in the United Kingdom (UK) had lived in Australia for forty years or more and so whilst it is acknowledged culture provides a contextual backdrop to interpret health-seeking behaviours (Davidson, Macdonald, Moser, et al., 2007), the data revealed no discernable variation in their navigation of the healthcare system to that of participants born in Australia. Assuming there may have been navigational differences attributable to UK culture in the first instance, it could be said both participants had adapted, or become 'accultured' to the Australian healthcare system (Sobo et al., 2006; Thomson & Hoffman-Goetz, 2009; Yeo, 2009).

4.2.2 HEALTH LITERACY

Health literacy was measured using the Newest Vital Sign (NVS) tool to address the question: how do participants score on health literacy? The majority of participants ($n=14$) had NVS scores suggesting limited literacy (scores of 0 to 3) whilst the remaining participants ($n=4$) had NVS scores suggesting adequate literacy (scores of 4 to 6). Those data were consistent with the high percentage (63 percent) of Tasmanians found to have low health literacy in the Australian ALLS (ABS, 2007a).

¹⁰ Defined by the ABS as a hierarchically structured classification with a number of spatial units to satisfy different statistical purposes. (www.abs.gov.au/ausstats/abs@.nsf/mf/1217.0.55.001 Accessed 23/7/11)

Moreover, the mean age, low income and poor educational attainment of the majority group of participants were among the demographic markers of low health literacy found through previous research (Crane Cutilli, 2007; Olives, Patel, Patel, et al., 2010; Paasche-Orlow et al., 2005; von Wagner, Knight, Steptoe, et al., 2007; Zahnd, Scaife, & Francis, 2009; Walker, Pepa, & Gerard, 2010).

Participants' responses to the SBSQ were tabulated with their NVS scores and are shown in Table 4.3.

Table 4.3
Participants' NVS scores correlated with their responses to the SBSQ^a

SBSQ Items	NVS Scores ^b		Total No. (%)
	0 to 3 (%)	4 to 6 (%)	
<u>Filling out forms^c</u>			
Confident	6 (42.9)	4 (100.0)	10 (55.6)
Not confident	8 (57.1)	0 (0.0)	8 (44.4)
TOTAL	14 (100.0)	4 (100.0)	18 (100.0)
<u>Reading hospital materials^d</u>			
No help	7 (50.0)	2 (50.0)	9 (50.0)
Need help	7 (50.0)	2 (50.0)	9 (50.0)
TOTAL	14 (100.0)	4 (100.0)	18 (100.0)
<u>Understanding written information^e</u>			
Few problems	3 (27.3)	4 (100.0)	7 (38.9)
Problems	11 (72.7)	0 (0.00)	11 (61.1)
TOTAL	14 (100.0)	4 (100.0)	18 (100.0)

^a As discussed in the design chapter of the thesis, the three score categories of the NVS were collapsed to just two categories (ie. 0 to 3 and 4 to 6) to make the descriptive interpretation of the data more meaningful given the small sample population from which it was derived (Burns, 2000). Moreover, the subsequent score interpretations of 'suggests inadequate literacy' (0 to 3) and 'suggests adequate literacy' (4 to 6) made intuitive sense without deviating from the intent of the original score interpretations (Saratakos, 1998). For the same reasons, the SBSQ responses were condensed and re-titled to represent those indicative of inadequate literacy (ie. not confident, need help and have problems) and adequate literacy (ie. confident, do not need help and have few problems) in relation to selected health literacy tasks.

^b 0 to 3: suggests limited literacy, 4 to 6: suggests adequate literacy

^c How confident are you filling out medical forms?

^d How often do you have someone help you read hospital materials?

^e How often do you have problems learning about your medical condition because of difficulty understanding written information?

When correlated, the NVS and SBSQ data revealed that among the participants with limited health literacy, more ($n=11$) had problems learning about their medical condition than they did filling out medical forms ($n=8$) and reading hospital materials ($n=7$). It could be argued that when filling out forms and reading hospital materials help from other people is commonly at hand and easily administered. In contrast, the act of learning about one's medical condition relies, in part, on individual cognitive ability, or 'health learning capacity' (Wolf et al., 2009), measures of which have been shown to correlate with those of health literacy (Federman, Sano, Wolf, et al., 2009; Levinthal, Morrow, Tu, et al., 2008; Morrow, Clark, Tu, et al., 2006). Thus, poor cognitive ability correlates with poor health literacy and may go some way towards explaining the NVS and SBSQ data, especially when coupled with evidence linking cognitive impairment to cardiac disease (Bennett & Sauve, 2003; Sloan & Pressler, 2009).

Wilson, Wolf, Curtis, et al (2010) and Waldrop-Valverde, Jones, Gould, et al., (2010) have suggested an appreciation of such correlations would inform future healthcare interventions designed to mitigate the implications of low health literacy. That is, it would focus attention on the cognitive demands (eg. working and long term memory requirements) of accessing, understanding and applying health information and not just the simplification of health information in an effort to improve its readability. Motivation to re-focus attention in that way can be found in evidence derived from the work of cognitive epidemiologists who have established a positive association between cognition and health outcomes (Deary & Der, 2005; Deary, Gale, Stewart, et al., 2009; Gottfredson & Deary, 2004; Pavlik, de Moraes, Szklo, et al., 2003; Singh-Manoux, Ferrie, Lynch, et al., 2005). Moreover, "this growing body of empirical evidence has demonstrated likely common causal pathways with health literacy research" (Wolf et al., 2009, p. S278).

That said, the strategy of simplifying written health information is not without merit (Liu, Kemper & Bovaird, 2009; Stableford & Mettger, 2007; Wallace, Seligman, Davis, et al., 2009) and especially given the many published instances of such material being beyond the readability of most people when it comes to navigating the healthcare system (Ache & Wallace, 2009; Baker & Gollop, 2004; Hills-Briggs & Smith, 2008; Murray et al., 2009; Nair & Cienkowski, 2010; Nielsen-Bohlman et al., 2004; Silver Wallace & Lennon, 2004; Smith, Wade, & Frew, 2008; Spandorfer, Karras, Hughes, et al., 1995; Weiss & Smith-Simone, 2010). Data from the present research would attest to that given the number of participants with adequate health literacy who reported needing assistance to read hospital materials was equal to that of participants with adequate health literacy who reported not needing assistance.

A complete table of participants' demographic characteristics correlated with their NVS scores can be viewed in Appendix 17. Age, ethnicity, education and income were previously mentioned as demographic markers associated with health literacy (see Literature Review) with data from the Australian Adult Literacy and Lifeskills Survey (ALLS) affirming those associations. The present dataset was similarly affirming with increased age; being born in a country other than Australia; leaving school at or before grade 10; and deriving an income from a government funded pension prevailing attributes of participants with limited health literacy compared to those with adequate health literacy. Participants' age and gender were correlated with their NVS scores in more detail and are presented in Table 4.4. The data show participants with scores suggesting adequate literacy were all male ($n=4$) and predominantly under 65 years of age ($n=3$). Those with scores suggesting limited literacy were mostly 65 years of age or older ($n=9$). All female participants ($n=6$) had scores suggesting inadequate literacy.

Table 4.4
Participants' NVS scores correlated with their age and gender

	NVS Scores ^a		Total No. (%)
	0 to 3 (%)	4 to 6 (%)	
<u>Age</u>			
Under 65	5 (35.7)	3 (75.0)	8 (44.4)
65+	9 (64.3)	1 (25.0)	10 (55.6)
TOTAL	14 (100.0)	4 (100.0)	18 (100.0)
<u>Gender</u>			
Male	8 (57.1)	4 (100.0)	12 (67.7)
Female	6 (42.9)	0 (0.0)	6 (33.3)
TOTAL	14 (100.0)	4 (100.0)	18 (100.0)

^a 0 to 3: suggests limited literacy, 4 to 6: suggests adequate literacy

Whilst the phrase 'NVS scores suggesting adequate/limited health literacy' is an accurate interpretation of the NVS scores, it is acknowledged the reader may tire of its ongoing use and be better served by an abbreviated reference. Thus, for the remainder of the thesis the following will apply:

NVS score suggesting adequate health literacy will become **adequate health literacy**
NVS score suggesting limited health literacy will become **limited health literacy**

4.3 THE QUALITATIVE DATA

Analysis of the QUAL data from the 18 interviews and 3 focus groups generated several themes encapsulating participants' experiences of healthcare system navigation, or more specifically, the factors impacting those experiences. The quantifiable elements of those navigational experiences (eg. diagnoses, dates of consultations, services used) were confirmed through a manual review of participants' paper-based Medical Records. Collectively, the QUAL data sought to

address the question: what is the experience of navigating a healthcare system like for people who have had, or are at risk of, a cardiac event? Whilst a number of factors were said to impact that experience, gender was clearly not one of them. Indeed, all participants reported in short that their gender had indiscernible impact on their experiences of navigation and thus, as a topic, made no contribution to the ensuing analysis. That was an unexpected finding given gender issues in healthcare appear well documented (eg. Bertakis, 2009; Calvert, Shankar, McManus, et al., 2009; Costello and Boblin, 2004; Johansson, Hamberg, Lindgren, et al., 1996; Sandhu, Adams, Singleton, et al., 2009; Wunderlich, Cooper, Devine, et al., 2010).

To better articulate the themes, or factors impacting participants' experiences of healthcare system navigation, each was grouped into one of three levels at which their impact was considered most apparent: the individual level, the service level and the system level (Table 4.5). That is not to say however, the themes were mutually exclusive in terms of content and level of impact. Rather, they were interrelated. For example, the 'interactions' theme could have been grouped to any one of the three levels of impact. That it was eventually grouped to the service level was because it was at that level interactions were analysed to have had the most impact on the navigational experiences reported by participants. Indeed, the analysis does not intend to imply an absolute difference between the themes. Appendix 18 shows which particular questions and their associated responses from the interview and focus group protocols informed each of the themes and again, highlights the interrelatedness of the thematic content.

4.3.1 MEDICAL RECORD REVIEW

With participants' written consent their paper-based Medical Records stored at the North West Regional Hospital in Burnie were manually reviewed. The purpose

of the review was to establish the congruity between the quantifiable elements of participants' self-reports about their navigation of the healthcare system

Table 4.5
Factors impacting participants' experiences of healthcare system navigation

.....at the <u>INDIVIDUAL LEVEL</u>		Description
• Experience	-	learning that has resulted from encounters with the healthcare system
• Knowledge	-	understanding of cardiovascular disease
• Motivation	-	drive to participate in self-management
• Health Literacy Self-Efficacy	-	self-perceived effectiveness of one's health literacy abilities
• Mindset	-	viewpoints regarding navigation decisions
• Disposition	-	"habitual ways of acting" ^a
• Navigational Skill Set	-	skills identified by focus group participants as requisite for navigating the healthcare system
.....at the <u>SERVICE LEVEL</u>		
• Guidance	-	advice to do with navigation and self management choices
• Support	-	assistance from others to look after own health
• Interactions	-	interpersonal considerations (eg. communication style)
.....at the <u>SYSTEM LEVEL</u>		
• Emergency Department Care	-	care through the Emergency Department of a hospital as opposed to a General Practice Clinic for example
• Accessibility	-	access to services
• Quality of Care	-	the quality of service delivery

^a (Facione, 2000, p.63).

(eg. diagnoses, dates of consultations, services used) and what was documented in their Medical Record, the latter being a true and accurate record of a person's medical history. Invariably, the two were found to be consistent where the detail existed in the Medical Record. A number of the Records were missing documentation that pertained to some of the quantifiable elements in participants'

self-reports. For example, reports from consultations participants attended that were outside the North West region, referral letters and discharge reports.

The incomplete compilation of information contained in participants' Medical Records corroborated with their reports of inter-professional communication breakdowns reliant on timely and accurate paperwork (See 4.3.3.3 & 4.3.4.3). The ramifications have been shown to not only impact continuity of care (Cummins, Smith, and Inui, 1980; Gandhi, Sittig, Franklin, et al., 2000; McEntee et al., 2009; Mead, Adres, Ramos, et al., 2010; Savage et al., 2005) but also navigation of the healthcare system (Sofaer, 2009). For example, Rasmussen et al. (2001) found poor information exchange between patients and health professionals resulted in delayed treatment decisions and the need for medical tests to be repeated. Certainly, the experiences of participants in the present research support those findings as well as highlight the sheer frustration of not having medical information at hand when required, not only from their perspective as patients, but also allegedly from the perspective of their healthcare providers.

4.3.2 IMPACTS ON NAVIGATION AT THE INDIVIDUAL LEVEL

4.3.2.1 EXPERIENCE

This theme covers learning that had resulted from participants' encounters with the healthcare system and the impact that had on their navigation. In the context of the present research, learning denotes the acquisition of knowledge and/or skills. Following is an overview of the data pertaining to experience.

For many and varied reasons (eg. comorbidity, caring for family members, common ailments), all participants reported encounters with the healthcare system in Tasmania prior to their cardiac event or onset of their cardiac condition. They were not, therefore, entering the system completing naïve of its processes when

seeking cardiac treatment. Moreover, a third of participants ($n=6$) had had their first of such treatment twelve months or more prior to being interviewed and several times in the interim, so it was of little surprise that collectively, participants reported learning based on those encounters which were either explicitly or implicitly said to impact how they navigated the healthcare system.

Principle among those lessons and perhaps somewhat ironically, was that it was a system that did not need navigating when it came to intervention for cardiac disease. According to several participants with varying literacy proficiencies, the level of guidance provided by the relevant health personnel and services throughout the system left them in no doubt about where they should go and who they should see regarding their cardiac conditions. For example, one participant spoke to that effect about the Cardiac Rehabilitation Program:

...the best thing I did was join the Cardiac Rehabilitation Program because...we're exposed to health professionals from...the local hospital and so...if we need help we know where to go. (J6)

whilst another participant spoke in more general terms on the same topic:

...everything is just kind of done for me. (B2)

Yet it was apparent in discussions with some participants, all of whom had limited health literacy, that despite such clarity of direction, their understanding of *why* they were following a particular course of intervention was far less apparent. For instance, when questioned about why they were on a particular medication (eg. Aspirin¹¹) they struggled to answer:

¹¹ An over-the-counter medication (acetylsalicylic acid) primarily taken for the relief of pain and to reduce inflammation and fever. A small, daily dose is prescribed indefinitely to people with CVD as part of an overall medication regimen because it has been found to have beneficial effects on cardiac functioning (National Heart Foundation of Australia & the Cardiac Society of Australia and New Zealand, 2006).

Why do I need the Aspirin? Well, I've been on Aspirin since 1988. I can't understand it. (F3)

A lack of understanding of treatment protocols did not seem to pose a barrier to navigating the healthcare system with the data suggesting encounters with the healthcare system had taught those participants to follow the navigational guidance without questioning, or perhaps feeling the need to question, its logic:

I've just gone with the flow. (K2)

For that group navigation was a passive endeavour, noted to be lacking any expressed or implied sense of control. Such passivity may also have evolved from feeling unable to question the logic behind the navigational guidance, especially given the limited health literacy of the participants concerned. Illustrating that point are comments made by one participant for whom navigation of the healthcare system remained an enigma, despite being a frequent user of its services. He reasoned:

...they [the healthcare providers] know me and they know what's going on so it [navigation] is not a problem. (M3)

In further qualification of that remark he expressed his approach to navigating the healthcare system based on what he had learnt from past encounters:

...you're just relying on where the doctors send you...they really choose the path where you go because it's in their hands...I think you've got to accept it because I don't think you've got the knowledge to...override it, you don't know whether it's right or wrong. (M3)

Participants with adequate health literacy also reported appreciating the navigational guidance that exists for people needing intervention for CVD in

Tasmania. However, in contrast to participants with limited health literacy, their depth of understanding of why they were following a particular course of intervention seemed greater and was evidenced by the detail, accuracy and noted confidence with which they spoke on the topic. Moreover, they had access to a broader medical vocabulary and better awareness of the roles of the various healthcare professionals they had encountered. Navigation for this group seemed more active. For example, one such participant had learnt from previous encounters with the healthcare system to book medical appointments early in the day to minimise delays, describing such practice as:

...know[ing] your way around the system. (J6)

Another had registered with a telephone company to guarantee telephone assistance should his landline fail in an emergency, having learnt how vital the telephone was at the time of his heart attack.

That is not to say it was only ever the participants with adequate health literacy who demonstrated active navigation. Indeed, there were similar examples among other participants with limited health literacy where experiential learning contributed to their approach to navigation. These included keeping a list of medications on hand so their names were not forgotten when discussing them with doctors and being prepared to:

...open your mouth [because if] you sit back and just say nothing you don't get nowhere. (D1)

Significantly, what was implicit in all instances of active navigation was participants' ability to reflect on and use the learning that had arisen from their encounters with the healthcare system to increase the efficiency and effectiveness of their passage through it. They presented as engaged in the process of learning from their

healthcare experiences which appeared in turn, to afford them a sense of navigational control, of not simply 'going with the flow'.

Yet it would be misleading to present an altruistic image of engaged healthcare consumers whose learning from past encounters was solely for the betterment of their future navigation. Not all learning it would seem had that motive or outcome, particularly in circumstances where past encounters were perceived as negative. For example, one participant described several negative encounters with General Practitioners (GP) whom she had since learnt not to trust and which, she claimed, lead to her reluctance to use GP services:

...if I had something wrong today I'd be looking to stay home and fix it myself than go to a GP. (I0)

Similarly, a negative encounter had led another participant to become "disillusioned" with the healthcare system which she felt had taught her to:

...rely more on myself than...on the system. (H2)

A third participant reported a negative encounter with a hospital he since vowed never to return to despite it being the closest such facility to his home. Notably, the impact of those negative experiences had caused all three participants to navigate away from the healthcare system which could not be understood as being for 'the betterment of their future navigation', if not their health.

Whilst the three participants with negative past encounters exercised navigational control, one questions the learning that generated their expressed desire to stay away from sources of care, particularly in light of their heart conditions. That all three participants had limited health literacy may be a consideration in so much as their understanding of health information, for example,

may have been a mitigating factor in each of the negative encounters. However, based on the available data, health literacy is likely too simplistic an explanation to appropriately account for such action.

4.3.2.2 KNOWLEDGE

This theme covers participants' understanding of their cardiac event(s) and/or condition in terms of pathophysiology, symptoms, risk factors and intervention. An overview of the data pertaining to participants' self-reported knowledge (from what they knew through to how they came to know) is proceeded by a discussion on how knowledge was understood to impact their navigation and self-management, the latter being integral to the former in so much as it influences when, how and why people navigate the healthcare system.

All bar two of the participants had undergone surgical intervention for blocked cardiac arteries with the majority of participants having experienced, to varying degrees, the 'classic' symptoms of severe chest pain radiating down the arm coupled with shortness of breath. Other reported symptoms included jaw 'locking' and wrist pain. Only one participant with limited health literacy reported recognising the cause of the symptoms in the first instance, having witnessed a heart attack in the workplace. The remaining participants attributed their symptoms, at least initially, to indigestion; working too hard physically; and/or old age despite three feeling within themselves that something was not right with their health. Seven participants reported a family history of cardiac conditions. Not surprisingly, where the symptoms culminated in an event (eg. heart attack) participants were all said to be shocked when told their diagnosis. The majority of participants ($n=13$) did not regard their conditions as chronic, reporting they were either 'fixed' or not sufficiently sick to warrant such a label.

That said, participants wanted to be more knowledgeable about their cardiac condition in order to better manage their health. However, the acquisition of knowledge for some, most notably those with limited health literacy, was perceived as difficult, if not undesirable. One participant for example, spoke of the pressure she felt to learn about her condition:

*It's bad enough putting up with the fact that you've got the problem without having to pressure yourself to understand it all.
(H2)*

She went on to report significant knowledge gaps about her cardiac condition:

I can't know where I stand. Do I have a problem? Do I live life normally or do I have to be careful...am I going to have the problem again?...is this long term? (H2)

Another described getting “lost in the text” (I0) of written health information and subsequently did not read it. For two other participants, knowledge was not always regarded as beneficial but rather, a source of anxiety:

When I had the last stent...before I went in...the doctors...said look you realise you could have a stroke or a heart attack...and that worried me, I'd have sooner not heard that. (K2)

*I think I'm better off not knowing [why my artery is blocked]...I don't want to worry about it, I just want to get on with my life.
(B2)*

Participants were asked a set-answer question about their ability to find out information to help them look after their health (Table 4.6). The data showed all participants with adequate health literacy ($n=4$) were mostly confident in their ability to find out health information to help them look after their health, as were the majority of participants with limited health literacy ($n=9$).

Table 4.6

Participants' confidence in their ability to find out health information correlated with their NVS scores

	NVS Scores ^a		Total No. (%)
	0 to 3 (%)	4 to 6 (%)	
<u>Find information^b</u>			
Mostly confident	9 (64.3)	4 (100.0)	13 (72.2)
Not so confident	5 (35.7)	0 (0.0)	5 (27.8)
TOTAL	14 (100.0)	4 (100.0)	18 (100.0)

^a 0 to 3: suggests limited literacy, 4 to 6: suggests adequate literacy

^b How confident do you feel about your ability to find out health information to help you look after your health?

Comments made in addition to the set answers revealed those who did not feel confident in their ability to find out information (all of whom had limited health literacy) were more amenable to finding out health information from people than written text because it afforded the opportunity to ask questions:

If you're just getting it in written information the questions you want to ask you got nobody to ask anything...whereas if you can ask somebody...they can explain it in a different way that you can understand it. (M3).

For three participants with limited health literacy, finding out information was portrayed as habitual:

You're striving for information aren't you whether it be for better or for worse, you always want someone to confirm your thinking. (Q0).

Others recognised the need to ask questions but did not think to ask at opportune times (eg. in a doctor consultation) or felt reluctant to occupy the time of healthcare professionals on account of not feeling their needs were important:

I feel like I'm only asking...a petty little thing and why waste their time when they've got more important things to take care of...I'm only one of the numbers. (H2)

Still two more were at pains to point out that they were not “unintelligent” (O6) or “illiterate” (F3) when questioned about their ability to find out information.

In terms of sourcing information, all participants indicated they prefer to get their health information in-person from healthcare professionals, be it one-on-one or in a group setting such as the CRP, because of their expert knowledge. Where television was mentioned as a source of health information ($n=4$) it was by participants with limited health literacy. An equal number of participants ($n=4$) used the Internet to source health information, had the Internet connected but did not use it or did not have the Internet connected in their home environment. The majority of participants using the Internet for health information had limited health literacy. The sheer quantity of literature handed out through the CRP was an issue for two participants with limited health literacy. One reference was made to the accumulation of knowledge over time and with experience, another (from a different participant) to the experience of having difficulty understanding written health information but no such difficulty with the same format in the non-health work environment. In all instances, the difficulty with written health information was reportedly the language, or jargon used.

By far the majority of participants, with varying literacy proficiencies, deemed information to be correct if it was coming from a ‘reliable’ source. For one this meant from the field of science:

There are a lot of things that come out...say[ing] this is good for you and this is bad for you...and unless there's a qualified medical background to it and support for it I don't take any notice of it. (G5)

For another it meant aggregating information from a number of reliable sources in order to “qualify it” (Q0). A reliable source was also seen to be a person within whom one had faith and a belief that “they are conveying accurate information to you to benefit you in the long run” (E0). In all such instances that person was described as a medical professional. One participant however, felt it was more to do with personal attributes than qualifications:

Occasionally somebody will rub me the wrong way and I’ll take whatever they have to say with a grain of salt. (A6)

In contrast to the notion that information coming from a reliable source would necessarily be accurate was one of taking information at “face value” (N1) and using commonsense to determine its accuracy. That response came from participants with varying levels of health literacy proficiency, as measured by the NVS. The process of using commonsense to determine the accuracy of information was described as one of “trial and error” (M3):

...do what’s best for you...try something, if it doesn’t work move on. (G5)

That process seemingly emanated from recognition of individual differences and what works for one person may not work for another. In the case of one participant, neither the reliability of source nor the process of trial and error assured the accuracy of health information. Rather, it was presumed that if it was in print then it was “pretty much spot on.” (P1)

Several participants with varying literacy proficiencies reported being skeptical of the accuracy of health information derived from the television and Internet:

You can believe about half you see on the television can't you?
(A6)

...[the Internet] is just informative. I wouldn't be guided by it or persuaded by it. (Q0).

For others, the level of skepticism reduced when the same messages were repeated:

It's amazing how much information you find on the Internet is repeated in chemist shops and...little pamphlets and whatever...it's reassuring to know that [it] must be right. (J6)

When the question arose as to how participants worked out if health information applied to them, three with limited health literacy simply said they did not know if they worked it out and if they did, how they did it. Others referred again to using commonsense and personal judgment in recognition of individual differences. Obvious references to their condition also helped some participants with the application of health information:

I suppose if it's got 'heart condition' in it it's applicable isn't it.
(Q0)

If it relates to any condition that I've had or have...then I'll listen to it. (G5)

Likewise, knowing one's own body reportedly helped with the application of information:

...you know what your limits are and what you can do and what you can't do. (M3)

Still others with varying health literacy proficiencies preferred to be told by their doctors as to the pertinence of health information to their own circumstances:

I just like to listen to what the doctors say and go from there because otherwise you get too confused. (D1)

I ask my doctor about [the information] because I may interpret it wrongly. (R0)

Analysis of the data revealed examples of how participants' cardiac knowledge impacted their navigation of the healthcare system for associated intervention. Most obvious was that knowledge equipped participants with an understanding of when and how to respond to their symptoms. Speaking on this topic with reference to the CRP, one participant offered the following comment:

Since we've been on this education thing we're probably now more aware of the fact that if we do experience some unusual situations then basically you can, well I feel I'm better equipped now to righto, I'll call an ambulance and I'll get myself to hospital and if it happens again I'll know where to go and what it is too. I won't be thinking this is indigestion it'll go away and I'll be fine. (A6)

Indeed, similar to their depth of understanding of why they were following a particular course of intervention (as discussed earlier), participants with adequate health literacy also tended to have a depth of knowledge about their conditions that made knowing when and how to respond to symptoms as straightforward as A6 seemed to suggest.

