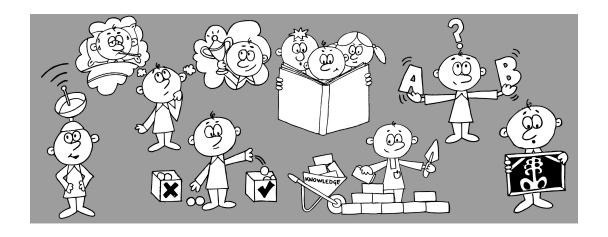
# Informed for health: Exploring variation in ways of experiencing health information literacy

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## Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy



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This research was supported financially by an Australian Postgraduate Award Industry (APAI) Scholarship
Keywords: health information literacy, information literacy, phenomenography, learning,
Keywords: health information literacy, information literacy, phenomenography, learning, health

#### **Abstract**

This thesis reports on a qualitative study that investigated the experience of health information literacy. It adopted a relational approach to information literacy, which emphasises the relationship between users and information when learning in different contexts, and interprets health information literacy as being the different ways in which people experience using information to learn about health.

Using interpretive phenomenography, a research approach that seeks to elicit and describe variation in experience, the study explored variation in people's experience of using information to learn about health from data collected through 23 semi-structured interviews with people aged between 45 and 64 years. The study revealed seven (7) categories of description that represent critically and qualitatively different ways in which people experienced health information literacy. These seven categories identified that health information literacy was experienced as *building a new knowledge base; weighing up information; discerning valid information; paying attention to bodily information; staying informed about health; participating in learning communities* and *envisaging health*. The study's findings also included an outcome space for the phenomenon of health information literacy, which depicts the relationships between the categories of description.

This study is significant because it has provided new knowledge about people's engagement with health information for learning in everyday life, and an enhanced understanding of what people experience as information that is used to learn about health. It also contributes to the nascent area of information literacy research conducted in everyday life contexts, and has further revealed the contextual nature of information literacy, as well as its complexity as a phenomenon and focus of study.

The findings provide empirical knowledge that can be used to inform consumer health information policy, the provision and design of consumer health information resources and services, and consumer education concerning health information.

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## Statement of original authorship

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signature: Date:

QUT Verified
Signature 15/12/2013

## **Acknowledgements**

My deepest thanks go to my two supervisors, Professor Helen Partridge and Professor Christine Bruce. Helen, I cannot thank you enough for all the time and energy you have invested in helping me to complete this research. Thank you for your endless enthusiasm to partake in theoretical and methodological discussions, your willingness to listen to and challenge my ideas, and for the guidance and suggestions you provided along the way that helped to shape and strengthen this research. I also extend my heartfelt thanks for the encouragement you provided that was instrumental in motivating me to take on a PhD, for persisting with this journey, and for ensuring that I reached the finish line. Christine, thank you for all the thoughtful and insightful input you provided to this research, and for so generously sharing your knowledge and understanding of phenomenography with me.

To Helen Hobbs, Deborah Ponting, Anna Hampson Lundh and Ann Gillespie. Thank you for being such amazing and wonderful friends, and for the much needed support and encouragement you provided along the way.

To Russell Morris, my most beloved husband and soul mate, without your support taking on this PhD would not have been possible. Thank you for encouraging me to challenge myself and for remaining by my side throughout this journey. My thanks also to you for drawing the wonderful illustrations that greatly helped to communicate and bring my research findings to life.

To my gorgeous canine companions, Indy and Moshio. Thank you for keeping me company by sleeping and snoring at my feet during the many hours I spent working on this thesis, and for making sure that I moved away from the computer from time to time to feed or play with you.

Finally, I extend my warmest thanks to those who generously gave their time to participate in this research, and who so willingly shared their experiences with me.

## **Chapter 1: Introducing the study**

#### 1.1 Introduction

This chapter introduces the study and is divided into five parts. In part one, I briefly explore the background to this research in order to orientate the study within the broader context from which it originated and was inspired. Then, in parts two and three, I present the study's aim and outline its significance. In part four, I discuss a number of key terms for the purpose of clarifying how these have been interpreted and understood in this study. Then in the final part of this chapter, I provide an overview of the remaining chapters contained in this account.

## 1.2 Background to the study

Over recent years the importance of consumer health information, that is, health information intended for use by the general public, has been increasingly recognised in the context of health and health care. This section provides a brief discussion of different motivations that have propelled the emergence of greater attention to consumer health information, and growing realisation of the crucial role that it plays.

In examining escalating interest in consumer health information it is impossible to overlook the impact of information communication technologies (ICTs). Over recent decades, ubiquitous growth and expansion in ICTs has dramatically influenced how people obtain information for health related purposes, and significantly altered the way in which knowledge on matters concerning health are now transferred to the general public (Campbell, 2008; Cullen, 2005).

In addition it has been suggested that the increased availability of health information through ICTs has similarly driven consumers' demands for health information within health care settings. This point was noted by Smith and Duman (2009) who emphasised that contemporary public expectation for health information as part of health care delivery was now 'a given', and that information provided in health services must be seen to meet consumer needs.

Similarly, the increased availability of consumer health information has been identified as exerting influence on consumers' perceptions of health care professionals. In this way, increased access to health information has been attributed to transforming consumers' potential to be 'informed' about various health matters, and shifted the health care

professionals role from the traditional gatekeeper of health knowledge, to an advisor and partner in health care (Cullen, 2005; Porter & Edirippulige, 2007).

However, aside from growth in ICTs enabling greater access to consumer health information, and changing demands for health information from consumers, the increased importance of consumer health information has also been attributed to overarching changes within national healthcare policy agendas (Smith & Duman, 2009).

First, it has been acknowledged that the widespread shift towards greater public and patient involvement in medical decision-making has dramatically contributed to increased attention to consumer health information. In many countries, information provision within the context of healthcare services is now a legal right for consumers, in that they must be provided with information in advance of medical treatment that identifies potential risks, alternative treatments, and the consequences of inaction. In this way, healthcare policy has mandated the provision of health information that consumers can understand, in order to be involved in discussions and decisions about their health care, and to ensure that they can provide 'informed consent' for medical procedures. This circumstance was acknowledged by Cullen (2005) who affirmed the role of consumer health information in safeguarding consumer or patient rights in contemporary health care delivery. Likewise Lambert and Loiselle (2007) reported that changing relationships between patients and providers in health care environments had caused an intensified emphasis on consumer health information. This was associated with the need for people to understand healthcare decisions, and the key role that health information plays in their ongoing effective self-care.

Second, the importance of information has also been recognised for the potential influence or impact it may play in addressing rising health challenges such as the escalating burden of chronic disease. For example, a 2010 report by the Australian Institute of Health and Welfare acknowledged that despite a rate of life expectancy that was higher than ever before, Australia's population was experiencing considerable health challenges. To illustrate this point, the report predicted that by 2023, Type 2 diabetes would become the primary cause of disease burden in Australia, and attributed this projection to the increasing number of people that are either overweight or obese (Australian Institute of Health and Welfare, 2010). Recognising these challenges, greater attention to consumer health information has resulted from a growing acknowledgement that it can play an influential role in providing people with health knowledge that can shape or change health behaviours that assist them to live longer and age more healthily. In the same way, reported linkages between information use and good health outcomes have substantiated the prominence of consumer health information in helping to address health concerns (Adams et al., 2009; Nutbeam, 2009).

Finally, widespread reform in national health policy has been another factor to exert influence on raising the profile of consumer health information. Examining this situation within the Australian context, three publications provide illustrations of a shift in national health policy. These include the 2009 final report from the National Health and Hospitals Reform Commission; the 2010 report 'Taking Preventative Action' released by the National Preventative Health Taskforce; and the National Primary Health Care Strategy, 'Building a 21st Century Primary Health Care System: Australia's Primary Health Care System' that was similarly released in the same year (Department of Health & Ageing). In examining these three documents it is evident that overarching policy change in Australian national health care recognises the key role that consumer health information can and needs to play. Collectively these reports acknowledge that greater attention to consumer health information may assist in reducing inequality in health status, enable people to better manage chronic conditions, and so it proves vital to increasing the focus on prevention and early intervention efforts. In summary, they signify an era of Australian health policy where consumer health information has started to come into its own.