Among the remaining sample population a similar depth of knowledge was less apparent but significantly, did not necessarily infer hardship with navigation. For example, one such participant reported being unable to distinguish the symptoms of angina from those of a heart attack so routinely went to the Emergency Department of his local hospital to have the tests to "prove" (M3) that it was not a heart attack. Indeed, his knowledge of when and how to respond was a navigational process as straightforward as that suggested by Participant A6. Yet, the obvious point of

difference was the accuracy of the knowledge upon which decisions about navigation were being made and if in fact the subsequent response represented an appropriate use of medical resources. That is, with better knowledge, could M3 have managed his symptoms independently to the point of not needing to use emergency services?

Another example of knowledge impacting upon navigation emerged from the analysis of three interviews in which participants reported canceling medical appointments intended for investigation of their cardiac conditions because of other priorities. In all three discussions it was apparent the participants did not have the knowledge at the time to appreciate the seriousness of their conditions and that it was only in retrospect they could concede the cancellations were ill-advised. In contrast, a group of six participants with varying literacy proficiencies reported knowing the seriousness of their conditions yet steadfastly denying it in the initial period:

...when they told me I'd had a heart attack I didn't want to believe them. (B2)

"It takes you a long while to tick the right spot on the sheet to say that you have heart disease." (G5)

Not unlike the cancellation of the aforementioned medical appointments, denial of their conditions reportedly caused participants to delay their eventual care. Conceivably then, knowledge impacts navigation whether present or absent.

Self-management is integral to navigation because in many ways it is the catalyst for when, how and why people need to use the services of the healthcare system. The impact of participants' cardiac knowledge on their self-management was evident in a number of examples that emerged from the data analysis. Knowledge about medication and its role in the treatment of cardiac disease for

example, seemingly influenced the self-management of two participants, but in strikingly different ways. For one participant medication was deemed an asset; something that gave him control over his symptoms. A discussion on the topic suggested his approach to that aspect of his cardiac self-management was because he had pertinent knowledge:

The spray¹² is there for two reasons, one it's there to assist medically but primarily it is there to get your mental state back into order, to take that thirty second break, sit down, veg, take the spray and give five minutes for it to wear, work in and...get your mind back into where you're supposed to be. It's more of a psychological as well as a medical thing, rather than just purely medical...I don't really consider it a problem. (O6)

In contrast, another participant spoke of being “one against tablets” (I0). Discussions on the topic inferred a lack of medication knowledge and associated poor self-management practices in so much as medication was not being taken as prescribed. For that participant, a lack of knowledge seemingly contributed to a distrust of medication and subsequent reluctance to use it. That the participants were at opposite ends of the health literacy proficiency scoring range on the NVS may have underscored their self-management behaviours regarding medication.

Another example of how participants' cardiac knowledge may have impacted their self-management dealt essentially with the motivation to act in health-promoting ways. Knowledge of cardiac disease and a subsequent appreciation of its seriousness were behind the comments of one participant:

I think it changes your thought patterns, it changes your way of thinking and your priorities, ways of doing things...it makes you more aware of taking care of your health better, eating better. (K2)

¹² Medically known as sublingual glyceryl trinitrate and considered a standard treatment for pain associated with angina (Fan, Mitchell, & Cooke, 2009).

Another participant acknowledged a link between cardiac knowledge and motivation to practice good self-management based on her own experience, claiming that if she understood her condition better she would feel more inclined to look after herself:

I'd like to know what's happening to me...do I really need to get the whip out...and say well get your arse into gear, do this, give up the smoking, don't have this kind of food and have that kind of food and understand the bloody charts. (H2)

That is not to suggest motivation to engage in good self-management practices was contingent on having knowledge of CVD. For some, merely having an appreciation of the seriousness of CVD without necessarily understanding it was enough to motivate them to act in health-promoting ways such as ensuring they attended follow-up appointments and took their medication as prescribed.

4.3.2.3 MOTIVATION

This theme covers participants' drive to participate in the self-management of their cardiac conditions. Following is an overview of the data concerning participants' self-management motivators/de-motivators and, as an illustration of their self-management practices, the frequency with which they complied with the health and medication regimens they had been prescribed. That is proceeded by a discussion on how participants' motivation was understood to impact their navigation of the healthcare system in Tasmania.

Participants were asked to reflect on what did and did not motivate them to participate in the self-management of their cardiac conditions. Concerning the latter, or de-motivators, the majority indicated they had none:

[I] try to do everything [I] can to keep [my] health good. (M3)

I wouldn't put anything off what were good for my health. (F3)

Where de-motivators existed they included tiredness; lethargy; inclement weather; pain when exercising due to pre-existing conditions; and a perception that healthy food was unappetising:

...you can have bread that's good for you but [it] doesn't taste very nice. (P1)

Less predictable de-motivators were people harrying or "going on at you" (I0); a past allergic reaction to medication that left an on-going fear of taking tablets; and a self-proclaimed inability to absorb and retain information leading to a lack of knowledge.

Factors that motivated participants towards the self-management of their cardiac conditions were for the majority, many and varied. They included preventing a cardiac event in the future:

The last thing you want to have is another heart attack. (G5)

general well-being and quality of life:

...if you've got good health you've got good quality of life. (M3)

longevity:

I want to stay alive...cause you only get one chance. (F3)

and family:

I would like to see [my grandchildren] grow up. (B2)

The responses of three participants implied self-determination underscored their motivation:

I go and see [my GP] regularly, I don't let months go by. You can't afford to I don't think. (F3)

If you don't do it for yourself nobody else can do it for you. (H2)

I [manage my condition] because I choose to do it, not because I have to do it. (O6)

Conversely, there were those whose motivation was at the behest of others:

...because they say you have to do it that's why. (R0)

...because he's the specialist [and] knows the body and heart where we don't really. (K2)

Two disparate yet interesting responses came from participants at opposite ends of the literacy proficiency score range of the NVS. For one, motivation came from a belief that if you did not try to help yourself doctors would no longer worry about you:

...you need someone there at the finish if anything does go wrong again, you got to have someone...so you got to try a little bit. (I0)

For the other participant, motivation was a function of upbringing and beliefs:

It's not your problem or how serious your problem has been or whatever [that motivates you] but...what you believe, how you've been brought up and whatever. (J6)

Three impressions emerged from the interviews complementing participants' reflections on their participation in the self-management of their cardiac conditions.

They were to do with compliance, incumbency to learn and the degree to which cardiac health could be controlled. The first and most overwhelming impression evident across the range of NVS scores was that of compliance:

I just do as I'm told. (R0);

If they tell me to take it I take it. (G5)

Similarly, for one participant whose first heart attack occurred twenty years ago:

*I had to go on a diet...and I've been on a low-fat diet ever since.
(L0)*

For two other participants, compliance seemed to be motivated by their perceived 'return' on invested effort:

...while the [health regimen I was prescribed] didn't fix the problem, it did something...[so] I'll stay on it. (C1)

I'm not taking the tablet if...they're not doing any good. (I0)

Still one other participant hinted at a sense of obligation to comply:

[The doctors] are giving you [treatment] that you otherwise wouldn't have so appreciate it and try and keep in line. (H2)

A difference was noted between compliance with prescribed medication regimens and those concerning diet and exercise. Generally, participants reported greater adherence to the former:

The medication is there for a reason, yes the diet is there...[but] you cannot follow it to the letter...for me to do that I would have to create my own food source. (O6)

Whether you think the [tablets are] doing you any good or not you've got to take them. (F3)

I wouldn't be strict in adhering to the [diet and exercise] guidelines but I attempt to do what is set out. (E0)

Certainly, the latter response was indicative of the effort of the majority of participants towards their diet and exercise which seemed to be made more or less difficult depending on their pre-morbid lifestyles. In other words, those who regularly exercised and ate healthily prior to their cardiac event or the onset of their condition did not report the same struggle to maintain those regimens as participants who were previously less active and/or diet conscious. Regardless, a pragmatic view of the overall compliance scenario was reflected in the comments of one participant:

...if one hundred people all have heart attacks you would find that...five percent would do everything they possibly could to not go through that [again]...and there would be five percent at the bottom who wouldn't give a rats...so everyone that has a heart attack they won't all do the right thing. (J6)

The second impression gleaned from participants' responses about the nature of their participation in the management of their cardiac conditions was a sense of obligation to learn, or at least gather information. This corroborated participants' reports of wanting to be more knowledgeable about their cardiac condition in order to better manage their health, as mentioned previously (see 4.3.2.2):

I think you've got to be very interested, you've got to do your research as best you can, ask as many questions as you can and pick up all the information you can on your particular problem. (J6)

...it's up to the individual to find out...understand a little bit more.
(H2)

Practical examples of such obligation included: keeping a daily record of weight, meals eaten and associated symptoms; purchasing a blood pressure machine to monitor the impact of medication; and collecting relevant pamphlets from pharmacies. Interestingly, where examples were reported, the participants invariably had limited health literacy. One participant reflected on the on-going nature of needing to learn how best to manage his condition:

Once you're well you've got to learn to stay there...if you don't you're wasting your time. (F3)

For others, the on-going nature of such learning was less apparent or indeed, compelling:

...because I had a heart attack twenty years ago...I already knew a lot about it. (L0)

I think that possibly we're...a bit blasé about [my health condition]. (E0)

The third, and final, impression that emerged from the questions to do with participation in self-management concerned participants' sense of control over their cardiac health. One participant was of the belief that they could "make [their] heart work for a lot longer" (J6) whilst at least six others (not all participants discussed this in their interviews) were less convinced, essentially suggesting it was in "the lap of the gods." (K2) Of the latter, all were assessed as having limited health literacy. Between those two sentiments were participant responses acknowledging that whilst there was no cure for cardiac conditions, it was possible to "slow it all down and extend things" (G5) through positive lifestyle changes.

When participants were asked how often they stuck to the health and medication regimens they had been prescribed a striking observation was the speed and assuredness with which they replied 'always' in relation to their medication:

I strictly adhere to the medication [I've] been prescribed. It would be crazy to ignore that. (E0)

It was viewed as an important aspect of the management of their cardiac health. The four exceptions to that observation were participants who responded with 'often'. That was reportedly because they sometimes inadvertently forgot to take their medication or reduced or ceased taking a medication due to an adverse reaction. In terms of the latter, for one it was an aberration from his usual practice of first consulting with his GP and was due solely to the intensity of the reaction he suffered whilst for another it was a decision based on past experience and seemingly made with confidence. In all four cases the participants had limited health literacy.

Perhaps a failing of the structure of the interview question on the topic of compliance was the fact that it asked about two regimens but allowed for only one answer. To a degree that was countered by instead asking for an answer specific to each regimen. In other words, two answers. Relative to their medication responses, those pertaining to health (ie. diet and exercise) were vague, with a third of participants failing to provide one of the set answers (ie. always, often, sometimes, occasionally or never). The remaining answers ranged from 'sometimes' through to 'always' and were given by participants with varying scores on the NVS.

Sticking to a prescribed diet was apparently more difficult than sticking to an exercise regimen. For one participant that was to do with taste:

My diet is up the bloody creek...because I can't go near any of that stuff...they've no taste. (R0)

For others, it was to do with rationalising the dietary recommendations:

...the sodium levels...they're a guideline so if you stick as close to it as possible you're fine. (O6)

and practicalities:

I'm suppose to have the right sort of diet...as far as fats and sodium and all the rest of it goes. Well that becomes difficult sometimes... you just do what you can do. (J6)

Certainly, the overall impression was that compliance with medication, relative to prescribed health regimens, was viewed as far more important, as one participant intimated:

I feel that if the doctors put me on a medication they're doing it for a reason and I should take them. (K2)

How then, did participants' motivation impact their navigation of the healthcare system? Foremost, analysis of the data revealed a group of individuals motivated to participate in the management of their cardiac conditions and willing to receive help to facilitate and guide their actions. That propensity was across the range of NVS scores. However, its manifestation varied between those actively engaged in activities to know and do as much as they could to prevent another cardiac event or deterioration in their condition to those who spoke of being motivated to participate but who portrayed a struggle to act on that feeling, adopting instead a less active approach and doing only what was directed and inferred as essential (eg. taking medication and attending appointments). For one participant, the struggle was palpable:

...it's like subconsciously...I'm holding back when I really need to step forward. (H2)

Thus, the impact of motivation on participants' navigation was to make it an active or passive endeavour and reiterates a previous interpretation of the data regarding the impact of experience on participants' navigation (see 4.3.2.1). An illustration of the notion of active/passive navigation in the context of the current theme can be inferred from participants' approach to asking questions:

You've got to...ask as many questions as you can and pick up all the information you can on your particular problem. (M3)

were comments depicting active navigation whereas:

I think, 'I'll ask [the doctor] that tomorrow' but either forget or I don't say anything. (I0)

was suggestive of a more passive approach.

Another illustration of how motivation appeared to impact participants' navigation of the healthcare system was in the pursuit of appointments. On more than one occasion participants reported needing to make follow-up medical appointments to do with the ongoing monitoring of their cardiac disease. For those best described as 'motivated' this activity was attended to as a matter of priority whilst for the others it was not. However, to suggest motivation underscores such behaviour is likely a premature conclusion based on the available data. Moreover, it sidelines the possibility the impact of motivation on navigation may be mediated by the barriers participants' encountered whilst navigating the healthcare system, not least of which may include those attributable to limited health literacy.

4.3.2.4 HEALTH LITERACY SELF-EFFICACY

This theme covers participants' perceived effectiveness of their health literacy abilities to do with filling out forms, reading hospital materials and learning

about their condition. That is, the abilities covered by Weiss et al's. (2005) Set of Brief Screening Questions (SBSQ) which were embedded in the interview schedule. Following is an overview of the comments participants made in addition to their set-answer responses to the SBSQ which are shown in Table 4.3. That is proceeded by a discussion on how participants' health literacy self-efficacy was understood to impact their healthcare navigation.

Comments made in addition to the set answers revealed the source of problems for participants when filling out forms was the ambiguity of the terms and questions they contained:

If they're well written they're OK you know, they'll tend to use laymans language, but if it's...got all medical stuff it's harder. (J6)

Two participants identified their difficulties in filling out forms in terms of their own skills. One reported a lack of confidence with spelling to the extent that she carried with her a pocket dictionary and preferred to take forms home to have more time to fill in the details. Another participant reported difficulty expressing herself in writing.

Participants' comments regarding having someone help them read hospital materials suggest that it was not sought help so much as help that happened to be on hand:

The wife usually comes with me all the time. (N1)

I find [hospital staff] usually read [the hospital materials] for you. (D1)

Where help was sought it was said to check understanding of terms. An unexpected high number of participants with limited health literacy ($n=7$) indicated they did not need help with reading hospital materials. This was perhaps reasonable given some

went on to report not to read them at all because of anticipated difficulties with understanding the text:

I don't read them..because I don't understand it. (I0)

and specifically in relation to consent forms:

I rarely read it anyway, I just sign it [but] I possibly would have to have [help understanding it]. (K2)

Another participant with limited literacy who also indicted 'never' needing help with reading hospital materials went on to say it was not that she did not need help, but rather, she did not want to ask for help. In the context of this participants overall interview it would be fair to surmise the reason for this could well be her heightened self-consciousness about having limited literacy:

I feel embarrassed that I don't understand. (H2)

The majority of participants who reported problems learning about their medical condition from written health information did so because of difficulty understanding the terminology:

...if it's written in lay language I'd understand it a lot better. (B2)

For others, the difficulty arose from the subject matter itself and was data that supported the notion of baseline knowledge being requisite to understanding health information. In other words and as an example, having knowledge of where the heart is located in the body, what it does and how it functions in order to better understand literature on heart conditions.

Compounding the difficulty of obscure subject matter for participants were its alleged contradictions:

The biggest problem is a lot of confusion. Even the information that comes from health professionals...is conflicting. (J6)

One participant felt they understood the information but could not be sure, underscoring the importance of opportunities provided by such activities as the CRP to ask questions of people with relevant knowledge to clarify understanding, as alluded to by some participants:

Since I've been talking with [the CRP Co-ordinator] she's actually filled in a lot of the gaps [and] you've got more of an understanding of what's going on. (M3)

and more generally:

...if you had someone to talk to you about what the information is all about you'd learn from that. (R0)

One barrier to availing of those opportunities was reportedly not knowing who to ask.

Finally, on the topic of learning from written health information, comments arose about the sheer quantity of literature now available and implicitly, the onus felt to understand it:

There's more information out there today than what there used to be. When I had my second [heart attack]...I had never heard the word cholesterol. (F3)

Another participant spoke about the quantity of literature in terms of its psychological impact:

You can get too much information and...get paranoid with it. (R0)

Quantity aside, the actual experience of gaining understanding was described by one participant as “an enlightening.” (M3)

Analysis of the data revealed filling out forms, reading hospital materials and learning about one’s medical condition are all health literacy tasks that have the potential to impact navigation of the healthcare system. Moreover, how effective one feels in performing those activities may compound their impact. Examples implicit in participants’ responses on the topic included the possibility of delayed care if one feels unable to complete a medical form correctly in the time and space provided; disengaging with health information if one is feeling overwhelmed and/or unable to comprehend the quantity and complexity of information available to healthcare consumers; avoiding services if support to help understand information is not forthcoming; signing documents without understanding their content and subsequent ramifications; being unable to understand and follow treatment recommendations because of poor baseline health knowledge; ineffective utilisation of services because one is embarrassed to ask for help; and providing misleading information to doctors because of an inability to explain oneself in writing which may compromise quality and timing of care.

Notably, those examples take a shortfall perspective in their portrayal of the impact of health literacy self-efficacy on navigation. That is, what may eventuate from low health literacy and poor self-efficacy. However, that is clearly not the only scenario. Should adequate health literacy and good self-efficacy prevail one would anticipate a more positive navigation experience. Examples implicit in participants’ responses on the topic alluded to this. They included knowing what questions to ask in medical consultations to inform medical decisions; being able to readily understand, and feeling confident enough to apply, new health information to personal circumstances to improve self-management; feeling more in control of

one's health trajectory as a consequence of that understanding; utilising services effectively and appropriately to maximize health outcomes; being able to judge information based on sound medical knowledge; and having a greater appreciation of how the healthcare system functions, as one participant eloquently commented:

The more knowledge you've got of what's going on the easier it is to understand...the medical system, the way it works. (M3)

Yet, what of a scenario that adopts neither a shortfall nor effectual perspective? In other words, where health literacy is adequate but self-efficacy is low, or conversely, where health literacy is inadequate but there is good self-efficacy? Whilst the data analysis precluded participants from the former scenario, a few seemingly met the criteria of the latter. That is, they had scores on the NVS suggesting limited literacy but portrayed good self-efficacy. In those instances two mechanisms seemed to be at work. Firstly, there was a 'commonsense' approach to navigation whereby participants made decisions based on perceived logic, not necessarily because they were accurate or appropriate. This seemed particularly the case when participants were judging the merit of information:

You've just got to use your own commonsense, you don't rule anything out. (N1)

...I think [it's] just a matter of probably commonsense. (L0)

Secondly, there was an oral approach to navigation. In other words, the writing and reading components of navigation were sidelined in favour of the spoken word:

I ask where do I have to go you know, what part of the hospital is this in...I'll say excuse me, where do I go to find so and so...they've got a tongue in their head. (D1)

Thus, it would seem the mechanisms of commonsense and verbal exchange, and the self-efficacy they generated or were derived, may have compensated the limited literacy of some participants in the context of healthcare system navigation.

4.3.2.5 MINDSET

This theme covers participants' viewpoints on navigation decisions and the impact those viewpoints had on the subsequent activities and interactions that directed them around the healthcare system. When participants were asked how they made decisions about which healthcare services they used, some responses seemed as much a reflection of the individual's mindset as they were of the decisional process. That observation emanated from the several examples in which a consistent mindset prevailed across participants' responses to that and other questions asked of them in the interviews and focus groups. Following is a précis of those mindsets and how they were understood to impact navigation.

Most prominent among the mindsets, because of the seven participants to whom it applied, was that suggesting healthcare services were used only when absolutely necessary:

[I] use whatever's needed, when needed and only when needed...if I can't look after it myself [or] if I don't recognize what the problem is myself. (O6)

I treat doctors a bit like dentists, I only go if I really have to. (A6)

I...wouldn't go to a doctor, I'd rather take me Panadol and hope it went away and if I had to go, yeah I'd go. (I0)

and regarding GP visits:

I go there only when I really have to...I keep putting it off and putting it off...saying it'll be right. (H2)

The obvious ramification of that mindset was a delay between needing healthcare and actually seeking it:

I think...the whole thing is I leave it. I can sit here [for] three or four hours with chest pain and...hope it'll go away...it just gets to the stage where you've had enough you know, so you think well I'll go and get it checked out. (M3)

I leave...things to the extreme limit before I ask or seek information about something. (H2)

One wonders, in the absence of reports to the contrary, if the health outcomes of participants who delayed seeking care because of an 'only when absolutely necessary' mindset may have been different. In other words, could an event or surgery have been avoided if intervention had been sought earlier?

Other examples of navigational mindsets evident in participants' responses included not feeling beholden or bound by loyalty to a particular healthcare professional but rather using "who's ever around at the time" (O6); a preference for orthodox treatments as opposed to those deemed 'alternative' (in this instance, acupuncture); and the judicious use of services:

...I wouldn't use the hospital or Accident and Emergency if it wasn't really necessary you know. (F3)

Yet, knowing what constitutes 'necessary' is not always possible and underscored the mindset of another participant who felt justified making 'false alarm' ambulance call-outs (albeit unintentionally) because he viewed it as "extremely good instruction [and] learning experience for [paramedics]." (J6) Finally, another mindset common among a number of participants intimated feeling unwell was not a barrier to

seeking care but rather, an impetus. The relationship between feeling unwell and seeking care was such that the sicker they felt, the harder they sought care:

...if you're not feeling well you're going to push [for care]...more so than if it's only just sort of minor. (K2)

to which another participant added, “you push harder.” (Q0)

Underscoring that mindset was the notion of vested interest, best articulated in the following comment:

It's your health...isn't it and it's your heart, so. (K2)

The impact on healthcare system navigation of the other mindset examples was not explicit in the data. Rather, by implication it was conceivable that breadth of choice may be greater for those not encumbered with a sense of loyalty to a particular healthcare service provider for instance, just as treatment options may be restricted if certain types of intervention were not considered. Regardless, the overall impact of the mindsets was inferred to be that of guiding participants in their navigational decision making. Moreover, they were not shown to be an idiosyncrasy of one particular NVS score group, perhaps suggesting they were not a function of health literacy.

4.3.2.6 DISPOSITION

This theme covers participants' dispositions or “habitual ways of acting” (Facione, 2000, p.63). In other words, qualities about their personality or character that granted a reasonably accurate prediction about how they would most likely act or react in a broad range of circumstances. As distinguishing features of the human character or personality, dispositions are not considered unintelligible, covert

qualities but rather, discernable, comprehensible and comparable by all and sundry (Facione, 2000). In the present research, four dispositions were identified from analysis of the data: amicable, accepting, assertive and independent. Following is an overview of participants' responses that subscribed to one or more of those dispositions¹³ which is proceeded by a discussion on how participants' dispositions were understood to impact their navigation of the healthcare system.

Half of the sample population ($n=9$) with varying literacy proficiencies were ascribed an amicable disposition denoting friendliness. That is not to say the remaining participants were unfriendly, but rather, it was a quality that permeated the responses of the former group to such an extent that it became easily discernable, comprehensible and comparable. For some, amicability was expressed in terms of co-operation:

I've never thought there's any point in you know, trying to be anything other than co-operative and things like that. (C1)

For others it was being "easy to get along with" (L0) and not "a pain in the arse." (E0) An amicable disposition was not something participants were conscious of but instead something they invariably described as being "just me." (D1) In contrast, participants seemed more conscious of a reciprocity effect of being amicable:

I think if you're a person trying to do the right thing...instead of being bombastic I think people treat you accordingly. (L0)

and perhaps more succinctly:

...you get what you receive in other words. (C1)

¹³ The character or personality qualities of one participant did not subscribe to any of the four dispositions that emerged from the data analysis and an alternative could not be readily inferred from her responses.