## 1.3 Aim of the study

To date interest in consumer health information has attracted attention from two distinct theoretical perspectives: health information behaviour and health literacy. Research enquiry into health information behaviour has examined various behaviours through which people acquire health information, while research into health literacy has investigated various literacies that are associated with cognitive apprehension of health information.

In contrast, the aim of this study was to investigate health information literacy, an alternative theoretical perspective that was similarly identified as relevant to consumer health information, and could potentially contribute new knowledge and understanding. The term 'health information literacy' is derived from information literacy, a concept that originates from the discipline of information and library science. Conceptually the idea of information literacy may be interpreted in a number of different ways. In this research study I applied what is known as a relational perspective to investigate health information literacy. Initially established by Bruce (1997a), the relational perspective of information literacy draws from an experiential framework that emphasises the relationship between users and information when learning in different contexts. In keeping with the relational perspective, this study interprets the concept of health information literacy as being the different ways in which people experience using information to learn about health.

The main research question was:

What are the qualitatively different ways in which people experience health information literacy?

Emanating from this question, the study's objectives were identified as follows:

- To identify the qualitatively different ways in which people experience using information to learn about health.
- To provide descriptions of the various ways in which people experience using information to learn about health.
- To develop greater understanding about the phenomenon of health information literacy among the study's participants.
- To develop greater understanding about what people constitute as information that is used to learn about health.
- To contribute knowledge about the various ways in which people experience health information literacy, and examine what this may provide to health information literacy education and consumer health information research.

## 1.4 Significance of the study

This study is significant because it has introduced health information literacy as a complementary theoretical lens for consumer health information research. In this way it has provided an additional focus to add another layer of understanding to this field. More specifically, this study is significant because it has applied a relational perspective to health information literacy to examine the various ways in which people experience using information to learn about health. In doing so, it has provided a contrasting focus of enquiry that complements existing research into consumer health information from the health information behaviour and health literacy fields.

This study is also significant because it has investigated the experienced relationship between people and what they constitute as information that is used to learn about health. Knowledge gained from this has provided a richer and expanded understanding of what people perceive as information in the context of health and healthcare. Finally this study is significant because it has investigated information literacy in a nascent context for research enquiry, that is, everyday life. As such, these research outcomes have further revealed the

contextual nature of information literacy, as well as its complexity as a phenomenon and focus of study.

It is anticipated that this study will be of interest to the research domains of information literacy, health communication and health education, providing new knowledge and understanding about people's engagement with health information for learning in everyday life. More specifically, the findings may be used to inform consumer health information policy; as an evidence base for the provision of consumer health information; to guide the design of consumer health services; and the development of curricula for educational programs concerning people's use of health information.

## 1.5 Key terms

This section provides a summary of key terms that are considered of relevance to this study. They are provided as a way to establish clarity about how such terms have been interpreted and understood in this account.

#### Health

This study recognises that ideas and definitions concerning the concept of health continue to evolve, and that its interpretation is often relative to particular contexts and social norms (Australian Institute of Health & Welfare, 2012). In explicating the question 'What is health?' this study draws upon the definition provided by the World Health Organisation that considers health as being "a state of complete physical, mental and social wellbeing and not merely the absence of disease and infirmity" (1946, p.1). Therefore, this study takes a broad view of health that incorporates both physical and mental dimensions, and which recognises that it encompasses a complex interplay of determinants such as genetic, cultural, socioeconomic and environmental factors (Australian Institute of Health & Welfare, 2012).

#### Information

In this study the concept of information is taken to denote anything that an individual may experience as 'informing'. As such, this study assumes that information may present itself in many different ways, from conventionally understood forms of information such as text based documents, to audio, visual, environmental, kinaesthetic, embodied or affective forms of information. Furthermore, this study also accepted that what is constituted as information is fundamentally linked to the context in which the users' experience with information takes place (Bruce, 2008).

#### **Information literacy**

This study embraces a relational perspective of information literacy. As such it interprets the concept of information literacy as being *the complex of ways in which people experience using information when learning in different contexts* (Bruce, 1997a, 2008). The relational perspective considers that the meaning of information literacy originates from the various ways in which people relate with information, or in other words, the different ways in which people interact with elements of their information world. Consequently the relational perspective considers that the phenomenon of information literacy may be understood from descriptions that portray the various ways in which it is experienced by the information user (Bruce, 1997b).

#### Way of experiencing

The term 'way of experiencing' denotes the knowledge interest of phenomenographic enquiry. In phenomenography, a way of experiencing refers to "a way of being aware of something" (Marton 1994, p. 4426) and "the basic meaning structure of individuals' experiences of a particular aspect of their reality" (Sandberg, 1994, p. 52). Phenomenography considers that a way of experiencing something represents a relationship between subject and object, or in other words an "internal relation between the experiencer and the experienced" (Marton & Booth, 1997, p. 113). In addition, a way of experiencing is also considered to be comprised of both meaning and structure, and dependent upon a person's awareness or consciousness at a given point in time (Marton & Booth, 1997). A number of elements are understood to influence a way of experiencing. These include past experiences, beliefs, values, education, culture and the historical context in which a way of experiencing is embedded (McCosker, Barnard & Gerber, 2004). In the development of phenomenography as an approach to research, several other terms have been used in the literature to represent its knowledge interest. These terms include conception, way of experiencing, way of seeing and way of understanding (Marton & Booth, 1997). In this account, the term 'way of experiencing' will be used throughout.

## 1.6 Overview of chapters

Following this introduction, in Chapter 2, I provide an overview of literature that comprises consumer health information research. Within this chapter I also introduce the concepts of information literacy and health information literacy as an alternative focus of relevance to consumer health information scholarship. In particular I present the relational approach to

health information literacy as an alternative theoretical perspective for enquiry concerning consumer health information.

Chapter 3 outlines the research methodology used for the study. It situates the study within the interpretivist research paradigm, and introduces phenomenography as the selected research approach. Also described within this chapter are details relevant to the research design. This includes aspects such as the study's participants, the interview procedure, and process followed for data analysis.

Chapter 4 presents the study's results. It describes the seven critically and qualitatively different ways in which people experienced health information literacy. Within this chapter I also present the outcome space for the phenomenon of health information literacy, which depicts the critical differences and relationships that were identified.

In Chapter 5, I discuss and summarise the research outcomes. It examines the contributions this study has provided to information literacy research, and to understandings of information in the context of health. In addition, it also considers the implications of the study's outcomes alongside current approaches to consumer education about using health information, and articulates the contribution it provides to consumer health information research. The study's limitations and suggested directions for future research are also outlined.

#### 1.7 Conclusion

This chapter has provided an introduction to the study. Primarily the chapter has outlined the background to the study, articulated the aim and objectives, and discussed the study's significance. Key terms used in this account and summaries of the chapters contained in this thesis were also presented. In the next chapter, I explore and discuss literature that comprises consumer health information research

# Chapter 2: Literature Review: Thematising consumer health information research

#### 2.1 Introduction

This chapter provides an overview of consumer health information research, that is, literature that has in different ways investigated information in the context of consumer health. The chapter is divided into four parts. In the first part, I explore literature from the field of health information behaviour, which has investigated how people acquire health information through behaviours such as seeking, scanning and sharing. The second part of this review looks at literature from the field of health literacy, a research domain that has investigated various literacies that are considered necessary for people's cognitive apprehension of health information, and for participating effectively as a consumer or patient in a health context.

In the final two parts of the chapter I introduce information literacy, and more specifically health information literacy as an alternative theoretical perspective that is of relevance to the field of consumer health information. In part three, I present and discuss the concept of information literacy, and outline three positions that represent different theoretical approaches that have comprised research and scholarship in this field to date. These positions comprise the behavioural, relational and socio-cultural perspectives of information literacy.

Finally, in part four, I turn to health information literacy. In this section I discuss the emergence of this concept within information literacy discourse and scholarship, and present an examination of existing literature in this area. The review concludes by affirming that a lack of research into health information literacy from a relational perspective presently exists. As such, it proposes that knowledge about the various ways in which people experience health information literacy in everyday life is needed, and that applying a relational approach to investigating health information literacy provides an alternative theoretical perspective that is of value to consumer health information enquiry.