The responses of over two thirds of the sample population ($n=13$), again with varying literacy proficiencies, were deemed by the researcher to be indicative of an accepting disposition that had the hallmarks of accommodation, compliance, and consensus. It seemed most evident in discussions of the healthcare system in general and its perceived failings in particular:

I accept the system for what it is. We'd all love to make it better but...you've got to go with the system as it exists. (E0)

I expected...a bit better [treatment] than what I got but at the same time I thought well I can't argue, I'm only on a benefit, I'm not paying for this so...be grateful that something was done. (H2)

...when I got to [the hospital] there were no beds available in the ward so I spent the night in the Emergency Department just in the little cubicle thing. But I mean, that was alright, it didn't worry me. (J6)

I just accept if they can't see me for a fortnight they can't see me for a fortnight, there's no good worrying about it. (C1)

Expressions of an accepting disposition also emerged from discussions with one participant about self-management. Namely, how he found taking medication:

...just take it and be done with it. (N1)

and how he found sticking to a prescribed diet:

If you want to live you've got to do it, that's the way I look at it. (N1)

The two remaining assertive and independent dispositions were certainly not as prevalent among the sample population given the small number to whom they were ascribed. Those with an assertive disposition expressed, or implied, bold and

persistent actions to achieve an outcome, most often answers to questions they had about their conditions. That those instances were inferred to imply an assertive disposition was perhaps telling in so much as the act of asking a health professional a question was deemed 'being assertive' rather than normal patient behaviour. However, the inferences arose from comparing all the data which revealed for the majority of participants 'normal' behaviour was to *not* ask questions.

By her own admission, one participant subscribed to an independent disposition:

I'm shockingly independent. (H2)

As a reflection of such independence she spoke of relying primarily on her own resources to maintain her health and not her family, friends or the healthcare system:

I'm determined that I can do it myself, don't rely on anybody. (H2)

The impact on healthcare system navigation of the identified participant dispositions revealed affinities between the experiences of those with ascribed amicable and accepting dispositions and to an extent, assertive and independent dispositions. Evidence for the former arose from the observation that all participants deemed amicable were also accepting in character. Thus, the impact on navigation of an amicable disposition also doubles as a discussion on that of an accepting disposition. For example, implicit in the comments of participants with both dispositions was a willingness to be guided in their activities and interactions within the healthcare system to achieve the health outcomes they were after. For many, this amounted to simply 'going with the flow' and accepting the fallibility of the system and the people working in it. What could easily have been perceived as significant barriers (eg. delayed care due to long waiting lists) were instead

portrayed by those participants as surmountable inconveniences. Indeed, it would seem both amicable and accepting dispositions forged 'paths of least resistance' for participants in their health navigation journeys.

In contrast, the experiences of those with ascribed assertive and independent dispositions did not reveal the same ease with navigation, thus suggesting an affinity of sorts for the purpose of discussion. In its essence, assertiveness implied participants were making demands on the system based on their needs at the time. When those needs were met participants felt in a position to make informed navigational decisions but when they were not met, participants expressed frustration. Notably, in trying to exert a level of control over their navigation, participants with assertive dispositions seemed more prone to frustration than those with accepting/amicable dispositions. The participant with an independent disposition also experienced frustration but this resulted more from confusion about the healthcare system than any demands she was making of it. Again, an irony presents itself in so much as her reluctance to avail of the system was likely sustaining her feelings of confusion about navigating it.

Finally, the discussion on the impact of dispositions on healthcare system navigation raises an important question the data seem unable to answer. That is, to what extent health literacy underscored the dispositions given they were, like mindsets, not shown to be an idiosyncrasy of one particular NVS score group¹⁴?

¹⁴ The obvious exception being the 'independent' disposition with its one subscriber having a NVS score suggesting limited health literacy. However, based on the available data it could be argued the question remains pertinent. That is, to what extent is her disposition a function of health literacy?

4.3.2.7 NAVIGATION SKILL SET

This theme covers the skills identified by focus group participants¹⁵ as requisite for navigating the healthcare system (Table 4.7). Following is a brief account of observations made during the focus groups in relation to the generation of that skill set as well as an overview of the skills in terms of their perceived parities with health literacy competencies.

Table 4.7
Skills identified by focus group participants as requisite for navigating the healthcare system^a

-
- Reading and writing
 - Communication
 - Listening
 - Honesty
 - Compliance
 - Tolerance
 - Identifying and using support networks
 - Preparing for medical appointments (eg. writing questions down on paper)
 - Knowing what questions to ask
 - Understanding and weighing up health information
 - Knowing what services are available and using them accordingly
 - Understanding how the healthcare system operates
-

^a In no order of priority and constituting an amalgamation of the three lists generated by each focus group.

Three notable observations were made from the focus group discussions on a navigation skill set. First was the lack of repetition between the lists generated by each group. In other words, each group came up with a unique skill set, the one exception being communication skills which made it on to the lists of two of the groups. Secondly, despite the (sometimes lengthy) discussions each participant had in their interviews on the subject of reading health information and completing

¹⁵ This was not a topic of discussion in the individual interviews, only the focus groups meaning those not in attendance ($n=6$) were unable to make a contribution. The participants attending the focus groups ($n=12$) represented both the adequate and limited health literacy groups, as measured by the NVS.

forms and other such tasks, the actual skills of reading and writing were mentioned only once as requisite for navigating the healthcare system. Thirdly, the majority of suggestions for the skill set were made by participants with adequate literacy.

Observations aside, the amalgamated list contains skills in common with the routinely defined health literacy competencies of accessing, understanding and applying health information thereby underscoring the pertinence of health literacy to navigation in the minds of participants, if not explicitly, then certainly implicitly. For example, in terms of accessing information were suggestions of being able to “read and write” (G5) and “communicate fairly well” (M3) which, combined with “good listening skills” (J6) helped with “writing a few questions down” (A6) as well as “asking the right questions” (I0). Understanding health information was implicit in the suggestions of “sorting the oats from the chaff” (A6) and more broadly, “understanding the system...the referral business and the way things go.” (Q0) Suggestions implying the application of health information included “being prepared to use what [services] you know about” (A6) and “seek[ing] support...so that you’ve got somebody there that’s going to help you.” (J6)

The WHO (1998) definition of health literacy, and the one adopted for the purpose of the present research, states in part “social skills...determine the motivation and ability of individuals to gain access to, understand, and use information.” (p. 10) Parity can be drawn between that aspect of the WHO definition and the social skills suggested by participants as requisite for navigating the healthcare system. Namely, being honest; being compliant or “doing what you’re told” (G5); and being tolerant by “accept[ing] the system for what it is.” (E0) Finally, given all the skills identified by participants as requisite for navigating the healthcare system are consistent with notions defining health literacy begs the question: is navigation a subcategory of health literacy or is health literacy a subcategory of navigation?

4.3.3 IMPACTS ON NAVIGATION AT THE SERVICE LEVEL

4.3.3.1 GUIDANCE

This theme covers the advice participants received in relation to their navigation and self management choices and the subsequent impact that had on their trajectory through the healthcare system. Whilst guidance has already been mentioned in the context of experience and its impact on navigation at the individual level, it was only to make the point that it reportedly existed for, and was appreciated by, the participants. Analysis of the data suggested guidance had the most impact on the navigational experiences reported by participants at the service level given it was predominantly at that level advice was provided. Following then, is a more detailed overview of the data concerning guidance and its subsequent impact on participants' navigation of the healthcare system.

Inferred from the data was the notion that navigation and self-management were decision making processes based on choices available at the time. Whilst a minority of participants indicated those processes were undertaken independently, for most they involved receiving advice from healthcare providers. Principal among the advisers were General Practitioners (GP) with almost half the participants regarding them as their "first port of call" (Q0):

I invariably go to my GP...for any real health problem. (G5)

If I found something via research to say well do this and that'll save your life...I'd think hang on, I better go to the GP and just check on this. (J6)

Moreover, participants implied the guidance role of the GP was not arbitrary:

I leave it more or less to [my GP], if he suggests that I go then that's it. (H2)

Your GP is there to push you in the right direction. (A6)

[The GP] guides you. (P1)

...it's nice to hear it coming from [my GP] this is what I want you to do and this is what I don't want you to do. (D1)

Other healthcare professionals said to provide advice, albeit to a lesser extent than the GP, were nurses, medical specialists and clinicians involved in the Cardiac Rehabilitation Program (CRP).

It could be argued the clinicians involved in the CRP acted as navigators for participants in much the same way the role is said to be undertaken in countries such as America given they provided participants with information, education, training and support to meet their cardiac care goals. Moreover, they remained an on-going point of contact within, and access to, the healthcare system for participants beyond the nine week duration of the program together with the network of other healthcare providers (eg. physiotherapists, dieticians, social workers and pharmacists) they introduced to participants:

The best thing I did was join the [CRP] because...we're exposed to health professionals...if we need help we know where to go...I know people I can contact. (J6)

Whilst one participant was of the opinion he “would have done alright even without the [CRP] classes” (R0), the overwhelming opinion of the CRP was positive, especially regarding its educative function:

...[it's] filled in a lot of gaps...you've got more of an understanding of what's going on. (M3)

...[it's] made me aware of things I wasn't aware of before [such as] the necessity of a healthy lifestyle. (Q0)

Not all advice on navigation and self-management issues came from healthcare professionals. For example, participants reported using “what’s happened to other people, their experience” (F3) to inform their decisions as well as the advice of their partners, family and friends. Consensus of opinion also seemed persuasive, particularly when it concerned making a choice about which healthcare professional to see:

...I'd heard a lot of good reports about him. (P1)

When you reveal that particular [GPs] name, everybody agrees with you [that he is good] so it vindicates... your choice. (Q0)

The credibility of the source of advice and its accuracy were also factors taken into consideration by participants, as was discussed in the context of knowledge and its impact on navigation at the individual level.

Participants’ navigation of the healthcare system was, in part, a function of the advice they received. If it was understood, perceived to have come from a credible source, and/or was deemed accurate then advice was inferred to have a positive impact on participants’ navigation by making the decision making process a seemingly straightforward one. Conversely, if advice was not understood, the source was considered unreliable, and /or it was deemed inaccurate then it was inferred to have a negative impact on participants’ navigation by evidently making the decision making process less straightforward and the task of navigation more frustrating. Significantly, the impact of advice on navigation did not seem to reflect participants’ health literacy proficiencies, as measured by the NVS. In other words, participants with adequate health literacy did not necessarily experience decision making as

straightforward as one might expect, just as those with limited health literacy did not necessarily experience decision making as difficult.

4.3.3.2 SUPPORT

This theme covers the assistance participants received from others to look after their health. The data suggest it was defined not by advisory assistance given in relation to navigational and self-management choices but rather, the assistance that sustained participants emotionally through their experience of a cardiac event or condition. All participants reported having support to look after their health, albeit to varying degrees and from different sources. Following is an overview of that support and its subsequent impact on participants' navigation of the healthcare system.

Whilst nurses were positively regarded for their support, allegedly being a "breed apart" (F3), participants' responses were largely focused on GPs and the CRP clinicians when discussing supportive healthcare providers. Notably, the discussions pertaining to GPs said as much about participants' expectations of GPs as it did about their support per se. For example, one participant lamented that "doctors are too bloody busy" (R0) to afford time to sit and discuss matters with their patients whilst others held expectations of their GPs using plain communication, being attentive listeners and showing empathy. GP support was also reflected in dialogue to do with frequency of contact. Those who said they frequently visited their GP also reported the support of their GP.

The CRP clinicians were said to provide reassurance to people who have not previously experienced a cardiac event or condition:

When...you've never had that experience before...having somebody beside you who...understands the...whole thing going with you step by step [is] a good way to go. (O6)

Likewise:

...[the CRP clinicians] talk to you as a person...as the person you are. (N1)

[It's] like I've known [the CRP coordinator] all my life...like a friend. (B2)

were comments suggesting a supportive group environment, no less a social one. Indeed, "just meeting the people" (D1) involved in the CRP apparently afforded some participants support:

I'm missing it a bit because we had that much fun up there. You were listening to all the serious stuff...doing the tests and all that sort of thing but you were meeting people that you hadn't met before, we all had the same problem. (K2)

[The] nine weeks up there was...a great thing, I really looked forward to each Thursday [because] you talked to people what was in the similar condition to yourself. (B2)

Participants' notions of support also permeated discussions on the follow-up conducted by the CRP clinicians:

I thought I'd finished but [the CRP Coordinator] wanted to see me...in three months time and then six months and then twelve months so it's good she's keeping an eye on me...[it's] just the reassurance by going back in three months, six months, twelve months. (Q0)

The CRP was deemed to be "very good for follow-up." (P1)

Partners, where applicable, were unanimously perceived to support participants in looking after their health:

She's a rock. (F3)

We're a two-man show. (N1)

She's number one. (P1)

The nature of support varied from overseer:

My wife watches me like a hawk...she makes damn sure that I do all the things that I'm suppose to do, that I take my medication, that I don't eat the wrong foods, that I do exercise and all these things. (J6)

to primary carer:

It's a good job there's nothing wrong, she's not telling me there's anything wrong with her...she seems alright, but if she wasn't I don't know what I'd do. (F3)

Apart from partners, family members in general were deemed to be largely supportive of participants' pursuit of health. Most references were to adult children whose involvement, according to one participant, redefined the experience:

When you get the kids involved...I think it becomes a family issue then and once it becomes a family issue it is a totally different concept than just...going through it by yourself. (M3).

The support was said to exist irrespective it would seem, of whether the family member(s) lived locally or afar and came in the guise of emotional support:

...when they brought me out of the hospital on the stretcher who should be standing outside but my son and it was just the most marvelous thing because my husband couldn't be...there and he came and sat in the ambulance with me while they sorted things out and that to me was support. (K2)

as well as practical support:

Our son and daughter...they're always about for transport...support at times with meals, 'come to our place for tea, here's a bowl of soup', this sort of thing. (G5)

Whilst most participants with family support accepted it willingly, some were not so inclined:

I've got [family] but I don't rely on them. (H2)

I have in ways told [my family] to back off but the baby is very dominant, 'but mummy...you've got to understand' and I feel like saying and yes, so do you. (B2)

In the absence of family (including partners) to provide support, close friends appeared to fill the void with similarly described roles. For example, one close friend was said to have “virtually pushed” a participant to exercise whilst another was reported to have accompanied a participant to her GP appointment to advocate on her behalf. Importantly, the support of close friends was no less valued than that of kin:

[My friend] looked after me; only for him I wouldn't be here. (I0)

Similarly, recognition was given to the difficulty people might have looking after their health without the support of either family or friends:

It is always handy to have someone. (O6)

Like guidance, participants' navigation of the healthcare system was, in part, a function of the support they received or were willing to accept. The data would suggest it 'nurtured' participants through their cardiac experience which was essentially described as one akin to an emotional roller-coaster. For example, participants described fear generated by inexplicable chest pain; shock when told about their cardiac event or condition; relief knowing treatment was possible; frustration waiting for treatment; happiness that treatment had resolved their symptoms yet uncertainty about the possibility of another event or deterioration in their condition. With support, such wavering emotions appeared not to detract from the task of navigation by allowing participants to share their burden. Whilst demonstrations of this varied, they included participants having someone accompany them to medical appointments and having engaging family discussions about treatment options and on-going self management.

Health literacy, as measured by the NVS, appeared not to be reflected in how participants received and used support. In other words, participants with scores suggesting adequate health literacy did not receive and use support in ways that appeared notably different to those with scores suggesting limited health literacy. Perhaps more notable was the frequency and importance with which support was discussed by all participants in the context of healthcare system navigation.

4.3.3.3 INTERACTIONS

This theme accounts for interpersonal considerations impacting participants' experiences of healthcare system navigation. Whilst specific questions were dedicated to understanding participants' relationships with their healthcare providers (Appendix 18), the topic permeated the interviews resulting in a broad representation of data. Following is an overview of those data, analysis of which generated five sub-themes: communication; attitude; relationships built over time;

trust; and strategy; the latter a reflection of participants' explicit use of their interpersonal skills to obtain health services. A discussion proceeding the overview will reflect how interpersonal considerations were understood to impact participants' navigation.

Principal among the interpersonal sub-themes was communication. Participants described good relationships with healthcare providers who were "easy to talk to" (L0); who provided information that was "easy to understand" (M3); and who communicated at their 'level':

...they don't talk down to you or up to you. (J6)

However, the majority of responses described negative communication experiences. For example, one participant lamented the lack of communication at the time of his first heart attack:

[The doctors] didn't tell me anything. They didn't say don't do this, you can do that. They didn't even tell me I couldn't drive. (G5)

He went on to describe a difficult relationship with one health provider due solely to the provider's poor communication skills:

...there's no way you can discuss your situation with him because he simply won't talk to you...I simply sit there and answer questions and leave because it's a waste of time trying to talk. (G5)

Another participant was left unsure if he had to organise an appointment because of poor provider communication:

...they didn't tell us whether we had to contact them or what...we've been sort of waiting for an appointment to arrive in the mail but nothing's happened. (A6)

In more general terms, participants spoke of health communication per se being vague; unnecessarily repetitious; based more on luck than good skills; and simply “not forthcoming in a lot of information.” (K2) Interestingly, the participant making the last response also claimed her health providers were good “because you can talk to them” (K2) which perhaps highlights, albeit simplistically, the responsibilities in communication of both the communicator and the receiver. In other words, health providers may not be ‘forthcoming in a lot of information’ because they just haven’t been asked for it. Moreover, by a recipient who may not even know or understand what to ask, as evidenced in the comments of one participant:

Things that are said I don't understand them so I'm more inclined to put them on the back shelf and try and wing it. (H2)

The difficulties experienced with communication included also its written form. For one participant that concerned illegible prescriptions whilst for another it was an omission in her Medical Record regarding the need for a stress test leaving her doubting its necessity. Surprising were the number of instances participants reported receiving no explanation from health providers, written or otherwise, as to what may have caused their condition; why they were being discharged from hospital; the side effects of medication; the results from tests; why there was a waiting period for treatment; and even what treatment was provided. Indeed, one participant was not made aware, and therefore did not know, that she had internal stitches following surgery until it was pointed out to her that she may have ruptured them.

Contrast was made by one participant between the efficacies of group and personal communication:

In the group environment...they explain something but it sort of goes over the top. (H2)

By way of recommendation, she went on to suggest that personalised explanations of treatment made one-to-one would be more effective because “people will actually absorb that more.” (H2). Other participants highlighted difficulties they experienced with health providers who had English as a second language:

[The doctor] thinks I’m deaf but I can’t understand her. (A6)

Another spoke of the importance of team communication:

There’s no use your GP not knowing what your cardiologist is doing. They’ve all got to be in the frame. (F3)

Healthcare providers not ‘in the frame’ were seemingly prone to issue contradicting advice to participants which had a negative impact on their relationship. So great was the inconsistency in advice for one participant that it caused her to withdraw from treatment in frustration and soured her relationship with the relevant providers. Contradicting advice was also shown to have implications beyond the relationship between provider and patient. For example, it was said to make navigating the healthcare system “a bit harder” (G5) in terms of following a single course of treatment; left another participant in doubt about his actual diagnoses; and a third questioning the accuracy of the Heart Foundation Tick¹⁶ when it came to the Recommended Dietary Intake (RDI) for sodium.

¹⁶ A self-funded public health program, under the auspice of the Australian Heart Foundation, aimed at improving the nutrition of foods people eat most often by bearing a Tick CERT TM on those foods that are lower in certain nutrients (eg. saturated fat, sodium) and/or higher in others (eg. fibre) compared with other foods in the same category. (<http://www.heartfoundation.org.au> Accessed 7/3/11)

A second interpersonal sub-theme concerned the attitude of healthcare providers. For example, two participants spoke of the perceived rudeness of some providers:

...it was just the attitude of the doctor...he was just rude the way he spoke to us. (M3)

[The doctor] is so rude...his approach is terrible. (K2)

Other participants spoke of perceived displays of arrogance:

I pay a doctor to look after my health not to be...arrogant with me. (R0)
He's too above himself. (F3)

...[the doctors] thought themselves really special people [like] they were above everybody else. (O6)

Providers displaying attitudes perceived as disinterest also raised the ire of participants:

[the doctor] didn't give a stuff. (O6)

[the doctor] didn't want to know. (I0)

When I had an angiogram [the doctor] came to me and said you've got serious heart disease and that was it and it was like a kick in the guts and he was off. (Q0)

Invariably, the ramifications of such displays in attitude were described as poor relationships. Conversely, when the attitude of healthcare providers was perceived in a positive light the relationships were reportedly good.

Several participants reported good relationships with their healthcare providers that had been built over extended periods of time, quite often decades, giving rise to a third interpersonal sub-theme. For some it was seemingly a matter of principle that they “don’t go willy-nilly to doctors” (09). For others it was important the provider knew them beyond a one-off consultation so they got to know their medical history and likewise, that participants knew their provider:

...they were in town when I first started work back in the sixties, I’ve been to a few other places in between but it’s still the same company so...we know them. (A6)

However, the relationship between patient and provider built over time was flawed in the eyes of one participant in so much as “they get a bit familiar with you [and] a bit slips through the net through not being investigated properly and things like that.” (M3) More specifically, participant M3 reported his doctor was “missing too many things” and felt he “shouldn’t have to ask can you send me here, can you send me there” because “you don’t go to see [the GP] to tell him what to do.” Nevertheless, the fact that it was invariably the GP with whom participants had enduring relationships highlights the important role they play in the health and well being of the community.

A fourth interpersonal sub-theme was trust held by participants in their healthcare providers. Once again, the GP figured prominently:

I have one hundred percent confidence in my GP...he’s my first port-of-call. (E0)

If you haven’t got faith in your doctor what’s the point of going to him. (K2)

I trust [my GP] and have complete faith in him. (G5)

One participant spoke of how difficult it was to establish trust in doctors based on past experiences but also the benefits to be gained from having it:

I sort of feel relaxed...I can actually be myself...and not feel like I'm some idiot. (H2)

For others however, the impact of bad experiences with healthcare providers was seemingly insurmountable leading one participant to remark:

Why should we have full trust in them? (P1)

An expression of trust was implicit in discussions on shared decision making with healthcare providers, most often the GP. Participants spoke of open dialogue and opportunities to proffer an opinion but when it came to actually making decisions about their on-going care the healthcare provider/GP was considered ultimately responsible. That arrangement not only seemed acceptable to participants, it was portrayed as their expectation because the healthcare provider/GP was the person with the knowledge and expertise to make the most informed decision and was trusted to do so in the participant's best interest. Moreover, it seemed to be based on a consensus of views between the two parties regarding health outcomes and how best to achieve them. The importance of such consensus was evident in the actions of two participants who were, at the time of being interviewed, changing their GPs primarily because a consensus of views was understood to be lacking in the relationships they had with their former doctors.

A fifth and final sub-theme from data pertaining to interpersonal considerations impacting healthcare system navigation was participants' strategic use of their interpersonal skills to obtain health services. Two reported being conscious of maintaining an open and honest relationship with their doctor, albeit effortlessly, to get their desired treatment options whilst another did so to ensure

good treatment, having witnessed the poor treatment of a “very abrupt” friend and concluded “[the doctors] do notice.” (F3) Similarly and perhaps disconcertedly, a participant spoke about the need to remain congenial and not “burn your bridges” by complaining about poor delivery of healthcare services in fear of compromised treatment:

...if you want something done the situation might call for you to shut up and say nothing [just] cop it and wear it. (N1)

He went on to rationalise:

...that's the way most of life is anyway, if you burn your bridges you're buggered. (N1)

In contrast, the advantages of being assertive were proclaimed more than once. In essence, that amounted to being verbally strong and not being afraid to ask questions “to know what’s happening to you.” (Q0):

...be straight forward with them, call a spade a spade so you know what's going on instead of being mucked around. (P1)

To that end one participant openly admitted to being a “pushy patient” if he felt he was being made to wait “longer than necessary” (O6) whilst another was happy to ask questions if the circumstances warranted it.

The complex nature of human interactions was highlighted by the five sub-themes emanating from the analysis of data on the topic. The subsequent impact of those interactions on participants’ navigation of the healthcare system was inferred to be equally complex, making one cautious of broad generalisations. That said, the data suggest a more positive navigational experience arose from instances where participants judged their healthcare providers to be good communicators with

facilitatory attitudes; where their relationships with providers was enduring and built on trust; and where participants had an awareness of their interpersonal skills and how they may best be used to achieve a desired outcome. In other words and for example, where plain language was used; where doctors explored treatment options in a transparent and consultative manner; where medical histories did not have to be repeated at each consultation; where 'silly' questions could be asked without embarrassment or shame; and where the expression of an opinion was welcomed and valued by providers. Conceivably, participants' health literacy may have had an impact on those experiences in so much as difficulties accessing, understanding and applying health information, or limited health literacy, may place heightened importance on human interactions as an alternative means to the same information. However, the data were not conclusive on that point, instead revealing navigational experiences common to participants across the range of NVS scores with regard to their interactions with healthcare providers.

4.3.4 IMPACTS ON NAVIGATION AT THE SYSTEM LEVEL

4.3.4.1 EMERGENCY DEPARTMENT CARE

This theme covers the care participants received through the Emergency Department (ED) of a hospital, as opposed to a GP Clinic for example, and the subsequent impact that had on their trajectory through the healthcare system. Whilst not abundant, the data underwriting this theme warrants delineation because it exemplifies an impact on navigation at the system level about which participants were explicit. Namely, the use of ED services to expedite care. More implicit in participants' discussions on the topic, yet equally relevant, was the navigational assistance afforded to patients admitted to hospital via an ED. Following is a synopsis of the data pertaining to ED care.