# 2.2 Health information behaviour: Acquiring health information

Information behaviour is a research domain that is concerned with investigating the process and dynamics of how individuals acquire information (Case, 2007). It comprises information seeking together with an array of unintentional or passive behaviours (e.g. information

scanning), as well as purposive behaviours where information may be actively avoided. According to Wilson information behaviour is:

the totality of human behaviour in relation to sources and channels of information, including both active and passive information seeking, and information use. Thus, it includes face-to-face communication with others, as well as the passive reception of information as in, for example, watching TV advertisements, without any intention to act on the information given (2000, p. 49).

The following sections of this chapter examine research that has investigated people's information behaviour within the context of health (i.e. health information behaviour). It will discuss studies that have explored four distinct health information behaviours: information seeking, information scanning, information sharing and information avoidance. Specifically it will focus on studies that have investigated people's health information behaviour with regard to two distinct social roles: patients or health care consumers. As such it does not examine research that has investigated health information behaviours as practiced by people within an occupational setting.

#### 2.2.1 Health information seeking

Health information seeking relates to the ways in which an individual obtains information about health, illness, health promotion activities and risks to health (Lambert & Loiselle, 2007). Research attending to the concept of health information seeking first emerged in the late 1980s (e.g. Lenz, 1984; Miller, 1987), however during the mid 1990s research attention escalated exponentially as a result of various forces of change. These forces included: the arrival of the information age and its resulting increase in potential information availability; a growing focus on self-monitoring and self-care in the context of consumer health; and a revival of interest in health promotion and illness or disease prevention activities (Case, 2007; Lambert & Loiselle, 2007). Within the overarching research domain of health information behaviour, studies devoted to investigating health information seeking have overwhelmingly received the majority of attention (Cutilli, 2010; Lambert & Loiselle, 2007).

In a review of scientific literature from 1982 to 2006, Lambert and Loiselle (2007) examined the concept of health information seeking in order to determine its maturity and essential characteristics. They observed that health information seeking is a concept with multiple understandings and without a universally dominant definition. However despite variation in how authors have defined this behaviour there is consensus that it involves the use of particular strategies or actions that individuals draw on to pursue or acquire health information (Lambert & Loiselle, 2007). These understandings concur with Wilson's

overarching definition of information seeking as "the variety of methods people employ to discover, and gain access to information resources" (1999, p. 263). Similarly information seeking is also regarded as a purposive behaviour, and an activity that is based upon the need to satisfy a particular goal (Wilson, 2000).

A number of terms are used synonymously in the literature to describe health information seeking. These terms include "information-seeking behaviour" (where the idea of health is merely implied), "health information seeking behaviour" and "information seeking" (Cutilli, 2010; Lambert & Loiselle, 2007). Stavri (2001) also noted the use of the term "consumer health information seeking" in social and behavioural sciences and health sciences literature. He proposed the term "personal health information seeking" as an alternative in order to denote the difference between health professionals seeking information for patients, to individuals seeking information for personal use.

Studies into people's health information seeking have primarily investigated this behaviour within three different settings. These settings comprise managing health-threatening situations; participating in medical decision making; and its influence in behaviour change and preventative behaviour (Lambert & Loiselle, 2007).

In coping with health threatening situations, research into information seeking has frequently centred on patients or survivors of various types of cancer (Lambert, Loiselle, & Macdonald, 2009; Mayer et al., 2007; McCaughan & McKenna, 2007a, 2007b; Nagler et al., 2010). In the same way, other studies have explored health information seeking behaviour among individuals with specific diseases such as multiple sclerosis (Bishop, Frain, Espinosa & Stenhoff, 2009) or diabetes (Longo et al., 2010). Research in this setting has endeavoured to identify the type of information an individual will seek to cope with a health threatening situation, the amount of information they seek, how this information is obtained, and the specific circumstances that determine a need for information. Therefore with this particular setting health information seeking is viewed as a coping strategy for a particular problem, and seeking information is a behaviour that may serve to manage or alleviate people's stress in a health-threatening situation.

Participation and involvement in medical decision-making has similarly drawn significant attention in health information seeking research. Within this line of enquiry research attention is directed to exploring an individual's preferred role in making medically related decisions (Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010; Davison et al., 2002; Hack, Degner, Watson & Sinha, 2006; Hashimoto & Fukuhara, 2004). The results of studies

within this setting have typically shown that individuals who prefer a more active or collaborative role in this context will be more active in seeking health information.

The impact that health information seeking may play in influencing behaviour change and preventative behaviour has been another area of interest. According to Lambert and Loiselle (2007), health information seeking has theoretically and empirically been identified as a key characteristic that influences the adoption of a healthy lifestyle, and a tendency to engage in preventative behaviours. Hence studies in this context have explored how health information seeking influences behaviour change or adopting preventative behaviours, along with factors that would encourage health information seeking for the same purpose (e.g. Ayers & Kronenfeld, 2007; Ross, Kohler, Grimley, Green & Anderson-Lewis, 2007; Warner & Procaccino, 2004; Yu & Wu, 2005).

In addition, research into health information seeking has investigated two particular foci of relevance. These foci include predisposing characteristics of health information seekers, and differences in people's practices of seeking health information (Anker, Reinhart & Feeley, 2011).

Considerable attention has been directed to research that has sought to identify particular characteristics that may (or may not) lead to an individual's engagement in health information seeking behaviour. Knowledge gained from research along this line of enquiry has shown that individuals with higher levels of education, and with greater income are more likely to search for health information (Cotten & Gupta, 2004; Dutta-Bergman, 2003; Ayers & Kronenfeld, 2007; Pandey, Hart & Tiwary, 2003). Studies have also uncovered that gender is a predisposing characteristic for using the Internet to seek health information, with females being more likely to utilise this channel in comparison to males (Arora et al., 2008; Drentea, Goldner, Cotton & Hale, 2008). In the same way, age, racial background and level of health literacy have also been identified as other characteristics that determine an individual's engagement in health information seeking behaviour (Shim, 2008; Ayers & Kronenfeld, 2007; Shieh, Mays, McDaniel & Yu, 2009). Collectively this body of research has converged on the conclusion that various disparities exist with respect to an individual's access to and use of health information.

Studies have also been undertaken to investigate various nuances that relate to the practice of seeking health information. Research enquiry in this area has examined specific channels through which people seek health information (e.g. health professional, the internet, friends), the specific content of information that people seek, the reliability of information obtained and people's self-efficacy to engage in the seeking process itself. According to Anker et al.

(2011) research into people's practice of seeking health information has provided greater specificity to understanding this phenomenon, as studies have often collectively investigated how an individual's particular characteristics (e.g. age, race) varies their search practice (e.g. Gilbert, Temby & Rogers, 2005; Nguyen & Bellamy, 2006; Shieh, Mays, McDaniel & Yu, 2009). Hence research enquiry in this area has provided knowledge concerning when and where people seek health information, along with how they evaluate the information obtained.

In examining the body of research that has investigated health information seeking two key observations can be made. First, there has been a dominant focus on researching information seeking in the context of an illness or health concern rather than for general health and wellbeing. This point was also noted by Lambert and Loiselle (2007) who commented on the need for research in this area to extend beyond an illness focus, and investigate health information seeking in a variety of contexts and different stages of illness or health. Second, studies have frequently limited their investigation to people seeking health information from the Internet. As such there is a need for further knowledge that examines people's search for health information from the broader information environment (Lambert & Loiselle, 2007).

In summary health information seeking is conceptualised as a purposive activity that emerges from an information need. As such it assumes there are underlying factors motivating an individual to search for information to meet a particular goal (e.g. decision making, solving problems) or to fill a gap of 'missing' information. In the context of health this behaviour is limited to actions or activities that are active and intentional, and therefore excludes instances where individuals are exposed to health information acquired without a specific request (Case, 2007). Finally, health information seeking is often assumed to be an 'all or nothing' phenomenon, in that people either exclusively seek or do not seek information, rather than a behavioural continuum that is determined by a range of factors. Consequently it can be considered that research into health information seeking provides only one facet through which people's health information behaviour may be understood.