A prevailing need for, and appreciation of, timely services was evident in the responses of many of the participants and was at the essence of one strategy to seemingly guarantee it: using the ED services of a hospital in preference to those of a GP Clinic:

The quickest way to get treatment is to get an ambulance because once you're in the paramedics care...things happen. If you go the other way and go to your local GP he won't do anything...I don't think it's as efficient. (J6)

I've found...going through emergency is the quickest way to get to where you want to go...going to your GP with a heart problem is...a waste of time because...they don't want to investigate it any further. It always seems to be the soft option, we'll sit back and wait. (M3)

I don't have any doubt it's call an ambulance [because] once you get in there [the Emergency Department] you're getting treated...they've got people buzzing around you. (G5)

Whilst participants use of ED services was consistent with advice given to them by service providers:

[The Paramedics] say you're not wasting our time...we'd rather go and pick you up with chest pain...instead of going and picking some drunk up off the street...what they say is look, don't be afraid to call us, we're here to help. (M3)

it was telling to note the perceived efficiencies of one service (ie. the ED of a hospital) over those of another service (ie. a General Practice Clinic) for the treatment of cardiac disease on the North West Coast of Tasmania. Two participants drew attention to the possibility the diagnoses may be responsible for those efficiencies:

If you [have] chest pain...the very first thing you do when you arrive at...emergency...[is] tell them because they treat you like royalty after that...[I] told them...and went through the system like you wouldn't believe...you go straight to the head of the queue, they don't muck around. (A6)

...you get a big star beside your name [if you have a cardiac condition] because I did and I said to the lady in the office, I said what's that for and she said you're a top priority. (P1)

Going 'through the system like you wouldn't believe' was a shared experience of a few participants and implicit in their discussions on the matter was assisted, if not effortless, navigation:

...you come in here [the Emergency Department] and go straight through the system and it's taken out of your hands...you're sent to the right area to get what you need. (M3)

The task of navigation seemed further assisted when participants were known to the ED they used and thus had a documented medical history with them, meaning "you don't have to repeat a lot of stuff" (G5) and "you don't have to go through all the other procedures [those pertaining to admission] to get...to where you've got to go." (M3) However, that aspect of ED care was not perceived as flawless:

...you do not see the same doctor so he has to research the whole procedure again...you've got to back track and...get the information in to him how you are. (M3)

Indeed, from participants' comments on ED care it was inferred that navigation had much to do with timely care which was perhaps justified given the cardiac events and conditions for which participants were seeking treatment. It was also inferred that ED care was accessed primarily because of this, not as a way to circumvent alternative treatment options such as General Practice Clinics which were otherwise being used. Furthermore, the navigational assistance afforded

through ED care was appreciated by participants across the range of health literacy proficiencies, as measured by the NVS.

4.3.4.2 ACCESSIBILITY

This theme covers participants' perceived access to services. Data was derived largely from questions that asked participants about the availability of services to them, how they made decisions about which healthcare services they used, and about their overall views of the healthcare system based on their experiences of a cardiac event or condition. Following is an overview of those data proceeded by a concluding commentary on how access to services was understood to impact participants navigation of the healthcare system.

On the topic of availability of services, participants were asked two questions. Firstly, did they feel where they lived influenced the services they received or where available to them? Seven participants lived in the more populated areas of Burnie and Ulverstone. The remaining participants lived in the less populated areas of Penguin ($n=4$), Somerset ($n=2$), Wynyard ($n=3$), Boat Harbour ($n=1$) and Smithton ($n=1$) (Appendix 15). All participants perceived little, if any, influence on the services available to them because of where they were living at the time of being interviewed. That said, one participant reported moving to Burnie from Smithton some years ago to afford better access to the health services he required.

It was acknowledged that to utilise some services (eg. specialist cardiology services) travel was involved. For the majority of participants that did not pose a problem because "you don't have to do it very often" (C1), even when the cost of travel was considered:

[I] just accept it because if it was something I needed to do cost wouldn't come in to it. (C1)

The travel for one participant was seemingly made tolerable because of the family support available at journey's end. For others however, the travel was perceived as intolerable:

It's the bloody travel that bugs me. (R0)

I just don't like long trips. (P1)

Whilst those comments pertained to travel from the North West Coast to the southern cities of Launceston and Hobart, distances in excess of 100 and 300 kilometres respectively, a third participant living in Ulverstone also spoke negatively of having to travel to Burnie or Devonport for services, distances of approximately only 30 and 15 kilometres respectively.

For one participant, the intolerability of traveling to services was made worse because "there's no consideration for area code." (R0) He told of the instance of having an early appointment made in Hobart:

The only thing I find that's an inconvenience about living up here [Smithton] is when you've got to go to Hobart. Half these people down there don't realise the distance because they made my appointment for eight o'clock in the bloody morning. I left here at three o'clock. (R0)

Perhaps also worthy of consideration and emanating from comments made by another participant was the expanded navigation skill set needed to utilise services that are considerable distance from home. For example, there may be the need to book accommodation; arrange transport; organise finances to cover expenses; plan

meals; and organise for an extended absence from home in terms of security, deliveries and so forth.

One participant who lamented the need to travel to specialist services harboured no expectation those services should be available locally. That view was shared by others, of whom two confessed to not realising the extent of services already available locally:

I had scans and things done in Burnie and I was quite surprised that they...could do all that stuff. (A6)

...you don't realise these [local] services are available to you. (L0)

Only one participant felt the services available in Hobart should be available on the North West Coast, suggesting that it was a case of spending available funds more prudently “rather than...on football teams¹⁷.” (P1) Certainly, he was adamant that more services would “help things a lot better.” (P1)

Emerging from participants’ responses in relation to the influence of residential location on service availability was the theme of comparability. More specifically, the comparison between the availability of services in the States’ two largest cities with those on the North West Coast:

Obviously living outside the capital city like Hobart and to a lesser extent Launceston, there are services that are not available here. (G5)

I think Hobart and Launceston have certainly got the better facilities. (M3)

¹⁷

That remark relates to a decision made by the Tasmanian Government to financially support a Victorian Australian Rules football team. Public opinions on the matter were divided as to whether it was a good investment of taxpayers money or whether the money could have been better spent on state-based needs.

That said, the air ambulance service was seen to “make up for a lot of the...isolation problems living outside the big cities” (G5) and that “while there’s isolation, there are worst places.” (G5) Illustrating the latter remark were comparisons made by participants between regional locations:

...if you lived in Tullah [a small, remote town on the West Coast of Tasmania] you’d be struggling...here in Wynyard it’s not so bad, you have access within a short period of time, minutes if you like, to receive medical services. (O6)

If you lived in Burnie you’re going to get fixed up better...the service is going to get there faster. (N1)

Remaining on the theme of comparability and reiterating the previously mentioned notion of timely care was the suggestion the availability of services on the North West Coast was “brilliant because it’s more concentrated within the region... I can get hold of people when I need to without having to wait hours on end.” (O6) Yet for one participant, the ability to actually choose who you ‘can get hold of’ was problematic, even on the Coast:

...we don’t just go to any doctor, you can’t...because they all have so many [patients] don’t they. I mean the doctor surgery where we go to now is full and I don’t think they’re taking on any more. (F3)

A similar sentiment was apparent in comments on service options per se in regional areas:

I think you’ve got no options to go anywhere else here...you’ve just got to use what’s available. (M3)

The second question on the topic of availability of services required a set-answer and asked participants how often they were able to access the health services they needed in their local area. For the majority ($n=16$) it was ‘always’ with the remaining two answers given as ‘often’ and ‘sometimes’. Noteworthy for their

stark contrast were the additional comments made by two participants to their set-answer responses on the question of availability of services. One, with adequate health literacy, added:

You're always able to access [services] if you want them. (A6)

The other participant had limited health literacy and spoke in relation to local healthcare services:

I don't know what's here. (M3)

To conclude that health literacy underscored those comments would be premature at best and a gross misinterpretation at worse based on the available data. They remain therefore, merely noteworthy.

Perceived access to services seemed also to be a function of how participants made decisions about which healthcare services¹⁸ they used. For some it was a pragmatic choice to utilise services closest to their homes or where they shopped. Perceived access was thus contingent on the services in those areas being able to meet participants' healthcare needs, which invariably was said to be the case. Other participants sounded less discerning:

...whoever is around at the time, I'll find the first available medical person I need. (A6)

For those participants, perceived access was contingent on services being available as and when required rather than in one specific location, which again, was said to have been the experience.

¹⁸

When participants discussed healthcare service choices it invariably pertained to GP and pharmacy services.

One theme that emerged from participants' discussions on their views of the healthcare system concerned private healthcare and the impact it had on perceived access to timely services as opposed to services per se in Tasmania. Three participants were enrolled in private healthcare. A fourth participant reported being "lost" (H2) in the information about "the difference between not having private healthcare and having private healthcare" (H2) and so her decision to remain in the public system was seemingly made by default rather than by choice and was, it could be argued, a ramification of limited health literacy. Among the remaining participants (not just the enrollees) there was strong consensus the primary benefit of having private healthcare was the impact it had on the wait time for treatment:

You can get very quick service from the same doctor who'll wait eighteen months to see you in the public system. (G5)

If you want to get [treatment] quicker I think you've got to...go in to private health. (M3)

Yet, for the treatment of cardiac events or conditions the impact was considered negligible:

If you've got something wrong with your heart...you're in there anyway whether you're public or private. (J6)

In summary, participants' perceptions regarding their access to healthcare services raised several points, not least of which being that the services they needed they were able to get. This may have required travel, reduced choice of provider and/or waiting to be seen but such examples were not portrayed by participants as insurmountable barriers to accessing services. Rather, they were portrayed more as impacting navigation and generally not sufficient to deter participants from using healthcare services. It would seem health, and availing of the services needed to maintain it, were a priority for participants and conceivably more so in light of their

cardiac event or condition given “it makes you more aware of taking care of your health better.” (K2)

So how do participants’ health literacy scores contribute to the understanding that potential barriers to accessing services impact navigation more than the perception of accessibility? Perhaps only in the degree of impact the barriers have on navigation given no one type of barrier, or set of barriers, were shown to be typically confronted by participants with either adequate or limited health literacy. That is to say, using an unknown health service facility for instance may prove a greater hurdle for someone with limited health literacy given the likely need to read, understand and follow signage in and around the facility. Likewise, using Patient Transport Assistance Services may be more of a barrier for those with limited health literacy if completing the claim forms is problematic.

4.3.4.3 QUALITY OF CARE

This theme covers participants’ perceived quality of the healthcare services they received. Relevant data were derived from a specific question on the topic, as well as from questions asking participants about how they made decisions about which healthcare services they used, their overall views of the healthcare system based on their experiences of a cardiac event or condition and whether the health outcomes of those experiences influenced their perceptions of the system and how easy or hard it was to navigate (Appendix 18). Given the suffuse nature of the topic data were also generated elsewhere in the interviews and focus groups, albeit to a lesser extent. Following is an overview of those data in the context of participants’ navigation of the healthcare system.

Across the gamut of NVS scores, participants viewed the quality of care they received in relation to their cardiac health needs¹⁹ from “quite OK” (Q0) through to “excellent.” (E0) In other words, positively. Influencing those sentiments was recognition of advances in health care delivery:

I often wondered, like years gone by when things were more slower, how long it took a person to get from point a to b with an operation compared to today, like the phones are just so quick and everything is just switched on whereas before it was you know, it was a whole lot harder. (P1)

the attributes of healthcare providers:

[I've] never, ever had to question the dedication and loyalty of those people. (E0)

including their fallibility:

Nobody is perfect and doctors and nurses make mistakes like everyone else. (D1)

the timeliness of care:

If...something's got to be done it seems to be fairly quick. (P1)

and the expertise of medical professionals:

If [the doctor] prescribes a pill for me I'm taking it because he's the expert. (H2)

Notably though, the positive sentiments to do with the quality of care participants received were expressed amid narratives counter to those sentiments. That was

¹⁹ All participants spoke with reference to acute care given the nature of their conditions and the subsequent treatment they experienced.

observed across a number of discussion topics including private versus public healthcare, record keeping, provider attributes and participants' service expectations.

Whilst acknowledgement was given to a person's "prerogative to do what they like" (E0) regarding private healthcare, it was evident the participants were not in the business of promoting its uptake. For example, the supplementary benefits of "free television and a quilt on your bed or a private room" (J6) provided to people with private healthcare were discussed somewhat flippantly, inferring their immateriality relative to the care received:

If you go private...so what! About the only difference is you get a free television. (G5)

Two privately insured participants questioned the value of their cover based on the inappreciable differences they perceived to the care available through the public healthcare system:

In theory you're suppose to get the top surgeon...in practice it's no different from the public. (G5)

And with reference to a hospital experience:

...there was a chap in there...and he wasn't in private and...I never got any more, better treatment than what he did. (P1)

Those sentiments were supported by comments from other participants:

...we've never had any real problems [with] speed of treatment or quality of treatment [in the public healthcare system]. (E0)

Aside from [the reduced wait period] the service wouldn't have been no different...I'd have had the same doctors, same everything really. (N1)

In essence then, private healthcare was considered little different to that available through the public healthcare system despite the associated expenses incurred by enrollees.

That is not to suggest however, the public healthcare system set the benchmark for quality care given, for example, the expressed opinions of participants whose incomes were derived from a government-funded pension:

I expected...a bit better [care] than what I got but at the same time I thought well I can't argue, I'm only on a benefit, I'm not paying for this so it's like second rate. (H2)

Given fifteen of the eighteen participants were on some form of government pension those comments were not without support:

*I'm on a pension, I'm not a private patient but...you do expect we live in a decent country [where] you're not classed. (F3)
...we're paying out of our taxes already for basic services, everybody should have the same right. (O6)*

For many, the discussion on private versus public healthcare epitomised “something wrong with the system” (G5) because “all patients should be treated the same...[and] if [a treatment] needs to be done it needs to be done.” (M3) Two participants could see no difference between private and public payment of healthcare because, they reasoned, “the public’s paying anyhow.” (F3) Certainly as far as quality of care was concerned, participants in one focus group agreed the source of payment “shouldn’t make any difference in procedure, timing, the doctor or whatever.” (J6) Extending that notion of parity, one participant reported “having

[the healthcare system] as private, public, state [and] federal, it becomes unwieldy.”

(O6) Instead he suggested a generic system:

...where it doesn't matter what state you're in, what part of the country you're in, what nationality you are or what race or religion you are, we should all receive the same sort of duty of care and level of care at the same cost structure. (O6)

Record keeping within the healthcare system was another discussion topic about which sentiments seemed contrary to those expressed by participants in relation to quality of care:

The first appointment had been cancelled and was to be re-scheduled [but] they had no record of it. (G5)

I fell through the cracks. The paperwork never came through...to get me into the [Cardiac Rehabilitation] Program. (R0)

I went to my GP...and I knew more than him, he'd never heard from the...hospital which was highly wrong. (Q0)

Tuesday morning I finally got transferred because [the hospital] forgot to send the paperwork through. (N1)

Significantly, the reported ramifications of those experiences had navigational implications. For example, participant G5 had to chase up an appointment which proved difficult and participant Q0 was put in a situation of having to relay medical information to his GP that he otherwise should have had which the participant considered “not fair” (Q0) and subject to possible misinterpretation. Participants N1 and R0 both experienced delays in their treatment due to poor record keeping which may have had navigational implications (eg. compromised health outcomes requiring on-going treatment) but were not made apparent by either participant.

At the same time healthcare provider attributes seemed to epitomise quality of care for participants, so too were they said to detract from it. For example, one participant denounced providers for their lack of empathy towards patients and endeavour to find “five minutes of...time to say ‘how do you feel’?” (H2) Whilst that comment was prefaced with an understanding “the system is so over crowded and...getting individual attention is not always possible”, the participant was explicit in how it may benefit:

If you want someone to understand themselves or to gain ground from their problem or to step up so that they're not still there in that situation, that five minutes of time, whatever the reason it is given, can be enough to put that person back on track and make them feel good and worthy about themselves. (H2)

That suggestion for improvement was perhaps not surprising given the participant who made it likened the experience of having a stent put in to being an animal in a slaughter yard with everyone “lined up in pens ready to have their heads chopped off.” (H2)

Another example of provider attributes detracting from quality care concerned the experience of a participant with an ambulance driver wanting to transport her to a hospital:

...he was so rude and he upset me so much...in the finish I said no, I'll stop here, I'll stay home. (K2)

That the participant elected to stay at home rather than receive hospital-based emergency care for her cardiac condition because of the driver's rudeness underscores the importance of provider attributes in the delivery of quality care. Certainly, an intolerance of similar experiences was apparent among other participants:

[The quality of service] has never become a problem otherwise I wouldn't be going to that particular GP. (E0)

Likewise, a participant changed where she filled her prescriptions “because [the chemist] wouldn't have [my medication] in stock and I just got jack of it.” (D1)

It could be argued the narratives counter to the positive sentiments participants expressed about the overall quality of care they received were indicative of their unmet expectations about how the healthcare system should function. There was, for example, an implied expectation of obtaining a second opinion:

I would have thought when he knew I was having the problems...I was having that he would have said...I think we should send you to like a heart specialist or something to get it re-checked out...but he didn't. (M3)

...it should have been a case of 'we believe it may have been an angina attack...but to be on the safe side we suggest you go and visit such and such hospital as soon as possible to get a clarification.' None of that was said. (O6)

I'd like to think I'd be sent to a specialist. (A6)

For one participant, the second opinion itself seemed to carry an expectation:

...so we travel all this way down to Hobart...we see this bloody specialist...and he tells me the exact same thing as my GP told me...what's the use. (R0)

The expectation of a second opinion corresponded to that of follow-up care for two participants:

Since I've had [my cardiac event] there was no follow-up...I've had to push to get a six month check-up...I understood it was automatic. (O6)

The only time I see the GP now is if I run out of tablets. No follow-up...tests...I mean, with what I've had. (I0)

Yet, not all participants expressed unmet expectations about the healthcare services they received:

Everything what's needed to be done has been done for me...I can't ask for anything more. (F3)

[The doctors] did what they had to do and that's all I expected. (K2)

There were no explanations accompanying those comments so it can only be speculated as to how participants F3 and K2 decided the treatment they received was all that could be done for them. Their decisions, for example, could have been influenced by the perception of good health outcomes, as was alluded to in a comment made by another participant:

If you go in...and you don't come out real well you're not going to be real happy are you. (D1)

The overtures of negativity emanating from participants' narratives were seemingly at odds with their positive sentiments about the quality of care they had received in relation to their cardiac event or condition. However, the data analysis revealed the overtures were, in comparison, not prevalent. Moreover, the perceived quality of care was reflected in participants overall view of the healthcare system:

I think the system does work well. (C1)

I've been treated very well. (L0)

It's all very efficient I found. (G5)

I haven't had any great problems with the health system...I've had a good run. (M3)

I find [the healthcare system] ever so good. (R0)

As far as the heart procedure and everything like that goes it's pretty good really. (Q0)

We're happy with the...system ...you can't go wrong. (F3)

I can't ever say that I've had any problems...I honestly have found the healthcare system very helpful. (D1)

It's been pretty good. (K2)

Our healthcare system works very well. (J6)

I think what we've got is pretty good...the system is not going to chuck you out the door and let you die in the gutter. (A6)

I really couldn't fault anything. (B2)

I reckon it's pretty good. (P1)

Whilst less explicit and lavish with their endorsements, two of the remaining participants reported a willingness to use the healthcare system should the need arise and, with the exception of one hospital, another reported:

...the rest of the system I don't have a problem with. (N1)

Professing to “understand the system and the situation” (E0), one participant directed their praise towards the people working in the system more so than the system itself:

Those people...they were completely and utterly committed to what they were doing but...the bureaucratic side of it sometimes leaves a lot to be desired...the system...doesn't run as well as it should [because] there are too many chiefs and not enough Indians. (E0)

That said, his overall view was philosophical:

Sometimes when [the healthcare system] goes wrong you are, like I am, very quick to criticise but in the long run it is the system...sometimes it works well, sometimes it doesn't...I accept the system for what it is. We'd love to make it better but then people tell you they haven't got the staff, they haven't got money, they haven't got this, that and everything else so you've got to go with the system as it exists. (E0)

Seemingly far less philosophical, another participant felt “very disillusioned with the medical side of it...and the system” (H2) based on experiences “going back many years” but remained “grateful there is such a thing as the services that are there...because who knows, I could be bloody dead.” (H2)

Participants' views of the healthcare system and the quality of care it provides seemed also to reflect their ability to avail of its services. That is, the majority expressed, or implied, confidence with navigation which was in keeping with their positive view of the system and the care they received:

I'm reasonably confident with it all. (A6)

I find you move through reasonably well. (O6)

It's relatively easy, we know the road map. (E0)

Perhaps then, it was not surprising the participant who reported being “disillusioned” (H2) with the system also reported a struggle “to understand it” (H2)

on account of not being “involved in it a bit more.” (H2) As did one other participant who reported few explicit endorsements of the system:

I've never had anything really to do with [the healthcare system] until now so...as for knowing me way about, no I don't. (I0)

A link between levels of use and understanding was evident in the comment of another participant who suggested the healthcare system was “designed that way...you get in to the system and you become knowledgeable.” (E0)

4.4 SUMMARY

Overall, the data present a demographically unremarkable group of participants with health literacy levels commensurate with the high percentage of Tasmanians found to have low health literacy in the Australian ALLS. More remarkable perhaps, in light of those data, was that participants’ experiences navigating the Tasmanian healthcare system were largely positive and reflect a sense of ease with the task. However, exploration of the themes emerging from participants’ recollections of those experiences reveals a complex, interrelated picture of:

- active versus passive navigation/self-management driven by experience/motivation;
- knowledge impacting navigation whether present or absent;
- commonsense and verbal exchange mediating the impact of health literacy self-efficacy on navigation;
- mindsets directing navigational decision making;
- guidance and support, together with certain dispositions, making the task of navigation more or less difficult;
- the complexities of patient-provider interactions in the context of navigation;
- timely care and how best to obtain it;

- service access barriers impacting navigation but not the priority to maintain health;
- perceptions about quality of care influencing navigational decision making about the providers and/or services used;
- perceptions about the healthcare system influencing navigation in terms of level of engagement;
- there being an array of requisite skills enabling navigation.

It will be the intention of the proceeding chapter to discuss, in the context of relevant literature, whether participants' health literacy helps to fathom such complexity.

CHAPTER 5 – DISCUSSION

5.1 OVERVIEW

The data revealed healthcare system navigation was something the majority of participants felt confident about. However, the simplicity of that statement belies the complexity of their navigational experiences and gives no indication as to the role participants' health literacy may have had underwriting them. This chapter therefore presents a discussion of the qualitative (QUAL) data in the context of relevant literature to address the question: do participants' health literacy scores contribute to an understanding of their experiences of navigating a healthcare system to manage their chronic cardiac disease? The discussion deals in turn with each statement in the summary of the previous chapter which were made to demonstrate the complexity of the thematic data to have emerged from participants' recollections of their navigation experiences. Necessarily, the focus of the discussion will be whether participants' health literacy scores make sense of those summary statements. The presentation of a framework that encapsulates the essence of the discussion will conclude the section.

5.2 ACTIVE VERSUS PASSIVE NAVIGATION/SELF MANAGEMENT DRIVEN BY EXPERIENCE/MOTIVATION

For the majority of participants, navigating the Tasmanian healthcare system was something they felt they attempted to their satisfaction. Moreover, they were motivated to participate in the management of their cardiac health which necessitated access to, and use of, that system. Intuitively, those data describe a group of people with adequate health literacy given, by definition, health literacy determines motivation towards actions (eg. healthcare system navigation) that promote and maintain good health (WHO, 1998). Yet, in reality, the data described a

group of people for whom health literacy skills were limited in all but four cases. That was evidenced by participants' understanding of treatment protocols, or rather, the logic behind why they were following a particular navigational path through the healthcare system to have their cardiac symptoms addressed. Whilst participants with adequate health literacy spoke with detail, accuracy and noted confidence on the topic, the same could not be said for those with limited literacy. That was not an unexpected finding given the numerous studies reporting an association between limited health literacy and poor understanding of treatment protocols (eg. Ishikawa & Yano, 2008; Kalichman, Bemotsch, Suarez et al., 2000; Paasche-Orlow, Riekert, Bilderback et al., 2005).

Lack of understanding alone, however, did not pose a barrier to participants' navigation so much as 'styled' their approach. In other words, there was a tendency for those with adequate health literacy to be active navigators and those with limited literacy to be passive navigators²⁰. Implicit in examples of the former were participants' abilities to reflect on and use their navigational experiences to positively influence their passage through the healthcare system and as such, assume a level of control. For Nutbeam (2000, 2008), such abilities represent an advanced level of functioning in the health environment; for Anderson and Funnell (2010), a sign of empowerment; and for Sofaer (2009), a sign of "activated patients [prepared to] take independent action to protect their health" (p. 79S).

In contrast, the experiences underwriting passive navigation had seemingly taught other participants with limited health literacy to be far more reliant on guidance and far less likely to question its logic. For those participants navigation was simply 'going with the flow' and noteworthy for its lack of expressed or implied sense of control. Moser and Watkins (2008) equate having a sense of control to

²⁰ The terms 'active' and 'passive' appear in health literature to describe patient behaviour that is consistent with the descriptions of active and passive navigation/self-management used presently (Morrow & Wilson, 2010; Naik, Street Jr., Castillo et al., 2010; Paasche-Orlow, Wilson, & McCormack, 2010; Sofaer & Gruman, 2003; Vogel, Leonhart, & Helmes, 2009).

believing in one's ability, perhaps suggesting participants with adequate health literacy had a greater belief in their ability to navigate the healthcare system than did participants with limited health literacy. Research linking health literacy to belief in ability (or self-efficacy) certainly attests to that suggestion (Dennison, McEntee, Samuel et al., 2010; Macabasco-O'Connell et al., 2011; Osborn, Cavanaugh, Wallston et al., 2010; Ussher, Ibrahim, Reid et al., 2010), although not unanimously, as will be discussed shortly in the context of health literacy self-efficacy.