#### 2.2.2 Health information scanning

According to Niederdeppe et al. (2007) information scanning "represents information acquisition that occurs within routine patterns of exposure to mediated and interpersonal sources that can be recalled with a minimal prompt" (p. 154). Historically speaking there have been a number of terms used to denote information scanning behaviour in the literature. Case (2007) proposes that 'browsing' was the initial expression used to characterise this type of information behaviour with 'encountering' and 'scanning' later emerging respectively as

descriptive vocabulary for this phenomenon. Other examples cited include 'casual seeking' (Johnson, Andrews & Allard, 2001), 'incidental' or 'mere exposure' (Shapiro, MacInnis & Heckler, 1997; Shapiro, 1999), 'incidental information acquisition' (Williamson, 1997), 'passive information acquisition' (Berger, 2002), 'routine information acquisition' (Griffin, Dunwoody & Neuwirth, 1999) and 'serendipitous retrieval' (Foster & Ford, 2003). Collectively these terms have been used to describe a particular type of information behaviour that was regarded as being less purposeful and more passive and unintentional in nature compared to information seeking.

In discussing this behaviour within a health context Niederdeppe et al. (2007) emphasise that the difference between scanning and seeking information is not simply akin to people's passive or active use of information sources. They consider that health information scanning involves an active choice to engage with a particular source of information, hence the individual is not entirely passive in the process of how information is acquired. Minsun, Kelly and Hornik (2006) similar concur with this assertion and consider that health context information scanning "goes beyond incidental exposure, to include information a person encounters in the normal flow of information but decides to attend to" (p. 158). As such examples of health information scanning may comprise browsing various news media; reading a newspaper article when a headline catches the reader's eye; tuning in to a health segment on the radio; paying attention to health content when it is presented in the course of routine television viewing; and hearing health related information as part of everyday interactions with family, friends and co-workers.

Although information scanning is an emerging area of interest within health information behaviour enquiry, understandings from studies conducted to date reveal three key observations that are important to acknowledge. Each of these observations will now be discussed.

First, studies have revealed that information scanning is a prevalent behaviour through which people acquire information about health. More specifically, studies have also shown that in comparison to information seeking, information scanning occurs on a more frequent and regular basis. For example Niederdeppe et al. (2007) and Kelly et al. (2010) both report on research to investigate the prevalence of information scanning compared to information seeking for cancer information within the general population. Using interviews (Niederdeppe et al., 2007) and surveys (Kelly et al., 2010) data was collected from and persons aged 50-70 years (Niederdeppe et al., 2007) and persons aged 40-70 years of age (Kelly et al., 2010). Findings from both studies confirmed information scanning as a significantly more prevalent

behaviour through which people engaged with information when compared to information seeking.

Second, research into information scanning has also uncovered more comprehensive understandings about the range of sources people report engaging with to acquire information about health. For example the results from a study by Longo et al. (2010) of adults diagnosed with diabetes identified a diverse range of sources from which information was acquired as a result of scanning behaviour in daily life activities. In particular the scope of sources that participants identified included many that had not been conventionally viewed as sources through which health information could be acquired (e.g. exercise videos, cookbooks, television talk shows). In a similar way the results from studies conducted by both Niederdeppe et al. (2007) and Kelly et al. (2010) noted the complexity and diversity of information sources that people may engage with through information scanning activities.

Third, research has also shown that information scanning can play an important role in the acquisition of information that people use for holistic health care. For instance participants in the study by Longo et al. (2010) identified that information acquired through scanning behaviour was frequently used to self-manage their diabetic condition on an ongoing basis. Continuing this idea, Niederdeppe et al. (2007) remarked that it was plausible to suggest information scanning played a significant and influential role in informing decisions regarding different aspects of health care, particularly in view of the behaviour's identified prevalence in people's daily life.

In summary health information scanning is a nascent area of study in health information behaviour. Although it has received significantly less attention, research findings have shown that greater understanding about other information behaviours that relate to people's acquisition of health information is needed. This point was emphasised by Longo (2005) who commented on the inevitability of health information being encountered in daily life and subsequently used at a later point in time as opposed to something that was only exclusively and intentionally pursued. As such Longo advocated the need for wider consideration of information behaviours in research to investigate people's acquisition of health information. In a similar way, deeper insights into sources people may acquire health information from through scanning behaviour has been a noteworthy outcome in this area. This too has suggested a need for further research to obtain greater understandings of information sources that people use in health contexts, and the various ways in which information about health may be obtained.