Self-management practices influence when, how and why people navigate the healthcare system (Coulter & Ellins, 2007; Horowitz, Rein, & Leventhal, 2004) and were similarly portrayed by participants as an active or passive endeavour. That is, participants were either doing as much as possible to prevent another cardiac event or deterioration in their condition (active self-management) or they were doing only activities as directed and considered essential, such as taking medication and attending appointments (passive self-management). So whilst all participants were reportedly motivated to engage in the self-management of their conditions, the translation of that drive into action varied. Moreover, the variation was across health literacy proficiencies with neither active or passive self-management indicative of participants with adequate or limited health literacy but rather, a combination of both.

Until recently, the "substantial body of literature" (Audulv, Asplund, & Norbregh, 2010, p. 94) explaining self-management behaviour articulated the role of health literacy somewhat tacitly. For example, Smith, Forkner, Krasuski et al. (2006) assessed whether educational attainment (as distinct from, but related to, health literacy) moderated outcomes in a group of heart failure patients and found it played only a limited role. Likewise, findings by Field, Ziebland, McPherson et al. (2006) cautioned against the presumption active self-management was indicative of better disease knowledge and understanding, inferred to mean better health

literacy. More recent studies, explicitly focused on the relationship between health literacy and self-management, have found a positive association (Macabasco-O'Connell et al., 2011), a negative association (Chen et al., 2011) and no association (Dennison et al., 2010; Mbaezue et al., 2010).

The literature then, is inconclusive as to whether health literacy impacts self-management and as such, provides three insights. Firstly, the variation in the present data on the topic is reflective of the literature in so much as it is unable to attribute self-management practices to level of health literacy. Secondly, the inconclusiveness of both the literature and present data suggest the possibility of confounding variables in the relationship between health literacy and self-management beyond motivation (von Wagner, Steptoe, Wolf, et al., 2009). For example: age (Evangilista et al., 2003; Kripalani, Gatti, & Jacobson, 2010; White, Chen, & Atchison, 2008); gender (Lubetkin, Lu, & Gold, 2010; Waldrop-Valverde, Jones, Jayaweera et al., 2009); the extent to which people accept a diagnosis of chronic illness (Gazmararian, Ziemer, & Barnes, 2009; O'Hair, Thompson, & Sparks, 2005) and responsibility for its management (Anderson & Funnell, 2010; Audulv et al., 2010); perceptions of illness (Wichowski & Kubsch, 1997; Horowitz et al., 2004) and self (Rubinelli, Schulz, & Nakamoto, 2009; Welstand, Carson, & Rutherford, 2009); cultural or individual values (Peerson & Saunders, 2009); cognitive functioning (Waldrop-Valverde et al., 2010) and memory (Kessels, 2003); prior exposure to illness through the experience of others (Peek, Wilson, Gorawara-Bhat, et al., 2009); whether sources of motivation are internal or external (Ell, Vourlekis, Xie et al., 2009; Shigaki, Kruse, Mehr et al., 2010); patient-provider interaction (Matthews, Peden, & Rowles, 2009; Phillips, 2010); and the circumstances, or context, in which self management decisions are made (Marmot & Bell, 2011; Mead et al., 2010; Moser & Watkins, 2008). Thirdly, it is an area in need of further research.

5.3 KNOWLEDGE IMPACTING NAVIGATION WHETHER PRESENT OR ABSENT

Research has found a positive relationship between health literacy and knowledge of disease (Ashida, Goodman, Pandya et al., 2010; Boulware, Carson, Troll et al., 2009; Federman, Wisnivesky, Wolf et al., 2010; Gazmararian et al., 2003; Johnson, McEntee, Samuel et al., 2010; McEntee et al., 2009; Osborn, Paasche-Orlow, Bailey et al., 2011; Pandit et al., 2009; Powell, Hill, & Clancy, 2007; Ussher et al., 2010; You, Wolf, Bailey et al., 2010), as well as knowledge of disease and its subsequent management (Beard, Clark, Hurel et al., 2010; Hawkins, Berkowitz, & Peipins, 2010; Jeon, Kraus, Jowsey et al., 2010; Johnston, Clark, Dingle et al., 2004; Kayaniyil, Arden, Winstanley et al., 2009; Khavjou, Finkelstein, Farris et al., 2009; Lainscak & Keber, 2006; Mead et al., 2010; Persell, Bailey, Tang et al., 2010). The present data confer those findings, the latter with reference to navigation as it pertains to disease management. Indeed, participants' cardiac knowledge was observed to equip them with an understanding of when and how to respond to their symptoms. The depth of cardiac knowledge of those with adequate health literacy seemingly made that aspect of navigation an accurate and straightforward process. A similar depth of knowledge was not as evident among participants with limited health literacy who reportedly struggled with knowing, for example, whether chest pain was coming from indigestion or a stressed heart muscle. Navigational responses in those circumstances were more prone to inaccuracies such as delayed treatment seeking or accessing emergency services unnecessarily.

The present data revealed why participants with limited literacy may have struggled to acquire the knowledge needed to understand and accurately respond to their symptoms given their expressed difficulties learning from, and applying, health information; not wanting to be informed to allay feelings of anxiety; and being overwhelmed by the quantity of information given out through the CRP. The

data also revealed why participants with adequate literacy may have found understanding and responding to their cardiac symptoms a more accurate and straightforward process given their expressed ability to learn; being able to discern the reliability of health information based on its source; a broader medical vocabulary; better awareness of the roles of the healthcare professionals they encountered; and a depth of understanding about their conditions that implied rudimentary knowledge about the human body and how it works.

However, congruencies between the literature and present data would suggest the inferred relationship between cardiac knowledge and navigation cannot be completely understood in terms of health literacy. For example, using the Commonsense Model of Illness Representation²¹ Ryan and Zerwic (2003) found when interpreting symptoms of cardiac disease, delayed treatment seeking was “a multidimensional phenomenon” (p. 186) incorporating cultural perspectives as to their cause. Included among those perspectives was the attribution of symptoms to normal ageing which reflect the sentiments expressed by the majority of participants in the present research. A small group of participants with varying health literacy proficiencies also reported an initial period of symptom denial which Buetow, Goodyear-Smith, and Coster (2001) describe as a psychological coping strategy, in turn producing outcomes like delayed treatment seeking (Beer, Fagan, Valverde et al., 2009).

Providing another example, Horowitz et al. (2004) found their research patients commonly perceived heart failure to be an acute rather than chronic illness and so in the absence of symptoms, health was deemed restored. The salient consequence was healthcare navigation based on reactions to acute episodes rather

²¹ A “widely cited” (p. 185) model according to Ryan and Zerwic (2003) that proposes how people respond to illness is a consequence of their cognitive and emotional representation of that illness. The representation serves as a framework to make sense out of information and has the following four components: symptoms and interpretation; perceived causes of the illness; expected consequences; and duration. (Leventhal, Brissette, & Leventhal, 2003)

than more preventive measures (eg. regular cardiac reviews) deemed crucial to the on-going management of cardiac conditions (Sindone, 2008). Sharing those perceptions were a number of participants in the present research and across the range of Newest Vital Sign (NVS) scores who showed little evidence of having adopted a “chronic model” (Horowitz et al., 2004, p. 637) that would enable them to recognise gradual changes in their symptoms as worsening cardiac health and cues for action to block or slow any deterioration. According to Riegel et al., (2007) that equates to poor self-management.

5.4 COMMONSENSE AND VERBAL EXCHANGE MEDIATING THE IMPACT OF HEALTH LITERACY SELF-EFFICACY ON NAVIGATION

Participants’ health literacy self-efficacy was related to filling out forms, reading hospital materials and learning about their cardiac conditions, as covered by the Set of Brief Screening Questions (SBSQ). Analysis of participants’ responses to those questions revealed perceived effectiveness in performing such tasks had the potential to impact navigation of the healthcare system and underscored the important relationship between understanding and action in the healthcare context (Wood, Price, Dake et al., 2009). For those with limited health literacy and low self-efficacy the impact on navigation was negative (eg. the potential for delayed care as a result of being unable to complete a medical form correctly in the time and space provided) and described as a ‘shortfall perspective.’ Conversely, for those with adequate health literacy and good self-efficacy the impact on navigation was positive (eg. being able to readily understand, and feeling confident enough to apply, new health information to personal circumstances to improve self-management) and described as an ‘effectual perspective.’

Whilst no comparative research could be found alluding to health literacy self-efficacy in the context of healthcare system navigation, the positive association

found between health literacy and self-efficacy concurred with previous research conducted in a variety of settings and contexts (Dennison et al., 2010; Gallagher et al., 2008; Macabasco-O'Connell et al., 2011; Osborn et al., 2010; Shieh, Mays, McDaniel et al., 2009; Ussher et al., 2010; von Wagner, Semmler, Good, et al., 2009; Wolf, Davis, Cross et al., 2007; Yehle, Hess, Plake et al., 2010). Conversely, research has also shown no direct association between health literacy and self-efficacy (Cameron, Ross, Clayman et al., 2010; Chen et al., 2011; DeWalt, Boone, & Pignone, 2007; Osborn et al., 2011; Sarkar, Fisher, & Schillinger, 2006), thus creating an agenda for further investigation.

Adding to that agenda are the present data that adopt neither a shortfall nor effectual perspective: where participants with limited health literacy exhibited good self-efficacy. By way of explanation, the mechanisms of commonsense and verbal exchange were found through analysis to account for those data. Whilst a commonsense approach to navigation is not evidenced in the literature, Zarcadoolas (2010) makes reference to 'ubiquitous' health literacy on the American National Institute for Literacy Health Literacy Listserv. Its essence is not dissimilar to that of commonsense in so much as it is said to account for the concepts and abilities people do have and do use when endeavouring to make meaning out of health information and subsequent health decisions. That those concepts and abilities are not necessarily grounded in a basic understanding of health implies they come from alternative sources which conceivably may include, but not be limited to, notions of commonsense.

Unlike the lack of evidence in the literature for a commonsense approach to navigation, one predicated on verbal communication can be inferred from research showing poor comprehension of written health information among those with low health literacy (Gausman Benson & Forman, 2002; Karnieli-Miller, Adler, Merdler et al., 2009; Kumar, Sanders, Perrin et al., 2010) who instead prefer oral

communication with health service providers (Baker et al., 1996; Friedman et al., 2009). That said, the literature depicts communication as a very complex field of enquiry (Aoroa, Street Jr., Epstein et al., 2009; Burton, Blundell, Jones et al., 2010; Easton, Entwistle, & Williams, 2010; Greenberg, Walker, & Buchbinder, 2006; Kreps, 2009; Larson, 2007; Leroy, Heinreich, & Cowie, 2010) and as such, is beyond the scope of the present discussion to explore more fully how it may account for the impact of self-efficacy on navigation.

5.5 MINDSETS DIRECTING NAVIGATIONAL DECISION MAKING

Whilst viewpoints among participants regarding navigation decisions varied, a prominent one concerned the use of health services. A number of participants were of the view health services were to be used only when absolutely necessary, implying a certain reluctance to avail of care. Moreover, it was a view shared among participants who achieved across the range of health literacy scores on the NVS. Australian research on peoples' experiences of accessing Emergency Department (ED) care evidenced a similar reluctance among its population sample of thirty elderly Victorians (Considine et al., 2010) but health literacy was not an explicit consideration. However, the authors did note a potential clinical risk as a result of delayed treatment seeking which was also remarked upon in the analysis of the present data.

Guerra, Dominguez, and Shea (2005) investigated the association between health literacy and beliefs and attitudes about, and reported usage of, colorectal cancer screening tests. Whilst their terminology differed from the present research, references to 'beliefs and attitudes' were deemed congruent with the intended meaning of 'mindsets' used in this thesis. Importantly, Guerra et al. (2005) found health literacy was neither independently associated with beliefs and attitudes nor use of the screening tests. Using similar terminology, Briggs, Jordan, Buchbinder

et al. (2010) also found health literacy was not related to beliefs and attitudes among a sample of people with lower back pain, all of whom were assessed as having adequate health literacy. Notably, those and the present data seem at odds with Berkman, Sheridan, Donahue et al.'s. (2011) claim that "attitudes result from knowledge" (p. 3) given the aforementioned link between knowledge and health literacy.

Participants' mindsets directing their navigational decision making were implicit in their approach to taking medication. Almost without exception participants reported adhering to the medication regimens they had been prescribed because it was viewed as an important aspect of the management of their cardiac health. Whilst Evangelista et al. (2003) also found a high rate of medication adherence among a sample of heart failure patients, the literature more commonly reports low medication adherence rates across various patient populations (eg. Cruess, Localio, Platt et al., 2010; Murray, Young, Hoke et al., 2007; Morrow & Wilson, 2010; Ngoh, 2009; Pound, Britten, Morgan et al., 2005; Vourlekis & Ell, 2007). The present finding on medication adherence then, was unexpected and one not readily attributable to the health literacy of the relevant participants given that both adequate and limited health literacy scores on the NVS were represented among them.

The literature similarly suggests that although health literacy has been associated with medication adherence (Aikens & Piette, 2009; Blake, McMorris, Jacobson et al., 2010; Gazmararian, Kripalani, Miller et al., 2006; Janisse, Naar-King, & Ellis, 2009; Murray et al., 2009; Ngoh, 2009; Persell, Osborn, Richard et al., 2007), so too has comorbidity (Dunbar-Jacob, Bohachick, Mortimer et al., 2003); self-efficacy (Cameron et al., 2010); information on medication (Carpenter, DeVellis, Fisher et al., 2010); memory (Evangelista et al., 2003); cognition (Waldrop-Valverde et al., 2010); age (Kripalani et al., 2010); support (Aoun & Rosenberg, 2004; Gerber, Cano, Caceres et al., 2010); economics (Jeon et al., 2009); change in beliefs over time

(Allen-LaPointe, Ou, Calvert et al., 2010); and patient-provider interactions (Karter, Subramanian, Saha et al., 2010).

5.6 GUIDANCE AND SUPPORT, TOGETHER WITH CERTAIN DISPOSITIONS, MAKING THE TASK OF NAVIGATION MORE OR LESS DIFFICULT

The present data revealed navigation and, by association, self-management to be a decision making process that was made more or less difficult for participants as a result of the level of guidance and support they received. In other words, decisions were inferred to be less difficult if advice was intelligible, accurate and/or from a credible source and if support allowed participants to share the burden of their wavering emotions. Conversely, decisions were inferred to be more difficult if advice was unintelligible, deemed inaccurate and/or from an unreliable source and if support was not available. Significantly in the context of the present research, the impact of advice and support on participants' navigational decision making was not reflected in their health literacy proficiencies given there was no clear delineation in interpretation of those data for either group.

Much has been written about decision making in the healthcare setting with the literature substantiating a positive association between health literacy and decision making ability (Amalraj, Starkweather, Nguyen et al., 2009; Peek et al., 2009). Whilst overall the present data were unable to conclusively support or oppose those findings, three features warrant mention in the context of relevant literature. Firstly, the majority of participants in the present research who used the Internet as a source of health information had limited health literacy as opposed to the higher literacy proficiencies of Internet users found more consistently in other research (Lee, 2009; Miller & West, 2007; Sarkar, Karter, Liu et al., 2010; Shaw, Ibrahim, Reid et al., 2009; Sheih et al., 2009; Walsh, Trentham-Dietz, Schroepfer

et al., 2010). One possible explanation for such variation, relative to the participants' health literacy, may be that it was a skill born out of necessity. In other words, they were unable to comprehend the information given to them by their healthcare providers and so used the Internet to fill the gaps in their knowledge. Participants with adequate health literacy were likely more able to comprehend the information they received from their healthcare providers and thus had less need to use the Internet. Another explanation may be the anonymity the Internet affords its users. Participants with limited health literacy may have felt a level of self consciousness that made asking basic questions of their health providers very difficult. The Internet therefore allowed them to obtain answers to those questions without the negative emotion. Clearly, more data would be needed to establish the validity of both explanations, especially given both groups reported being skeptical of the accuracy of health information obtained from the Internet.

According to Wangberg, Andreassen, Kummervold et al. (2009), such skepticism safeguards the position of the healthcare provider as a source of health information. Concurring with those sentiments is the second notable feature of the present data on health-related decision making. That is, the principal role of the General Practitioner (GP) as the face-to-face health adviser in the minds of participants across the NVS score range. Notwithstanding the availability of other health professionals (eg. Cardiac Rehabilitation Program - CPR staff, pharmacists, nurses) and sources of health information (eg. the Internet, media reports) to advise participants, the GP as the 'first port of call' reflects an historical role (Ishikawa & Yano, 2008) and one described by Stille, Jerant, Belle et al. (2005) as a "defining principle of their work" (p. 700). Moreover, it is a role that dominates the Australian healthcare landscape (AIHW, 2010c) and has been noted in other research (Bunn, Lange, Urrutia et al., 2006; Davidson et al., 2007; Gaglio, 2010; Jeon et al., 2010; Rasmussen et al., 2001; Schoen, Osborn, & Doty, 2007).

The third notable feature of the present data to do with the decision making process inherent in healthcare navigation was the frequency and importance about which the support of others was discussed by all participants. There appears no shortage of health literature validating their sentiments (eg. Bakeera, Wamala, Galea et al., 2009; Davidson et al., 2007; Johnson, Jacobson et al., 2010; Jones et al., 2010; Lee, Arozullah, & Cho, 2004; MacMahon & Lip, 2002; Mead et al., 2010; Moser & Watkins, 2008; Pier, Shandley, Fisher et al., 2008; Riegel et al., 2007; Rosland, Heisler, Choi et al., 2010; Sayers, Riegel, Pawlowski et al., 2008; Wathen & Harris, 2007; Wouters, Van Damme, Van Loon et al., 2009). Of pertinence are data showing a positive association between health literacy and the presence of support (Kalichman & Romper, 2000; Lee, Gazmararian, & Arozullah, 2006; Osborn, Bains, & Egede, 2010; Santos Zanchetta, Perreault, Kaszap et al., 2007; Ussher et al., 2010). Arozullah, Lee, Khan et al. (2006) on the other hand, found medical patients with lower literacy were more likely to always have support than those with higher literacy. The authors reasoned that was because it reduced the stress of dealing with the healthcare system for those with low literacy. The present data would attest to that logic but with broader application to also include participants with adequate health literacy. An intuitive explanation would be that both groups found dealing with the healthcare system stressful. Whilst that would account for data showing all participants reported having the support of others to help with their navigational decision making, it remains inconclusive as to whether participants health literacy scores contribute to an understanding of those data.

Just as guidance and support made participants' navigational decision making more or less difficult, so too did their varyingly ascribed dispositions of amicableness, acceptance, assertiveness and independence. Analysis of the data suggested participants who were amicable and accepting were more willingly guided on their navigational journeys and condoning of the fallibility of the healthcare system as well as the people working in it. For them, navigational decision making

was about surmountable barriers and portrayed as less difficult because it was most often the ‘path of least resistance.’ In contrast, participants with assertive and independent dispositions experienced more frustration and thus more difficulty making navigational decisions. Respectively, this was said to be a result of the unmet demands they were making on the healthcare system and the confusion it generated. Whether participants’ health literacy explained their dispositions remains speculative given they were, like mindsets, not shown to be an idiosyncrasy of any of the NVS score groups²².

So too is it difficult to ascertain in the relevant literature whether health literacy contributes to an understanding of dispositions given the paucity of information specific to the topic. Inferences may nevertheless be drawn from research on related matters. For example, Kempen, Sanderman, Miedema et al. (2000) studied the influence of “psychological attributes” (p. 439) (specifically: neuroticism, mastery and self-efficacy expectancies) on functional decline after selected cardiac conditions. They found an association between the studied attributes and health outcomes through a variety of behavioural and cognitive mechanisms. In the context of the present research those findings suggest health literacy could mediate the impact participants dispositions (or ‘psychological attributes’) have on their navigation of the healthcare system if understood in terms of ‘behavioural and cognitive mechanisms’.

More recently, data from two studies provide insight into the possible impact dispositions may have on interactions in the healthcare setting and its navigational implications. Jensen, King, Guntzviller, et al. (2010) investigated communication satisfaction with healthcare providers among low-income adults. They found lower satisfaction among adults who were “active” (p. 30) in doctor-patient interactions

²² Whilst only one participant subscribed to an independent disposition and had limited health literacy, based on the available data the question remains pertinent. That is, whether her low health literacy accounted for her independent disposition?

and higher satisfaction among those who, in similar situations, were more withdrawn. Conceivably, the assertive participants in the present research compare favourably to Jensen et al's. (2010) 'active' adults whilst the amicable/accepting participants equate to the withdrawn adults. If the levels of communication satisfaction hold true for both groups it may help explain their aforementioned experiences of navigational decision making.

Similarly focused on patient-provider communication, Street and Haidet (2011) revealed providers had a better understanding of their patients' health beliefs if the patient "asked questions, expressed concerns and stated preferences and opinions" (p. 24). Bearing the same hallmarks of the assertive participant described in the present research, the implications of providers having a better understanding of their health beliefs could, as Street and Haidet (2011) suggest, improve decision making and quality of care. Interestingly, the aggregated data of both studies imply a conundrum for the assertive participant in terms of their navigational decision making: an unsatisfying experience fraught with difficulty, yet with the potential for better care. More saliently, the three examples of research, chosen for their pertinence to the topic at hand, provide no clues to determining whether health literacy may underscore dispositions because health literacy was not a variable under consideration. It therefore remains a question in search of an answer.

5.7 THE COMPLEXITIES OF PATIENT-PROVIDER INTERACTIONS IN THE CONTEXT OF NAVIGATION

Coutler and Ellins (2007) attest to the importance of patient-provider interactions in the healthcare setting when they write:

Health information materials, decision aids, self management action plans and other “technologies” of patient engagement are most effective when they supplement, or augment, rather than replace, interactions between patients and professionals (p. 27).

For participants, the importance of those interactions was implicit in their recounting of experiences navigating the Tasmanian healthcare system. Each had their story to tell and each story varied from the one before resulting in a broad representation of complex data across five sub-themes: communication; trust; attitudes; relationships built over time and participants strategic use of their interpersonal skills to obtain health services. Moreover, the data were inconclusive as to the contribution participants health literacy made to understanding the sub-themes given the range of NVS scores to which each pertained.

On that point, the literature appears sympathetic. For example, there is evidence to suggest limited health literacy acts as a barrier to effective patient-provider communication (Evangelista et al., 2010; Kripalani, Jacobson, Mugalla et al., 2010; McEntee et al., 2009; Sudore, Landefeld, Pérez-Stable et al., 2009; Williams, Davis, Parker et al., 2002; Wynia & Osborn, 2010), but not always to the exclusion of the those with adequate health literacy (Baker et al., 1996). The present research found vague, uninformative and jargonistic communication was experienced by participants from both health literacy score groups and with similar effect: it made navigation more difficult.

The sub-theme of trust provides another example where accord can be demonstrated between the inconclusiveness of the present data and the relevant literature. The notion of trust was implicit in participants' discussions on shared decision making with their healthcare providers. They spoke of open dialogue up to the point of needing to make a decision at which time the provider was considered ultimately responsible. In essence, the participants trusted their providers to make medical decisions in their best interest and that was evidenced across both health

literacy score groups. Those data are supported by literature reporting no relationship between health literacy and trust in the context of medical decision making (DeWalt et al., 2007; Smith et al., 2009).

The literature does however report a positive relationship between health literacy and involvement in the context of medical decision making (Edwards, Davies, & Edwards, 2009; McCaffery, Smith, & Wolf, 2010; Naik et al., 2011). Mancuso and Rincon (2006) reason those with low health literacy participate more passively in decision making because they find medical information a challenge to understand and as a result, do not have the confidence to be more actively involved. Yet, in the present research, participants with adequate health literacy also inferred passive involvement by delegating authority to providers to make their health decisions. One explanation could be that they were “patients of previous generations [who] merely needed to decide whether to seek medical attention and whether to follow their physician’s advice; it was not their place to decide which options were best” (Woolf, Chan, Harris et al., 2005, p. 293). They were of a generation in which the doctor knew best and participation was about good communication, not the onus of decision making (Ekdahl, Andersson, & Friedrichsen, 2010). Another possible explanation could be overlooked for its simplicity: they were participating as much as they wanted to participate. That both explanations could equally apply to the participants with limited health literacy who inferred passive involvement in medical decision making further underscores the inconclusive nature of the data.

The sub-themes of attitudes, relationships built over time and participants’ strategic use of their interpersonal skills to obtain health services found in the present research are also evident in the literature. For example, Jeon et al. (2010) undertook a systematic narrative review of qualitative studies concerning peoples’ experiences of living with chronic heart failure and found negative experiences were

related to providers being inattentive, unconcerned and insensitive. Likewise, Mead et al. (2010) reported on poor provider attitudes that “appeared to alienate patients from their own care” (p. 73). The literature reflects data from the present research that relationships built over time can be both a positive experience (Goff, Mazor, Meterko et al., 2007) and a negative experience (Welstand et al., 2009). Moreover, strategic use of interpersonal skills to obtain health services was found in the analysis of data emerging from a series of interviews with women living in rural Canada (Wathen & Harris, 2007). Examples included women engaging the help of others (eg. nurses) in acute care settings to alert them to the “more sympathetic” (p. 644) doctors on duty and of remaining silent about poor quality care for fear of developing reputations as “troublemakers” (p. 644) and putting their relationships with their doctors at risk. Towle, Godolphin, Manklow et al. (2003) similarly report on the sanctity of the patient-doctor relationship in the minds of patients and how they avoid being assertive to preserve its longevity. Notably, the extent and ways health literacy may underscore the three sub-themes appears as elusive in the literature as it is inconclusive in the present data. Using the sub-theme contexts, research could not be found in which health literacy was a considered variable, thus suggesting they are areas for further investigation.

5.8 TIMELY CARE AND HOW BEST TO OBTAIN IT

Explicit in participants’ experiences of healthcare navigation was their appreciation of timely care and the methods through which it was best obtained. Foremost was using the ED services of a hospital in preference to those of a GP Clinic, but there was also strong consensus having private healthcare insurance similarly reduced the wait time for treatment. Analysis of whether participants NVS scores helped to explain those data was confounded by the range of health literacy proficiencies they represented. In other words, neither strategy appeared to be indicative of adequate or limited health literacy. Regarding the use of ED services,

data from published research is more definitive: low health literacy equates to higher use (Berkman et al., 2011; Herman, Young, Espitia et al., 2009; Murray et al., 2009). Lee et al. (2004) claim the association is mediated by poor disease and self-care knowledge, limited use of preventative measures, poor medication compliance, infrequent doctor consultations and worse health behaviour generally.

It would be a misrepresentation of the present data however, to draw parallels with Lee et al's. (2004) claims in so far as they may pertain specifically to the participants with limited health literacy and their use of ED services. They, along with their health literate counterparts, reported accessing emergency care for its timeliness, not as a way of circumventing consultations with their GPs or because of reasons that could be attributed through analysis to poor self care, medication compliance and the like. Indeed, their actions were entirely appropriate and recommended for the cardiac symptoms they described (National Heart Foundation of Australia & The Cardiac Society of Australia and New Zealand, 2006). Perhaps more telling was the navigational assistance ED care afforded participants and how that differed from their reported experiences of non-acute care. Once participants were admitted through the ED for on-going care they reported not having to navigate their trajectory through acute care services because it was determined by their treating team of health professionals. That was in contrast to participants' experiences of non-acute care in which they needed to assume navigational responsibilities. According to Goddard (2009), the former involved less 'work' for participants and as such, represented a more 'permeable' service option. That participants from both health literacy score groups could appreciate the differences in the permeability of acute and non-acute services suggests health literacy may not be requisite for identifying navigational efficiencies within healthcare systems. Clearly though, more data would be needed to validate such a claim.

More data are also needed to substantiate any link between health literacy and use of private health insurance to expedite care. The present data was inconclusive and the literature offers no insights given the dearth of information on the subject. One notable exception however, was the difficulty people with low health literacy may have understanding information to do with private healthcare insurance, such as coverage options, financing and enrolment (Gazmararian, Beditz, Pisano et al., 2010; Morgan, Teal, Hasche et al., 2008; Vitt, Siegenthaler, Siegenthaler et al., 2002) which corroborate the reported experience of a participant in the present research who had similarly low health literacy. That aside, the fact participants with both adequate and limited health literacy articulated the benefit of private health insurance in reducing the wait time for treatment again suggests health literacy skills may not be essential for identifying navigational efficiencies within healthcare systems and warrants further investigation for the understanding it would bring to health service utilisation.

5.9 SERVICE ACCESS BARRIERS IMPACTING NAVIGATION BUT NOT THE PRIORITY TO MAINTAIN HEALTH

The perception among participants was unanimous: services could be accessed when required. For some, that meant traveling distances whilst for others it meant waiting for treatment and/or having limited opportunity to choose a preferred service provider. Those data were inferred as barriers to accessing services and not unprecedented in the context of the “vast literature” (Goddard, 2009, p. 196) on the topic. For example, in their summary of research investigating barriers to participation in cardiac rehabilitation programs, Daly et al. (2002) found traveling distances were among those cited and others have since replicated that finding (Auon & Rosenberg, 2004; DeVoe, Baez, Angier et al., 2007; Jerant, von Friedrichs-Fitzwater, & Moore, 2005). Prolonged waiting times have reduced completion of colorectal cancer screening (Denberg, Melhado, Coombes et al., 2005) and made

connecting with primary clinicians difficult (Newcomb, McGrath, Covington et al., 2010). Furthermore, access to services and staff as a result of restricted funding were among the many barriers to heart failure care reported by McEntee et al. (2009).

Given all participants were living in regional areas, as classified by the Remoteness Structure of the Australian Standard Geographical Classification (ABS, 2006), the fact that they encountered service access barriers was not unexpected. In his 2009 report *A Social Inclusion Strategy for Tasmania*, Professor David Adams wrote of the need for services such as those to do with health to be accessible to ensure people can participate fully in society. He noted from responses to the Social Inclusion Consultation Paper and associated forums the differential access Tasmanians had to services. It emerged transport barriers were at the heart of that situation given many services were beyond the perimeters of peoples immediate environs (Adams, 2009). The present research supports that finding, as do the literature portraying such barriers to be a reality of regional areas (Gillis & Quigley, 2004; Krumwiede, 2009; Sanborn, Manuel, Ciechanska et al., 2005).

Less apparent among the literature on accessing health services is how people choose to approach the barriers they encounter. Participants in the present research were positive in their approach given the barriers were invariably portrayed as surmountable. Moreover, the barriers were outweighed by the priority participants had given to maintaining their health. In their exploratory research on access issues for people with Type 1 diabetes, Rasmussen et al. (2007) similarly found a positive approach to barriers and prioritisation of health. For example, they found people were prepared to travel long distances if it meant getting the specialist care they were after. In both instances it could be inferred service access barriers such as traveling distances had a navigational impact more than a dissuasive impact on participants' use of health services. For some participants in the present research

for example, traveling out of the region to obtain specialist cardiac services meant using unfamiliar roads, pre-planning accommodation, knowing how to reclaim expenses and invariably finding a service facility that was new to them. Had those services been local then it would be reasonable to surmise the experience of navigation would have been easier.

Whilst the present data were not explicit about the contribution participants' health literacy made to understanding navigation in the context of accessing services, it made implicit the inference that a person's health literacy could define the degree to which access barriers were, in fact, barriers. Goddard (2009) confers that notion when using Dixon-Woods, Cavers, Agarwal et al's. (2006) sociological concept of 'candidacy' to describe a person's eligibility, or 'qualifications', for medical attention. Said to be influenced by factors at the individual, provider and system level, a person's candidacy essentially interprets the accessibility²³ of a service. In other words, a service requiring few qualifications for candidacy would be more accessible than one requiring more. In the context of the present research that would mean a service placing few demands on health literacy skills (or, 'requiring few qualifications for candidacy' such as the need to read and complete complex forms) would be more accessible than one placing higher demands on those skills. Research showing an association between low health literacy and service access barriers attests to that explanation (Baker et al., 1996; Lee & Vang, 2010; Sudore, Mehta, Simonsick et al., 2006), as do the patient navigation programs designed to address it (Sarfaty, Hurley Turner, & Damotta, 2005; Schwaderer & Itano, 2007).

According to Goddard (2009), the concept of candidacy not only helps to identify the degree to which service access barriers exist for people on their healthcare journey but underscores their occurrence in any guise and at any stage along the way. Indeed, the latter may help to explain why the barriers found through

²³ Similarly described by Goddard (2009) as 'permeability' and mentioned as such in the discussion to do with participants' use of ED services.

the present research were not readily associated with participants from either health literacy score groups so much as they were experiences of vulnerability recalled by participants at different stages on their healthcare journeys. That participants with adequate health literacy recalled service access barriers may simply validate the point Goddard (2009) makes about the aforementioned levels of influence on candidacy and subsequent interpretation of service accessibility. Thus, in the absence of data, it could be speculated reasons other than health literacy caused the service access barriers experienced by that participant group.

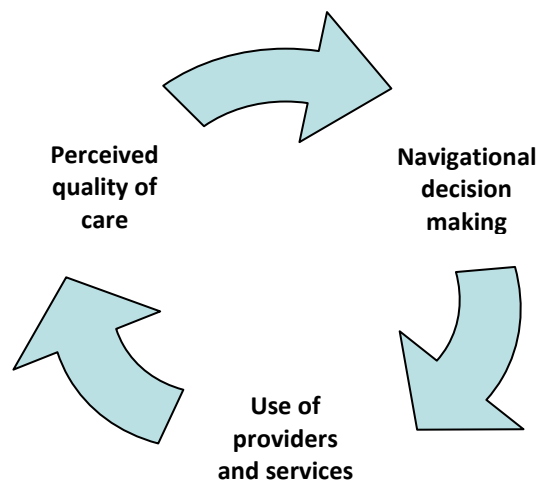
5.10 PERCEPTIONS ABOUT QUALITY OF CARE INFLUENCING NAVIGATIONAL DECISION MAKING IN TERMS OF THE PROVIDERS AND/OR SERVICES USED

Despite overtures of negativity, participants' prevailing sentiments regarding the quality of care they received were positive. Whilst not measured formally, the data made implicit a sense of satisfaction among participants concerning their cardiac care. Defined as the fulfillment of expectations (Sitzia and Wood, 1997), satisfaction does not imply superior service, only service that is acceptable (Crow, Cage, Hampson et al., 2002). The present data corroborate both works. Firstly because they implied healthcare expectations and secondly because participants' expressions of satisfaction were amid narratives suggesting less than superior service. More specifically, participants held perceptions that there was negligible difference between private and public hospital care; poor record keeping and displays of provider attributes; and that certain services should have been provided but were not (eg. referrals to specialists and follow-up care).

It follows, the impact of participants' perceptions regarding the quality of care they received was two-fold: they were satisfied to the point of being amenable to using the healthcare system for their cardiac needs, however, the perceptions

they held about aspects of the system influenced which providers they consulted and/or services they used. For example, some participants reported avoiding appointments with doctors whom they perceived as rude, and likewise, some questioned their on-going monetary contributions to health insurance in order to receive private hospital care when the quality was perceived as little different to public-funded hospital care. Thus, perceptions about quality of care impacted participants' navigational decision making in terms of the providers and/or services they used. Conceivably, the providers and services they used also impacted their perceptions about quality of care resulting in a 'cycle of influences' (Figure 5.1).

Figure 5.1
A cycle of influences involving perceived quality of care, navigational decision making and use of providers and services



The data, not unlike the literature, do not show the extent and ways participants' health literacy may contribute to an understanding of that cycle. The overall perception of quality among participants was unanimously positive across the range of NVS scores and no discernable trends linked their subsequent navigational decision making and use of providers and services to those scores. Certainly, there is a "sizable literature" (Sofaer & Firminger, 2005, p. 521) on what

constitutes quality care from the patient perspective. In their review of findings from studies of patient definitions of quality Sofaer and Firminger (2005) were able to generate several categories ranging from patient-centered care to the structure and facilities of healthcare organizations. Affirmation of those categories can be found in more recent studies. For example, Shaw et al. (2009) cite as a positive example of patient-defined quality doctors who listen, allow time for their consultations and make patients feel at ease. Kowalski, Nitzsche, Scheibler et al. (2009) found among patients undergoing treatment for breast cancer that perceptions about the organisational climate and communication skills of physicians underscored their sense of trust in health professionals and subsequent perceptions of quality care.

Significantly, patient characteristics such as age, gender and socioeconomic status have also been shown to influence perceptions of quality (Sofaer & Firminger, 2005). Health literacy however, does not appear in the context of such findings, or more recently in associated research. It thus remains unknown as to whether health literacy influences patient-perceived quality and the impact that may have on navigational decision making and subsequent use of providers and services.

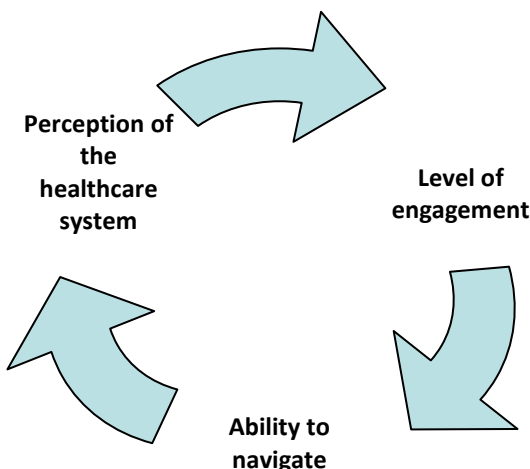
5.11 PERCEPTIONS ABOUT THE HEALTHCARE SYSTEM INFLUENCING NAVIGATION IN TERMS OF LEVEL OF ENGAGEMENT

For most participants, their overall positive perceptions about the quality of care they received were similar to their perceptions about the healthcare system in general and their ability to navigate it in particular. In the few instances this did not apply, participants' perceptions about the healthcare system were negative and navigation was inferred as difficult on account of their minimal engagement with health services. Conceivably, those data give rise to another 'cycle of influences' whereby participants' perceptions of the healthcare system influenced their level of

engagement with its services, which influenced their ability to navigate, which influenced their perceptions and so the cycle continues (Figure 5.2)²⁴.

Figure 5.2

A cycle of influences involving perception of the healthcare system, level of engagement and ability to navigate



Perhaps less appreciable, but no less significant, is the influence of health literacy on that cycle. The data were not conclusive. There was the suggestion that limited health literacy may predispose a person to a negative view of the healthcare system, infrequent use and difficulty with navigation based on the accounts of participants who subscribed to that scenario. But what of the other scenario involving participants who had limited health literacy yet maintained a positive view of the healthcare system, were more frequent users of its services and reported little difficulty with its navigation? Simply to suggest health literacy was not a

²⁴ That the cycles have been represented individually does not negate their similarities in so much as they both deal with perceptions, navigation and service use. However, participants' perceptions of quality essentially influenced *what* services/providers they used whereas their perceptions of the healthcare system essentially influenced *if* they used services/providers. The presentation of two figures provides the best illustration of that difference.

function of such dichotomous scenarios would be to discount the significance of the data.

Unfortunately, the literature provides little in the way of insight to either support or refute that claim. Apart from the generalisation of experiences leading to perceptions of trust/mistrust in healthcare systems (LaVeist, Isaac, & Williams, 2009), the vast proportion of literature on patient perceptions of healthcare systems and their subsequent levels of engagement appears focused on culture. For example, Lee and Vang (2010) found a mistrust of Western medical systems among ethnic minorities had a negative impact on their willingness to use healthcare services. Earlier research would suggest their findings were not unprecedented (Anderson, Scrimshaw, Fullilove et al., 2003; Eiser & Ellis, 2007; Peiris, Brown, & Cass, 2008; Shaw, Huebner, Armin et al., 2009).

Potentially of more significance in the context of the present research is the recognition given to the relationship between health literacy and culture, evidence of which can be found in the seminal USA Institute of Medicine (IOM) report *Health literacy: A prescription to end confusion* (Nelson-Bohlman et al., 2004). In essence, the relationship underscores “culturally competent” (Chang & Kelly, 2007, p. 413) healthcare whereby increased ethnic concordance improves the communication of health information to aid its access, understanding and application (Anderson et al., 2003; Andrulis & Brach, 2007). However, given cultural did not materialise in the present data, the significance of the relationship between culture and health literacy in explaining the cycle shown in Figure 5.2 is tenuous. Further investigation is therefore needed to establish the impact health literacy may have on patient perceptions of healthcare systems, levels of engagement and ability to navigate.

5.12 REQUISITE SKILLS ENABLING NAVIGATION

The skills identified by participants as requisite for navigating the healthcare system were consistent with the routinely defined health literacy competencies of accessing, understanding and applying health information, as well as the social skills the WHO (1998) contend underscore those competencies. The requisite skills not only highlighted the importance of health literacy to navigation in the minds of participants but prompted the question: is navigation a subcategory of health literacy or is health literacy a subcategory of navigation? Analysis of the data suggests the latter given the vast majority of participants indicated being able to navigate the healthcare system, most of whom had limited health literacy.

It could be argued, albeit simplistically, as a subcategory health literacy would be one of many factors impacting navigation and as such may be sufficiently compensated by those factors (eg. support, guidance, accessibility) without greatly impacting the overall level of difficulty incurred with navigation, as the data seem to suggest. It is an argument that finds support in Ross Adkins and Corus' (2009) view of people with limited health literacy being "resourceful agents" (p. 203) in the healthcare setting which the authors' present in opposition to "a substantial amount of research [that] concludes low literate individuals are incapable of taking on the tasks associated with healthcare." (p. 202)

Conversely, if navigation is the subcategory then the relative importance of health literacy is amplified along with any associated limitations which would, in turn, be reflected in the extent of navigation proficiency. Navigation is far more susceptible to health literacy skill levels in that scenario with low levels necessarily making the task of navigating the healthcare system more difficult. It follows, had that scenario been exemplified in the data then the majority of participants would

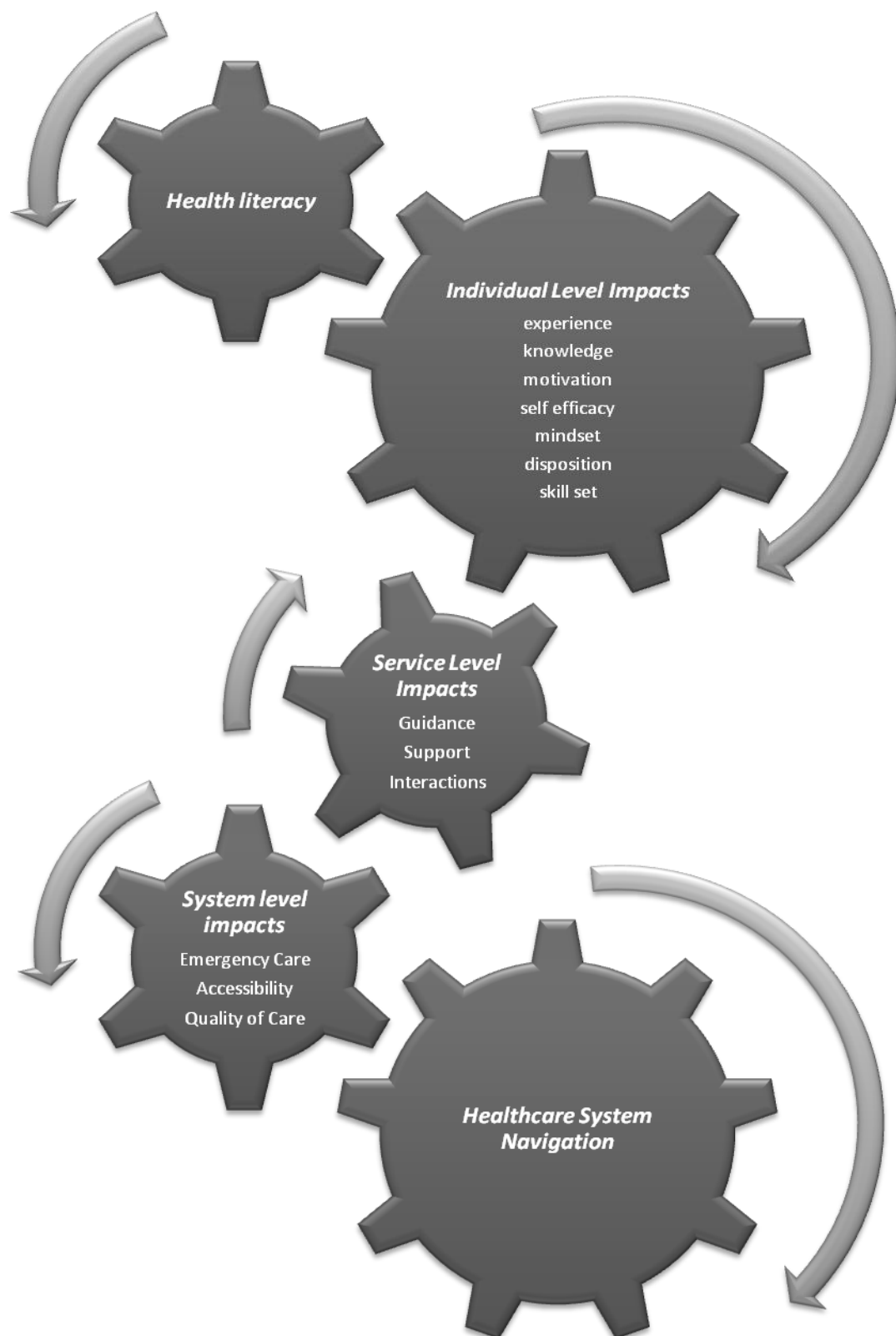
have most likely reported navigation difficulties on account of being assessed as having limited health literacy, yet clearly that was not the case.

5.13 SUMMARY: A FRAMEWORK FOR UNDERSTANDING THE THEMATIC DATA

The collection and analysis of the interview and focus group data culminated in a framework for understanding the factors impacting participants' navigation of the Tasmanian healthcare system (Figure 5.3). The visual representation of that framework as cogwheels serves three purposes. Firstly, it depicts the interrelated nature of the factors impacting navigation at the individual, service and system levels as discussed throughout the thesis. For example, participants' motivation to seek out guidance impacted their access to services just as their interactions with healthcare providers created experiences from which perceptions about quality of care were formed.

Secondly, the cogwheels symbolise the dynamic nature of healthcare system navigation. It was portrayed by participants not as an endpoint in a linear process but rather, as an on-going, circular process reflective of their circumstances at any one point in time. For example, the need to consult a new doctor; an exacerbation of their cardiac condition; or the development of comorbidities were all circumstances that changed the dynamics of participants' healthcare navigation in terms of the decision they had to make, the skills they had to use and so on. Metaphorically, the ease with which the cogwheels subsequently turned represented the ease with which participants were able to undertake the healthcare navigation required at that point in time and in so doing, manage the factors impacting that process.

Figure 5.3
A framework for understanding the factors impacting participants' navigation of the Tasmanian healthcare system



The third purpose for representing the framework as cogwheels is to highlight the pervasive impact of health literacy on healthcare system navigation at the individual level and the contribution it made towards understanding the complexities of participants' navigational experiences. A more orthodox representation would have been to include health literacy as part of the list of individual level impacts. However, as a key variable of the present research it needed to be highlighted, but in a way that did not alter its interpretation within the framework. Health literacy was thus given its own cogwheel abutting that of individual level impacts. That said, the contribution participants' health literacy scores made towards understanding the complexities of their navigational experiences were at once conclusive and inconclusive.

Conclusively, the data revealed, as did the literature, a positive relationship between participants health literacy scores and their depth of cardiac knowledge and subsequent ability to respond appropriately when symptomatic; their understanding of treatment protocols; and their self efficacy with filling out forms, reading hospital materials and learning about their cardiac conditions. Regarding the latter, limited health literacy was found in some instances to be compensated by mechanisms of commonsense and verbal exchange yet respective references to those mechanisms in the literature were absent or vague. Similarly at odds with the literature was the negative relationship found between participants' health literacy scores and use of the Internet as a source of health information to aid their navigational decision making.

For the bulk of the data however, the contribution participants' health literacy scores made towards understanding their navigational experiences was inconclusive because there was no clear delineation in interpretation of those data for either score group. That is to say, the data represented participants who achieved across the range of health literacy scores on the NVS implying their health

literacy had a possible, but not categorical, impact. Data to which that pertained at the individual level included the translation into action of participants' motivation to self manage their cardiac health as well as aspects of participants cardiac knowledge that revealed the attribution of symptoms to normal ageing. Also common to participants from both score groups was an initial period of symptom denial when confronted by a confirmed or impending diagnosis of cardiac ill health. Likewise, both groups shared an acute rather than chronic perception of illness, so whilst reportedly there was good compliance with prescribed medication regimens, use of services was very much on an 'as needed' basis tending towards reaction rather than proaction across both groups. Participants' health literacy scores could also not account for their ascribed dispositions.

At the service level neither limited nor adequate health literacy predicated the impact of advice and support on participants' navigational decision making, nor their interactions with providers. Similarly across both score groups the GP was thought of, and used, as the first-port-of-call for cardiac health matters. At the system level participants' navigational experiences revealed the use of ED services and private health insurance to expedite care as well as largely positive perceptions of service accessibility, quality of care and the healthcare system overall. Not revealed was the contribution participants' health literacy scores made towards understanding those data given it had representation from both groups. With the exceptions of medication adherence (a positive relationship with health literacy) and use of ED services (a negative relationship with health literacy), the literature was also found to be inconclusive regarding those individual, service and system level data and the contribution health literacy made towards understanding them.

Whilst unrelated to the cogwheel appearance of the framework, another purpose it serves is to allow comparison with other frameworks sourced from the relevant literature to inform the validity of the present data. Von Wagner et al's.

(2009) framework, for example, draws attention to the influence health literacy has on health actions and their determinants (Appendix 19)²⁵. Not unlike the present framework, the authors posit knowledge and experiential learning (among other things) influence health literacy which in turn influences motivation towards the health actions of gaining access to, and use of, health services; self management; and interaction with providers. Similarly, Sobo et al's. (2006) "phenomenologically motivated" (p. 157) depiction of parents' experiences of paediatric care (Appendix 20)²⁵ underscores the importance of experience at the individual level in the present framework when navigating healthcare. A final example of a comparative framework can be found in Jordan et al's. (2010) conceptualisation of health literacy from the patient's perspective (Appendix 21)²⁵. It shows (among other things) a patient's disposition, attitudes, experiences, interactions and social supports can influence, and be influenced by, their health literacy abilities. In the absence of a direct comparison then, the present framework bears similarities to those developed by others in the area of health literacy research suggesting the data from which it is derived has demonstrable validity.

²⁵ These figures have been removed from the electronic version of the thesis because of copyright.

CHAPTER 6 – CONCLUSION

6.1 OVERVIEW

This final chapter summarises the findings as they pertain to the research questions. It draws attention to the significance of those findings in terms of the resultant framework illustrating the factors impacting participants' navigation of the Tasmanian healthcare system; the statistical geography of the sample population; and the high percentage of participants with inadequate health literacy. The need to increase health literacy in the community and develop a standardised measure of healthcare navigation are advanced as implications of the research together with a list of topics for future research. A concluding comment highlights the need to appreciate the onus of responsibility that comes with being a patient in Australia.

6.2 SUMMARY OF THE FINDINGS

Answers to the two precursory questions revealed the majority of participants had Newest Vital Sign (NVS) scores suggesting limited health literacy and that a similar majority reported largely positive navigational experiences that were expressed, or implied as proportional to their confidence in being able to navigate the healthcare system. The amalgam of those findings answered the principal question of whether participants' health literacy scores on the NVS made a contribution towards understanding their experiences of healthcare navigation. To an extent they did: compared to participants with adequate health literacy, those with limited health literacy had less cardiac knowledge and awareness of treatment protocols as well as less self efficacy when it came to filling out health-related forms, reading hospital materials and learning about their cardiac conditions, all of which impacted their navigational experiences.

To a greater extent however, the contribution of participants' NVS scores towards understanding their experiences was inconclusive: the data applied to both score groups, not one or the other thereby implying health literacy had a possible, but not categorical, impact. Aggregated, those data highlighted the vulnerability of participants with limited health literacy whilst simultaneously demonstrating health literacy was one of a number of factors impacting the healthcare navigation experience. Thus, health literacy had the potential to make navigation more difficult but could be sufficiently compensated by other factors impacting at the individual, service and system levels (eg. motivation, support, guidance, accessibility) to make the overall experience a positive and manageable one.

6.3 SIGNIFICANCE OF THE FINDINGS

As the first study looking at health literacy and healthcare system navigation in Tasmania the present findings make a unique contribution to the area of Australian health literacy research. Foremost among that contribution is a framework illustrating the impact of health literacy on navigation alongside other individual, service and system level factors that emerged from the data analysis. It shows healthcare navigation to be a complex and dynamic process in which health literacy has a pervasive impact, seen most conclusively in terms of disease knowledge, symptom responsiveness, comprehension of treatment conventions and self-efficacy with using, understanding and applying health information. A wholly regional demographic also adds significance by providing a single statistical geography²⁶ in which to contextualise the findings. That participants' assessed health literacy levels, as measured by the NVS, were largely inadequate was significant for the congruence those data had with the high percentage of Tasmanians found to have low health literacy in the Australian Adult Literacy and

²⁶ Defined by the Australian Bureau of Statistics (ABS) as a hierarchically structured classification with a number of spatial units to satisfy different statistical purposes.
(www.abs.gov.au/ausstats/abs@.nsf/mf/1217.0.55.001 Accessed 23/7/11)

Lifeskills Survey (ALLS). Indeed, little appears to have changed in terms of prevalence of low health literacy in Tasmania and as such, appears to be a health determinant that has to date flown under the radar of people charged with the responsibility of intervening to ensuring the health of the state's residents. Certainly, the present data suggest low health literacy in Tasmania may at least, in part, explain differences in health data compared with the other Australian states and territories.

6.4 IMPLICATIONS

The aim of the present research was to determine the viability of health literacy as a focus for intervention to better equip people with the skills and abilities needed for healthcare navigation. The findings intimate such a focus would need to be part of a multifactorial strategy that took into consideration the other individual, service and system level factors shown to impact the navigation experience given their interrelated nature. However, that is not to suggest efforts towards improving levels of health literacy in the community are less warranted because those skills may be compensated when it comes to such activities as healthcare system navigation. On the contrary, that would be akin to putting a Band-Aid™ on a pressure sore: it masks the problem but does not fix it. Rather, improving health literacy would help ensure people have the personal skills and abilities to better deal with the complexities and demands of what is required for health, including but not limited to, accessing and using related services. Much could be gained from basic but potentially efficacious strategies such as increasing patients' understanding of their conditions through improved patient-provider communication; simplifying medical forms for completion; and improving the readability of hospital materials. Moreover, such strategies need not be directed only towards those with limited health literacy as the present research would attest. Indeed, even those participants with adequate health literacy reported difficulties at times with accessing,

understanding and applying health information in the context of navigating the healthcare system.

The present research also attests the effort invested in improving levels of health literacy in the community needs to be matched by the effort invested in designing a standardised measure of healthcare navigation for clinical and/or research purposes. To date, no such measure exists and using the available health literacy measures as proxies can generate additional limitations. For example, it was found in the present study that participants who scored 2 to 3 on the NVS were more often able to get the last two prose questions correct compared to those scoring 0 to 1, perhaps reflecting the sensitivity of the NVS in defining “suggests inadequate literacy” as a numeracy or prose issue.

Based on the present findings, consideration given to the design of a standardised measure of healthcare navigation would be well advised to incorporate the factors that impacted participants’ experiences given their apparent ubiquity. Healthcare navigation was also shown to be a dynamic process reflective of participants’ circumstances at any given point in time. For example, being acutely unwell could make navigational decision making more difficult as could the temporary absence of supportive friends and family. A measure of navigational ability in a health setting would necessarily have to capture that circumstantial component to ensure a more accurate assessment. Certainly, the task of designing a measure of navigational ability would not be an easy one given the complexity associated with that skill set. Nevertheless, the benefit of any such measure would be in the contribution it made to service planning and evaluation as well as to better understanding the healthcare experience from the patient perspective.

6.5 RECOMMENDATIONS FOR FUTURE RESEARCH

The present data were inconclusive on a number of issues related to healthcare navigation, as alluded to in Chapters 4 and 5. Further research is therefore suggested to investigate the impact health literacy may have on:-

- the self-management of chronic illness
- perceptions of chronicity
- self-efficacy in the healthcare environment
- levels of engagement with health services as a function of mindsets
- the availability and use of support networks
- dispositions
- interactions with healthcare providers
- identifying navigational efficiencies within healthcare systems
- access to services
- perceptions about healthcare systems and the quality of care they provide.

By achieving greater clarity on such issues a better understanding would emerge of the impact health literacy has on patients' navigation of healthcare systems and with it, an evidence base upon which to better inform healthcare delivery and target future intervention research.

6.6 CONCLUDING COMMENT

Underpinning the present research has been the premise that for those with low health literacy the challenge of healthcare navigation may prove as great a burden as the task of staying well, especially given the navigational demands made on those skills by complex healthcare systems and the requirements of chronic disease management. For very few participants did that premise hold true. Rather, for the vast majority of participants the task of healthcare navigation was reportedly managed with confidence, irrespective of their assessed health literacy. Whilst not

discounting the impact of health literacy, the interplay of other individual, service and system level factors on healthcare navigation underscored a process that is both complex and dynamic. To appreciate that is to acknowledge the onus of responsibility that comes with being a patient needing to access and use health services in Australia. Indeed, it is a responsibility that has the potential to affect a patient's health outcomes.

APPENDIX 1

The literature search strategy

The following sources of literature and data were most frequently used because of their relevance to the field of health literacy research:

- ABS (Australian Bureau of Statistics)
- AIHW (Australian Institute of Health and Welfare)
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- Cochrane Library
- CSA Databases
- DHHS (Department of Health and Human Services – Tasmania)
- DoHA (Department of Health and Ageing – Australia)
- EBSCO Databases
- Google Scholar
- Medline
- Proquest
- PsychInfo
- PubMed
- ScienceDirect
- SpringerLink
- Web of Knowledge
- Web of Science

Databases were consistently queried using the subject terms “health literacy” and “healthcare system navigation”.

Abstracts (if available) were examined in the first instance to determine the relevance of the information contained in the associated document. If deemed relevant, the document was stored in EndNote for future reference.

Time limit periods were not imposed for the search strategy given the relative short history of the field of health literacy research. However, every effort was made to ensure the most recent literature and/or data on a particular aspect of the review was included in the final version. More seminal work was exempt from such endeavour.

Articles pertaining to mental health literacy were excluded due to the more specialised nature of that field (Bankson, 2009).

APPENDIX 2

Description of the ALLS skill domains²⁷

<i>Prose literacy:</i>	the ability to understand and use information from various kinds of narrative texts, including texts from newspapers, magazines and brochures.
<i>Document literacy:</i>	the knowledge and skills required to locate and use information contained in various formats including job applications, payroll forms, transportation schedules, maps, tables and charts.
<i>Numeracy:</i>	the knowledge and skills required to effectively manage and respond to the mathematical demands of diverse situations.
<i>Problem solving:</i>	goal-directed thinking and action in situations for which no routine solution is available.

²⁷

(ABS, 2008)

APPENDIX 3

Description of the health-related activities embedded as items across the skill domains of the ALLS²⁸

- Health promotion:* the ability to enhance and maintain health (e.g. plan an exercise regime or purchase health foods) by locating and using health-related articles in magazines and brochures, or information contained on charts of food or product-safety labels.
- Health protection:* the ability to safeguard individual or community health (e.g. the ability to select from a range of options) by reading newspaper articles, information about health and safety, or air and water quality reports, or participating in referenda.
- Disease prevention:* the ability to take preventive measures and engage in early detection (e.g. determine risks, seek screening or diagnostic tests and follow up on courses of treatment) by understanding health alerts on TV or in newspapers or understanding letters about test results.
- Healthcare maintenance:* the ability to seek and form a partnership with health care providers, including providing health history forms or following directions on medicine labels, or being able to understand and discuss the merits of alternative forms of treatment with a health professional.
- Systems navigation:* the ability to understand and to access needed health services by completing application forms, reading maps to locate appropriate facilities or understanding health benefits packages.

²⁸ (ABS, 2008)

APPENDIX 4

Description of the skill levels of each domain of the ALLS²⁹

The skill levels for the health literacy domain are the same as for prose and document literacy and numeracy. Only four levels were defined for the problem solving scale.

PROSE LITERACY

Level 1	Most of the tasks in this level require the respondent to read relatively short text to locate a single piece of information which is identical to or synonymous with the information given in the question or directive. If plausible but incorrect information is present in the text, it tends not to be located near the correct information.
Level 2	Some tasks in this level require respondents to locate a single piece of information in the text; however, several distractors or plausible but incorrect pieces of information may be present, or low-level inferences may be required. Other tasks require the respondent to integrate two or more pieces of information or to compare and contrast easily identifiable information based on a criterion provided in the question or directive.
Level 3	Tasks in this level tend to require respondents to make literal or synonymous matches between the text and information given in the task, or to make matches that require low-level inferences. Other tasks ask respondents to integrate information from dense or lengthy text that contains no organisational aids such as headings. Respondents may also be asked to generate a response based on information that can be easily identified in the text. Distracting information is present, but is not located near the correct information.
Level 4	These tasks require respondents to perform multiple-feature matches and to integrate or synthesize information from complex or lengthy passages. More complex inferences are needed to perform successfully. Conditional information is frequently present in tasks at this level and must be taken into consideration by the respondent.
Level 5	Some tasks in this level require the respondent to search for information in dense text which contains a number of plausible distractors. Others ask respondents to make high-level inferences or use specialized background knowledge. Some tasks ask respondents to contrast complex information.

DOCUMENT LITERACY

Level 1	Tasks in this level tend to require the respondent either to locate a piece of information based on a literal match or to enter information from personal knowledge onto a document. Little, if any, distracting information is present.
Level 2	Tasks in this level are more varied than those in Level 1. Some require the respondents to match a single piece of information; however, several distractors may be present, or the match may require low-level inferences. Tasks in this level may also ask the respondent to cycle through information in a document or to integrate information from various parts of a document.

²⁹

(ABS, 2008)

Level 3	Some tasks in this level require the respondent to integrate multiple pieces of information from one or more documents. Others ask respondents to cycle through rather complex tables or graphs which contain information that is irrelevant or inappropriate to the task.
Level 4	Tasks in this level, like those at the previous levels, ask respondents to perform multiple-feature matches, cycle through documents, and integrate information; however, they require a greater degree of inferencing. Many of these tasks require respondents to provide numerous responses but do not designate how many responses are needed. Conditional information is also present in the document tasks at this level and must be taken into account by the respondent.
Level 5	Tasks in this level require the respondent to search through complex displays that contain multiple distractors, to make high-level text-based inferences, and to use specialised knowledge.

NUMERACY

Level 1	Tasks in this level require the respondent to show an understanding of basic numerical ideas by completing simple tasks in concrete, familiar contexts where the mathematical content is explicit with little text. Tasks consist of simple, one-step operations such as counting, sorting dates, performing simple arithmetic operations or understanding common and simple percentages such as 50%.
Level 2	Tasks in this level are fairly simple and relate to identifying and understanding basic mathematical concepts embedded in a range of familiar contexts where the mathematical content is quite explicit and visual with few distractors. Tasks tend to include one-step or two-step processes and estimations involving whole numbers, benchmark percents and fractions, interpreting simple graphical or spatial representations, and performing simple measurements.
Level 3	Tasks in this level require the respondent to demonstrate understanding of mathematical information represented in a range of different forms, such as in numbers, symbols, maps, graphs, texts, and drawings. Skills required involve number and spatial sense, knowledge of mathematical patterns and relationships and the ability to interpret proportions, data and statistics embedded in relatively simple texts where there may be distractors. Tasks commonly involve undertaking a number of processes to solve problems.
Level 4	Tasks at this level require respondents to understand a broad range of mathematical information of a more abstract nature represented in diverse ways, including in texts of increasing complexity or in unfamiliar contexts. These tasks involve undertaking multiple steps to find solutions to problems and require more complex reasoning and interpretation skills, including comprehending and working with proportions and formulas or offering explanations for answers.
Level 5	Tasks in this level require respondents to understand complex representations and abstract and formal mathematical and statistical ideas, possibly embedded in complex texts. Respondents may have to integrate multiple types of mathematical information, draw inferences, or generate mathematical justification for answers.

PROBLEM SOLVING

Level 1	Tasks in this level typically require the respondent to make simple inferences, based on limited information stemming from a familiar context. Tasks in this level are rather concrete with a limited scope of reasoning. They require the respondent to make simple connections, without having to systematically check any constraints.
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	The respondent has to draw direct consequences, based on the information given and on his/her previous knowledge about a familiar context.
Level 2	Tasks in this level often require the respondent to evaluate certain alternatives with regard to well-defined, transparent, explicitly stated criteria. The reasoning however may be done step-by-step, in a linear process, without loops or backtracking. Successful problem solving may require the combination of information from different sources, e.g. from the question section and the information section of the test booklet.
Level 3	Some tasks in this level require the respondent to order several objects according to given criteria. Other tasks require the respondent to determine a sequence of actions/events or to construct a solution by taking non-transparent or multiple interdependent constraints into account. The reasoning process goes back and forth in a non-linear manner, requiring a good deal of self-regulation. At this level respondents often have to cope with multi-dimensional or ill-defined goals.
Level 4	Items in this level require the respondent to judge the completeness, consistency and/or dependency among multiple criteria. In many cases, the respondent has to explain how the solution was reached and why it is correct. The respondent has to reason from a meta-perspective, taking into account an entire system of problem solving states and possible solutions. Often the criteria and the goals have to be inferred from the given information before actually starting the solution process.

APPENDIX 5

Additional findings of the ALLS

Firstly, all domains showed similar relationships with demographic and socio-economic markers such as education. For example, those with a greater number of years of formal education achieved higher literacy scores across all five domains of the survey. Those data support the notion that literacy, in whatever guise, is a multifaceted (Hanchate, Ash, Gazmararian et al., 2008) and interdependent skill best enhanced through the collaborative effort of stakeholders rather than in isolation (Agre et al., 2006; Foulk et al., 2001; Humphreys, 2000; Levy, 2007; Nutbeam, 2000). An example would be the education sector, on the basis of its vested interest in literacy, collaborating with the health sector to address low health literacy.

Secondly, the comparison between genders found negligible difference in health literacy levels with 40 per cent of males and 41 per cent of females recording skill Level 3 or above. The studies reviewed by Crane Cutilli (2007) were reportedly inconclusive regarding differences in health literacy based on gender.

Thirdly, a comparison of health literacy levels between the states and territories revealed “no outstanding differences” (ABS, 2008, p. 9). Indeed, a difference of only 6 per cent separated people living in major Australian cities (42%) with those living in ‘outer regions’ (36%) who achieved a health literacy skill Level 3 or above.

A fourth and final comparison of the Australian ALLS data concern self-assessed health status and social participation. In both instances the relationship with health literacy was found to be positive. For example, almost half (48%) of those who reported feeling ‘calm and peaceful for a good bit of the time’ in the month prior to the survey achieved a health literacy skill Level 3 or above. In contrast, of those who reported never feeling calm and peaceful during the same period only 19 per cent achieved the same levels of health literacy. Regarding social participation it was found the greater the level of participation in groups, organizations and/or volunteer work the greater the percentage of people who achieved a health literacy skill Level 3 or above.

APPENDIX 6

The relevancy of the present research to Australian and Tasmanian health agendas

- **The National Health and Hospitals Reform Commission**

<http://www.health.gov.au/internet/main/publishing.nsf/Content/nhhrc-report>

Established by the Federal Cabinet in February 2008, the Commission was “tasked...to provide [a] report...to the Commonwealth Government...for tackling future challenges in the Australian health system.”

In the Executive Summary of its final report released in June 2009, “A Healthier Future for All Australians”, the Commission recommends action to:

- ⇒ Tackle the major access and equity issues that affect people now;
- ⇒ Redesign [the] health system to meet emerging challenges; and
- ⇒ Create an agile, responsive and self-improving health system for future generations

The present research is considered relevant to all three recommendations for action.

- **The National Primary Health Care Strategy**

<http://www.health.gov.au/internet/yourhealth/publishing.nsf/Content/report-primaryhealth>

Released in 2010 and prepared by the Australian Government Department of Health and Ageing (DoHA), the Strategy is deemed “a road map to guide current and future policy and practice in the Australian primary health care sector.” The present research bears direct relevance to its four priority directions for change:

- ⇒ Improving access and reducing inequity
- ⇒ Better management of chronic conditions
- ⇒ Increasing the focus on prevention
- ⇒ Improving quality, safety, performance and accountability

- **Tasmania’s Health Plan**

http://www.dhhs.tas.gov.au/about_the_department/our_plans_and_strategies/tasmanias_health_plan

Released in May 2007, Tasmania’s Health Plan represents the State Government’s blueprint for reform of its health services now and into the future. It aspires to have a population that enjoys a quality of health and life that ranks with the best in Australia. The Plan has at its core key principles deemed fundamental to creating a sustainable and quality health and human

service system. It is in the description of these principles that key words emerge as relevant to the current research on HL. Namely, 'active participation', 'people-orientated', 'partnerships' and 'targeting opportunities.'

The following elements of the Plan have most relevance to the present research:

- ⇒ a greater focus on primary health
- ⇒ better management of chronic illnesses
- ⇒ illness prevention
- ⇒ support for people to manage their own health

- **Tasmanian Government Department of Health and Human Services
Direction for 2009-2012**

http://www.dhhs.tas.gov.au/news_and_media/2009-10_dhhs_annual_report

Released in May 2009 and contained in the DHHS Annual Report 2009-2010, the following key strategic objectives of the Department are given for the period 2009 – 2012 and deemed relevant to the present research:

- ⇒ Supporting individuals, families and communities to have more control over what matters to them
- ⇒ Promoting health and wellbeing and intervening early when needed
- ⇒ Developing responsive, accessible and sustainable services
- ⇒ Creating collaborative partnerships to support the development of healthier communities

A recent initiative under the auspice of the DHHS and supporting its key strategic objectives has been the development of a *Communication and Health Literacy Action Plan* for implementation across the Agency in 2011 and beyond. The principal objectives of the Plan are:

1. To improve the way DHHS provides information to clients and the community, and
2. To improve health literacy in the Tasmanian community, in order to improve health outcomes for Tasmania.

The present research will likely inform the implementation of the Plan.

- **Tasmania *Together* (TT)**

<http://www.tasmaniattogether.tas.gov.au/about>

Tasmania *Together* is a vision for the State, owned and driven by the community. It currently includes 12 goals and 151 benchmarks that reflect the concerns people expressed during two of the largest community

consultation processes ever undertaken in Tasmania (in 2000 and 2005).TT
goals and standards of particular relevance to the present research are:

- ⇒ Goal 3: High quality education and training for lifelong learning and a skilled workforce
 - Standard 3.2: Support improved levels of community literacy.”
- ⇒ Goal 4: Active healthy Tasmanians with access to quality and affordable health care services
 - Standard 4.1: Improve Tasmanian’s health through promotion and support of healthy lifestyle choices

APPENDIX 7

The REALM-S³⁰

**RAPID ESTIMATE OF ADULT LITERACY IN MEDICINE
(REALM)[®]**

Terry Davis, PhD • Michael Crouch, MD • Sandy Long, PhD

Patient Name/ Subject # _____ Date of Birth _____

Date _____ Clinic _____ Examiner _____

Reading Level _____
Grade Completed _____

List 1	List 2	List 3
fat _____	fatigue _____	allergic _____
flu _____	pelvic _____	menstrual _____
pill _____	jaundice _____	testicle _____
dose _____	infection _____	colitis _____
eye _____	exercise _____	emergency _____
stress _____	behavior _____	medication _____
smear _____	prescription _____	occupation _____
nerves _____	notify _____	sexually _____
germs _____	gallbladder _____	alcoholism _____
meals _____	calories _____	irritation _____
disease _____	depression _____	constipation _____
cancer _____	miscarriage _____	gonorrhea _____
caffeine _____	pregnancy _____	inflammatory _____
attack _____	arthritis _____	diabetes _____
kidney _____	nutrition _____	hepatitis _____
hormones _____	menopause _____	antibiotics _____
herpes _____	appendix _____	diagnosis _____
seizure _____	abnormal _____	potassium _____
bowel _____	syphilis _____	anemia _____
asthma _____	hemorrhoids _____	obesity _____
rectal _____	nausea _____	osteoporosis _____
incest _____	directed _____	impetigo _____

SCORE

List 1 _____

List 2 _____

List 3 _____

Raw Score _____

APPENDIX 8

The Participant Information Sheet

This information sheet relates to the following study:

Health literacy and health care system navigation for people who have had, or are at risk of, a cardiac event

The study is being conducted by Winifred van der Ploeg to fulfill the requirements for a Doctor of Philosophy (PhD) degree through the University of Tasmania. Winifred will be the Principal Investigator for the study and is based at the Rural Clinical School (RCS) in Burnie. Her supervisors are Professor Judi Walker and Dr. Ali Maginness.

The study has received ethical approval from the Human Research Ethics Committee (Tasmania) Network which comprises representation from the Department of Health and Human Services (DHHS) and the University of Tasmania. Approval has also been received from the CEO of the North West Regional Hospital (NWRH) through which the Cardiac Rehabilitation Program (CRP) is conducted.

The purpose of the study is to explore whether the health literacy of people with, or at risk of, a cardiac event contributes to an understanding of their experiences of navigating a healthcare, where:

Health literacy means the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health;

Health care system means the infrastructure, personnel and processes that combine to support the care of peoples' health;

Navigation means the process by which people move into and through the multiple parts of a healthcare system to gain access to and use the services it provides;

A cardiac event means an acute, physical state involving the heart that threatens life.

Both yourself and the wider community may expect to benefit from this study. For you, the benefits may include the opportunity to tell your experience of navigating the Tasmanian health care system in a supportive, one-on-one interview with Winifred which may lead to a feeling of 'being heard' regarding those experiences. You may also feel the support and acceptance that can come from involvement in a

focus group discussion as well as gain a greater awareness of your navigation experiences. For the wider community the benefits of the study may include a better understanding of how people who have had, or are at risk of, a cardiac event have experienced navigating the Tasmanian health care system. The study may also provide information that could be used by the Government and/or organisations to replicate the positive aspects and address the negative aspects of those experiences for the benefit of the wider community. Conversely, the study may be of no benefit to yourself or the wider community.

You are at no identifiable risks as a result of your involvement in the study. Likewise, involvement in the study will not affect your involvement in the CRP or any other service and/or care you receive in relation to your health needs.

Participation in the study is completely voluntary and you are free to withdraw at any stage without consequence.

The whole study will run from mid 2010 to the end of 2011. As a voluntary, consenting participant, the duration of your involvement will be significantly less and occur as two distinct phases:

PHASE 1:- At a time and place of your convenience, Winifred will conduct with you an in-person, 1:1 interview. It will commence with a 2-3 minute exercise in which you'll be asked some questions based on an ice cream nutrition label. You will next be asked a number of questions to do with your demographic details (eg. age, address and education), your medical history and your experiences of navigating the health care system. The questions will allow you to give both short and long answers. The duration of this phase will be between 1 and 2 hours. At a later date, but as part of the information gathered in this phase, your medical record will be checked by Winifred for key medical events and care received to support the information you give in response to the questions.

PHASE 2:- Along with other participants you will be asked to join in a small group discussion soon after your interview. The discussion will again focus on each person's experiences of navigating the health care system and will be guided by Winifred. The duration of this phase will be between 1 and 2 hours.

Both phases (excluding the 2-3 minute exercise in which you'll be asked some questions based on an ice cream nutrition label) will be audio taped to assist Winifred in recalling the details of the discussions. Regarding Phase 1, Winifred will provide you with a transcript of the discussion for you to edit, modify or withdraw. All information Winifred collects from you will be kept confidential and secure in a locked filing cabinet within the RCS (in the case of hard copies and tapes) and on a password-protected, secure server (in the case of data stored as electronic documents). All original transcripts (the raw data) will be kept securely by the

University of Tasmania for a period of 5 years from the date of the study completion and awarding of the degree. At the end of this period the data will be destroyed in accordance with the University guidelines.

A copy of the results of the study can be made available on request to Winifred:

Winifred van der Ploeg
c/- Rural Clinical School
Brickport Road
BURNIE TAS 7320
P. 6430 4565
E. wjv@utas.edu.au

If you have any concerns of an ethical nature or complaints about the manner in which the project is conducted you may contact the Executive Officer of the Human Research Ethics Committee (Tasmania) Network. The Executive Officer can direct you to the Chair of the Committee:

Executive Officer of the HREC (Tas) Network
P. 6226 7479
E. human.ethics@utas.edu.au

As a participant you will be asked to sign, and be given a copy of, a Participant Statement of Consent Form to keep for your records.

Your consideration towards becoming a participant in this study is appreciated.

APPENDIX 9

The Participant Statement of Consent Form

1. I acknowledge the details of the study have been fully explained to my satisfaction by the study Researcher and my consent is given voluntarily.
2. I understand the purpose of the study is to better understand the relationship between health literacy and health care system navigation for people who have had, or are at risk of, a cardiac event and that it has been explained that my involvement may, or may not, be of benefit to me.
3. I acknowledge the details of my involvement in the study have been explained to me, including the length of time it will take, where it will take place and what will be expected of me. I understand that my involvement means:
 - I will, as Phase 1 of the study, complete an exercise in which I will answer some questions to do with an ice cream nutrition label. I will then go on and answer questions from the Researcher who may also check my medical record for information to support my answers.
 - I will, as Phase 2 of the study, participate in a small group discussion with other study participants.
4. I understand I am at no identifiable risk as a result of my involvement in the study and that my involvement will not affect my involvement in the Cardiac Rehabilitation Program or any other services and/or care I receive in relation to my health needs.
5. I understand I am free to withdraw from the study at any time and that my withdrawal will not affect my involvement in the Cardiac Rehabilitation Program or any other services and/or care I receive in relation to my health needs.
6. I understand that no information discussed with, and recorded by, the Researcher will be reported in a way that identifies me and that all information will be stored and disposed of in accordance with relevant guidelines.
7. I understand the study will be conducted in accordance with the latest versions of the Declaration of Helsinki, Australia Good Clinical Research Practice Guidelines, National Health and Medical Research Council Guidelines

including the National Statement on Ethical Conduct in research Involving Humans and applicable privacy laws.

8. I understand that I will be given a copy of the Information Sheet and a signed copy of this Statement of Consent Form for my records and that I am not giving up my legal rights by signing this form.
9. Given the information outlined above please tick ONE of the boxes below that matches your response.

☐ **YES** - I voluntarily wish to participate in the study

Name of Participant _____

Contact Phone Number _____

Signature of Participant _____ Date ____/____/2010

☐ **NO** - I do not wish to participate in the study.

10. I have explained the study and the details concerning participation in it to this participant and I believe their consent is informed and understood.

Name of Researcher _____

Signature of Researcher _____ Date ____/____/2010

APPENDIX 10a

The Newest Vital Sign – Nutrition label³¹

Nutrition Facts			
Serving Size		½ cup	
Servings per container		4	
Amount per serving			
Calories	250	Fat Cal	120
			%DV
Total Fat 13g		20%	
Sat Fat 9g		40%	
Cholesterol 28mg		12%	
Sodium 55mg		2%	
Total Carbohydrate 30g		12%	
Dietary Fiber 2g			
Sugars 23g			
Protein 4g		8%	

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

³¹

(Weiss et al., 2005)

APPENDIX 10b

The Newest Vital Sign – Score sheet

Score Sheet for the Newest Vital Sign Questions and Answers

READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?

Answer: 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?

Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container. Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl."

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer: 33 is the only correct answer

4. If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer: 10% is the only correct answer

READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?

Answer: No

6. (Ask only if the patient responds "no" to question 5): Why not?

Answer: Because it has peanut oil.

Interpretation

Number of correct answers:

Score of 0-1 suggests high likelihood (50% or more) of limited literacy

Score of 2-3 indicates the possibility of limited literacy.

Score of 4-6 almost always indicates adequate literacy.

ANSWER CORRECT?

yes	no

APPENDIX 11

The interview questions

NAVIGATION QUESTIONS:

Intro. Medical history & how well do you feel at the moment?

The first set of questions are to do with what you know about and how you respond to your body, what you've learnt from past experiences getting around the health system, how you like to get health information and your confidence in finding and using health information.

KNOWLEDGE ABOUT THE DISEASE PROCESS

1.1.1 The job we have of looking after our health and knowing when to use health care services means we need to be aware of, and understand, the signs our bodies give us telling us if our health is OK or not.

Are there any particular signs you get from your body which tell you when your health is good or not so good?

1.1.2 What do you do when you get those feelings?

LEARNING FROM PAST EXPERIENCE

1.2 Can you tell me a bit about what you've learnt through experience (especially in relation to your cardiac condition) when it has come to finding your way around the health care system?

SOURCES OF INFORMATION TO INCREASE KNOWLEDGE

1.3 Can you tell me the ways you like to receive information on looking after your health?

CONFIDENCE IN FINDING AND USING HEALTH INFORMATION

1.4.1 How confident do you feel about your ability to find out information to help you look after your health?

(1) Extremely (2) Quite a bit (3) Somewhat (4) A little bit (5) Not at all

1.4.2 How often do you have problems learning about your medical condition because of difficulty understanding written information? *(Chew et al., 2004)*

(1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

1.4.3 How confident are you filling out medical forms by yourself? *(Chew et al., 2004)*

(1) Extremely (2) Quite a bit (3) Somewhat (4) A little bit (5) Not at all

1.4.4 How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials? *(Chew et al., 2004)*

(1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

1.4.5 How often do you stick to the health and medication regimen you have been prescribed?

(1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

The next set of questions are all to do with how and why you make health-related decisions.

DECISIONS MADE IN RELATION TO SERVICES USED/NOT USED

2.1.1 Could you please tell me a bit about how you make decisions about which health care services you use?

2.1.2 Does anyone else in your family help you make those decisions?

AMOUNT OF PARTICIPATION IN THE SELF-MANAGEMENT PROCESS

2.2.1 What gives you the motivation to do things that are good for your health?

2.2.2 What tends to put you off doing things that are good for your health?

QUALITY OF THE INFORMATION RECEIVED

2.3.1 We get information from a lot of different sources about what we should be doing to look after our health. How do you work out if the information is correct or not?

2.3.2 How do you work out whether the information applies to you or not?

The next couple of questions concern the relationships you form and the support you receive when it comes to using the health system to look after yourself.

HEALTH CARE PROVIDER ATTRIBUTES

- 3.1 Our use of health services almost always involves interacting with people. Could you please tell me a bit about how you get on with your health providers and why that's so?

SUPPORT IN/OUTSIDE THE HEALTH CARE SYSTEM

- 3.2 Do you have support available to you when it comes to looking after your health?

If Yes: Can you tell me a bit about it?

If No: Is this something you could ever see changing?

The next question is to do with your gender and is optional, so you don't have to answer it if you don't want to.

GENDER INFLUENCES

- 4.1 Can you tell me a bit about any experiences you have had where being male/female has influenced your activities and interactions within the health care system?

The second last lot of questions ask for your thoughts on the health care system and the services it provides.

ATTITUDES TOWARDS/PERCEPTIONS OF THE HEALTH CARE SYSTEM

- 5.1.1 Have you found your experiences have led you to form a view on the health care system?
5.1.2 How has this view influenced your approach to using the health care system?

QUALITY OF CARE

- 5.2.1 On the whole, what is your view of the quality of care you have received in relation to your health needs and why do you think that is so?

AVAILABILITY OF HEALTH CARE SERVICES (RURALITY)

5.3.1 Do you feel where you live has influenced the services you receive or are available to you?

5.3.2 How often are you able to access the services you need in your local area?

(1) Always (2) Often (3) Sometimes (4) Occasionally (5) Never

OBTAINING HEALTH CARE SERVICES

5.4 Do you have any strategies, or things you do, to make it easier for you to get the services you need to look after your health?

THEME(S) NOT COVERED

6.0 Finally, do you have any comments on issues we may not have covered which relate to how you have navigated the health care system.

DEMOGRAPHIC QUESTIONS:

DOB _____ / _____ / _____

Gender Male ☐ Female ☐

Aboriginal/TSI Yes ☐ No ☐

Relational Status Married ☐ Defacto ☐ Divorced ☐

Widowed ☐ Single ☐ Other _____

Living Arrangement _____ (to specify)

Residential Postcode _____ (to specify)

COB Australia ☐ Other _____ (to specify)

Years living in Australia _____ (to specify)

Language Spoken Primary _____ (to specify)

Native _____ (to specify)

Highest Educational Attainment* Year 10 or below ☐

**specify completed or not*

Year 11 ☐

Year 12 ☐

Tertiary ☐

Labour Force Status Employed ☐

Not in the Labour Force ☐
_____ (to specify)

Gross Weekly Income* _____ (to specify)

**Optional*

Private Health Insurance Yes ☐ No ☐

Medical History (to specify, with focus on cardiac condition)

THANK YOU FOR YOUR TIME AND COMMENTS.

APPENDIX 12

The focus group questions

FOCUS GROUP 1

KNOWLEDGE ABOUT THE DISEASE PROCESS

1.1 How interested are you in knowing about your cardiac health problems?

1.1.1 *If interested:* What are you are interested in knowing?
What do you hope this knowledge will achieve?

If not very interested: Tell me more about that.

1.1.2 What things help you to be / stop you from being interested?

1.2 Do you see yourself as having a chronic illness or being chronically ill?

1.2.1 *If yes:* What does that mean for you?
Has it changed your use of the healthcare system?

If no: Tell me more about that.

LEARNING FROM PAST EXPERIENCE

2.1 If you had to give someone advice on how best to navigate/get around the healthcare system what would you tell them based on your own experiences?

AMOUNT OF PARTICIPATION IN THE SELF-MANAGEMENT PROCESS

3.1 How much control do you feel you have over the health of your heart?

3.1.1 Can you give me some examples?

3.1.2 What helps / hinders that feeling of control?

HEALTH CARE PROVIDER ATTRIBUTES

4.1 When it comes to looking after your cardiac condition do you see your relationship with your GP (as your primary healthcare provider) as a partnership?

4.1.1 Why?

4.1.2 Is it an equal one?

SUPPORT IN/OUTSIDE THE HEALTH CARE SYSTEM

5.1 How does the way the healthcare system operate make navigating it easy and / or hard?

5.1.1 Tell me more about that.

5.1.2 How could the things that make it hard to navigate be addressed?

OBTAINING HEALTH CARE SERVICES

6.1 If you had to list a set of skills people need to navigate the healthcare system what would they be?

THANK YOU FOR YOUR TIME AND COMMENTS.

FOCUS GROUP 2

LEARNING FROM PAST EXPERIENCE

- 1.1 If you had to give someone advice on how best to navigate/get around the healthcare system what would you tell them based on your own experiences?

SUPPORT IN/OUTSIDE THE HEALTH CARE SYSTEM

- 2.1 How does the way the healthcare system operates make navigating it easy and / or hard?
 - 2.1.1 Does a) how well you feel, b) your disposition or temperament, and c) the level of information you receive help or hinder?
 - 2.1.2 How could the things that make it hard to navigate be addressed?

KNOWLEDGE ABOUT THE DISEASE PROCESS

- 3.1 How interested are you in knowing about your cardiac health problems?
 - 3.1.1 *If interested:* What are you are interested in knowing?
What do you hope this knowledge will achieve?

If not very interested: Tell me more about that.
 - 3.1.2 What things help you to be / stop you from being interested?
- 3.2 Do you see yourself as having a chronic illness or being chronically ill?
 - 3.2.1 *If yes:* What does that mean for you?
Has it changed your use of the healthcare system?

If no: Tell me more about that.

AMOUNT OF PARTICIPATION IN THE SELF-MANAGEMENT PROCESS

- 4.1 How much control do you feel you have over the health of your heart?
 - 4.1.1 Can you give me some examples?

4.1.2 What helps / hinders that feeling of control?

HEALTH CARE PROVIDER ATTRIBUTES

5.1 When it comes to looking after your cardiac condition do you see your relationship with your GP (as your primary healthcare provider) as a partnership?

5.1.1 Why?

5.1.2 Is it an equal one?

OBTAINING HEALTH CARE SERVICES

6.1 If you had to list a set of skills people need to navigate the healthcare system what would they be?

THANK YOU FOR YOUR TIME AND COMMENTS.

FOCUS GROUP 3

LEARNING FROM PAST EXPERIENCE

- 1.1 If you had to give someone advice on how best to navigate/get around the healthcare system what would you tell them based on your own experiences?

SUPPORT IN/OUTSIDE THE HEALTH CARE SYSTEM

- 2.1 How does the way the healthcare system operates make navigating it easy and / or hard?
 - 2.1.1 Does a) how well you feel, b) your disposition or temperament, and c) the level of information you receive help or hinder?
 - 2.1.2 How could the things that make it hard to navigate be addressed?

KNOWLEDGE ABOUT THE DISEASE PROCESS

- 3.1 How interested are you in knowing about your cardiac health problems?
 - 3.1.1 *If interested:* What are you are interested in knowing?
What do you hope this knowledge will achieve?

If not very interested: Tell me more about that.
 - 3.1.2 What things help you to be / stop you from being interested?
- 3.2 Do you see yourself as having a chronic illness or being chronically ill?
 - 3.2.1 *If yes:* What does that mean for you?
Has it changed your use of the healthcare system?

If no: Tell me more about that.
- 3.3 Has your experience of a cardiac health problem changed you as a person?

AMOUNT OF PARTICIPATION IN THE SELF-MANAGEMENT PROCESS

4.1 How much control do you feel you have over the health of your heart?

4.1.1 Can you give me some examples?

4.1.2 What helps / hinders that feeling of control?

HEALTH CARE PROVIDER ATTRIBUTES

5.1 When it comes to looking after your cardiac condition do you see your relationship with your GP (as your primary healthcare provider) as a partnership?

5.1.1 Why?

5.1.2 Is it an equal one?

OBTAINING HEALTH CARE SERVICES

6.1 If you had to list a set of skills people need to navigate the healthcare system what would they be?

ATTITUDES TOWARDS/PERCEPTIONS OF THE HEALTHCARE SYSTEM

7.1 Does the outcome of your cardiac event influence your perception of the healthcare system and by association, how easy or hard it is to navigate?

THANK YOU FOR YOUR TIME AND COMMENTS.

APPENDIX 13

The interview and focus group preambles

THE INTERVIEW PREAMBLE

Thank you for agreeing to take part in this interview.

I want to learn more about how you access, understand and use health information but specifically in relation to the activities and interactions that provide you with direction around the health care system when it comes to your cardiac condition.

Most of the questions I'll ask will allow you to answer in your own words in as much or as little detail as you want.

Some are also optional so if you feel you would prefer not to answer them that's OK but the more information you are able to give me the more meaningful and useful the results of the study will be.

Do you have any questions for me before we get underway?

THE FOCUS GROUP PREAMBLE

- Welcome (toilet, mints, water)
- Introductions
- Purpose of group; why selected; recorded; handling of data
- 'group rules':-
 1. You have the right to withdraw at any time.
 2. Everyone is encouraged to have their say.
 3. Everything said is valid and needs to be respected.
 4. The goal of the group is not consensus of opinion and that diverse viewpoints are important in informing research.

5. I cannot guarantee confidentiality because I have not control over your behaviour once you leave this group. I therefore ask that you respect each others privacy and not disclose information outside of this group.
 6. The amount you disclose is up to you.
 7. For the purpose of the recording I ask that you try not to interrupt/talk over others and that you talk clearly and with volume.
 8. I'll be asking a series of questions which I aim to fit within an hour timeframe.
- Any questions before we begin?

APPENDIX 14

The inter-respondent matrix³²

THEMES	A6	O6	J6	G5	M3	F3	H2	B2	K2
....at the individual level									
Experience									
Knowledge									
Motivation									
Mindset									
Self-efficacy									
Disposition	Amicable	Assertive	Amicable Accepting	Accepting Assertive	Amicable Accepting	Amicable Accepting	Indep.	Amicable Accepting	Accepting
....at the service level									
Guidance									
Support									
Interactions									
....at the system level									
ED care									
Accessibility									
Quality of care									

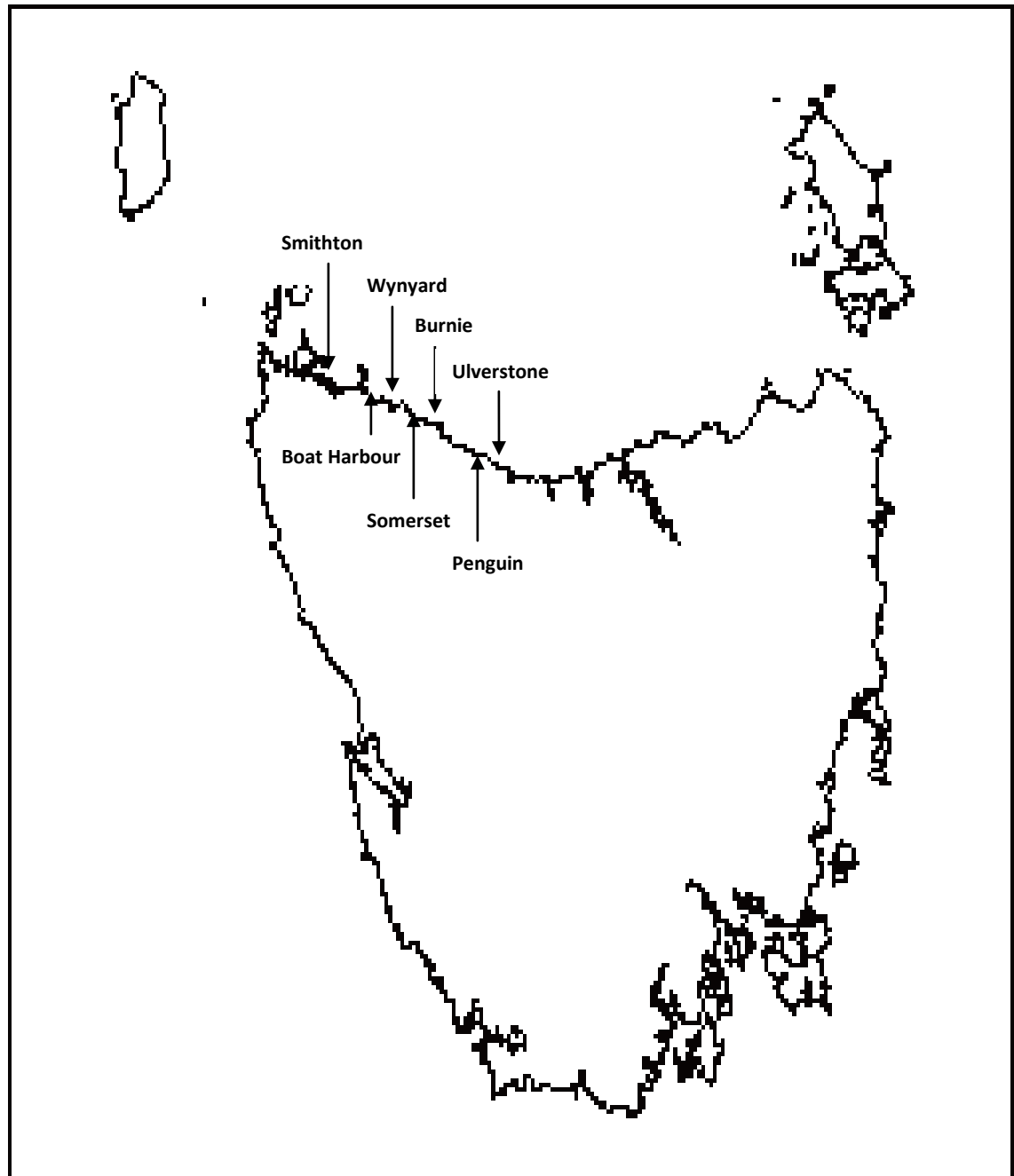
THEMES	C1	N1	D1	P1	L0	R0	Q0	E0	I0
....at the individual level									
Experience									
Knowledge									
Motivation									
Mindset									
Self-efficacy									
Disposition	Amicable Accepting	Assertive Accepting	Amicable Accepting Assertive	Assertive	Amicable Accepting	Accepting	Accepting	Amicable Accepting	
....at the service level									
Guidance									
Support									
Interactions									
....at the system level									
ED care									
Accessibility									
Quality of care									

³²

The matrix has been shown as two halves to accommodate formatting requirements.

APPENDIX 15

Participants' residential locations across North West Tasmania³³



³³

<http://www.lib.unimelb.edu.au/collections/maps/digital/outline-maps/index.html>

APPENDIX 16

The Socio-Economic Indexes for Areas (SEIFA) 2006^a

<i>Area</i>	<i>Index of Relative Socio-Economic Disadvantage (IRSD) Deciles^b</i>
Ulverstone	3
Penguin	4
Burnie	2
Boat Harbour	4
Somerset	2
Wynyard	2
Smithton	3

^a (ABS, 2006)

^b The IRSD deciles divide the distribution of SEIFA scores into ten equal groups. A high decile reflects a relative lack of disadvantage whilst a low decile indicates relatively greater disadvantage based on 17 different measures, including income and education.

APPENDIX 17

Participants' demographic characteristics correlated with their NVS scores

	NVS Scores		Total No. (%)
	0 to 3 (%)	4 to 6 (%)	
Age, mean (SD)	68.6 (8.1)	63.0 (14.4)	67.3 (10.0)
Gender			
Male	8 (57.14)	4 (100.0)	12 (66.67)
Female	6 (42.86)	0 (0.00)	6 (33.33)
Aboriginal/TSI	0 (0.00)	0 (0.00)	0 (0.00)
COB			
Australia	12 (85.71)	4 (100.0)	16 (88.89)
UK	2 (14.29)	0 (0.00)	2 (11.11)
Language			
English	14 (100.0)	4 (100.0)	18 (100.0)
Diagnosis			
Angina	2 (14.29)	0 (0.00)	2 (11.11)
Angina with stenting	3 (27.27)	0 (0.00)	3 (16.67)
HA with stenting	3 (27.27)	4 (100.0)	7 (38.89)
OHS ^f	6 (42.86)	0 (0.00)	6 (33.33)
Income			
Pension	13 (92.86)	2 (50.0)	15 (83.33)
Wage	1 (7.14)	2 (50.0)	3 (16.67)
Highest Educational Attainment			
Year 10 or below	14 (100.0)	2 (50.0)	16 (88.89)
Tertiary	0 (0.00)	2 (50.0)	2 (11.11)
Labour Force Status			
Retired	10 (71.43)	2 (50.0)	12 (66.67)
Disability Pension	3 (21.43)	0 (0.00)	3 (16.67)
Working	1 (7.14)	2 (50.0)	3 (16.67)
Relational Status			
Married	9 (64.29)	3 (75.0)	12 (66.67)
Divorced	2 (14.29)	0 (0.00)	2 (11.11)
Defacto	0 (0.00)	1 (25.0)	1 (5.56)
Widowed	3 (27.27)	0 (0.00)	3 (16.67)
Living Arrangements			
With Partner	9 (64.29)	4 (100.0)	13 (72.22)
With Relation	1 (7.14)	0 (0.00)	1 (5.56)
Alone	4 (28.57)	0 (0.00)	4 (22.22)
Private Health Insurance			
Yes	2 (14.29)	1 (25.0)	3 (16.67)
No	12 (85.71)	3 (75.0)	15 (83.33)
Residential Area			
Ulverstone	3 (27.27)	0 (0.00)	3 (16.67)
Penguin	3 (27.27)	1 (25.0)	4 (22.22)
Burnie	3 (27.27)	1 (25.0)	4 (22.22)
Boat Harbour	1 (7.14)	1 (25.0)	2 (11.11)
Somerset	3 (27.27)	0 (0.00)	3 (16.67)
Wynyard	0 (0.00)	1 (25.0)	1 (5.56)
Smithton	1 (7.14)	0 (0.00)	1 (5.56)

APPENDIX 18

Questions and associated responses from the interview and focus group protocols that informed the themes

<i>Theme</i>	<i>Interview Questions</i>	<i>Focus Group Questions</i>
<i>Experience</i>	1.2 / 5.4 4.1*	2.1 / 1.1 / 1.1
<i>Knowledge</i>	1.1.1,2 / 2.1.1,2 1.3* / 1.4.1* / 2.3.1,2*	1.1 / 3.1,2 / 3.1,2,3
<i>Motivation</i>	2.2.1,2 1.4.5*	3.1 / 4.1 / 4.1
<i>Mindset</i>	2.1.1,2	
<i>Self-efficacy</i>	1.4.2,3,4 / 2.1.1,2	
<i>Disposition</i>	2.1.1,2	
<i>Navigational skill set</i>		6.1 / 6.1 / 6.1
<i>Guidance</i>	2.1.1,2	
<i>Support</i>	3.2	5.1 / 2.1 / 2.1
<i>Interactions</i>	3.1	4.1 / 5.1 / 5.1
<i>ED care</i>	5.4	
<i>Accessibility</i>	5.3.1,2 / 2.1.1,2	
<i>Quality of care</i>	5.2.1 / 2.1.1,2 / 5.1.1,2	7.1

**Indirect relevance*

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