#### 2.2.3 Health information sharing

Information sharing is a largely unexplored facet of information behaviour, however over the past decade research interest in this phenomenon is reported to have enjoyed a substantial increase in attention (Wilson, 2010). One of the first researchers to draw attention to the notion of information sharing was Wilson (1981). Initially referring to this behaviour as 'information exchange', he stated it to be an activity where

...the user may seek information from other people, rather than from systems, and this is expressed... as involving 'information exchange'. The use of the word 'exchange' is intended to draw attention to the element of reciprocity, recognised by sociologists and social psychologists as a fundamental aspect of human interaction (1981, p. 4).

To date research into health information sharing has typically examined this behaviour through two distinct lines of enquiry. First, the sharing of information between consumers and health care professionals or health organizations. Second, the sharing of health related information among consumers themselves.

With respect to the first line of enquiry, studies in this area have investigated consumer concerns or issues with the exchange of personal medical data in health care systems. For example, the 2009 study by Simon, Evans, Benjamin, Delano and Bates investigated patient attitudes towards the electronic exchange of medical data between health care providers. Their research findings revealed three key themes. First, that patients were concerned about the privacy and security of shared information. Second, that patients wanted to learn about the potential health care benefits that may result from sharing information. Third, that patients wanted further information about the process that would be used to obtain consent for sharing information. The study concluded that patients needed to have access to concise educational materials about the benefits and risks of exchanging personal medical data electronically between health care providers. It also recommended that patients needed to be given opportunities to engage in conversations with health care professionals about this practice.

Other examples of research that has explored consumer attitudes to sharing health information and reported similar findings include studies by Wen, Kreps, Zhu and Miller (2010) and Anderson and Agarwal (2011). Collectively research in this area has revealed that issues such as trust, data protection, openness, privacy and adherence to legislative requirements are significant for consumers with respect to information sharing that involves the exchange of personal medical details with health care professionals or organisations.

In addition, studies have also been conducted to investigate information sharing in situations where consumers may share health related information with each other. Typically research in this area has looked at consumers' information sharing behaviour in the context of health related support groups that are conducted in either face-to-face or online environments.

For example in 2009 Percy, Gibbs, Potter and Boardman undertook a study to explore the experiences of women with polycystic ovary syndrome attending a face-to-face nurse-led support group at a public hospital in the United Kingdom. Data was collected through qualitative interviews conducted with thirteen female patients. Their findings showed how the exchange of personal experiences of the disorder provided an important socio-emotional function. They concluded that opportunities to share this kind of information helped to reduce women's sense of isolation and difference, and enabled them to engage in social comparison with others who were perceived as being either 'better' or 'worse' off.

Similarly, the study by Veinot (2010) provides another example of research that has investigated information sharing among the general population. Veinot's study investigated the value of peer-based health information exchange among rural people in Canada with HIV/AIDS through in-depth semi-structured interviews with thirty-four persons. Research findings reported that people valued the process of information sharing among their peers for two key reasons. First, because sharing information enabled them to access unique informational content in the form of 'experiential information', which included practical strategies for dealing with HIV/AIDS, as well as information about emotional and spiritual issues connected with the disease. Second, findings also revealed that people valued the positive emotions they experienced as a result of informational interactions with their peers. Veinot concluded that peer-based information sharing filled a significant informational gap in participant's lives, and emphasised the need to develop and support this type of activity in public health information services.

The growth and advancement of information and communication technology has provided another avenue through which consumers can 'share' or 'exchange' health information through online support groups or social networking sites. In 2010, Colineau and Paris conducted an online survey with seventy participants to study patients information sharing on health-related social networking sites. Their findings showed that people engaged in information sharing as a way of obtaining emotional and informational support that would help them learn about medical conditions from people with similar afflictions. Participants reported that social networking sites enabled people to share information that helped them to more deeply understand how certain conditions would affect them as an individual, to learn about different strategies or treatments people used to deal with particular conditions, and

provided an opportunity to share personal experiences as a form of information. In a similar way, the 2010 study by Hess, Weinland and Beebe of women's involvement in an online support for peripartum cardiomyopathy provides another illustration of research in this area that has reported similar findings concerning health information sharing behaviour.

In summary, research into the exchange of health related information among consumers has shown that people regard this as a valuable and beneficial activity through which information about health may be acquired. Furthermore, research into information sharing has also revealed 'experiential information' as a distinctive kind of information that is exchanged with this behaviour, and that this is shared more frequently than factual or clinical health information. Finally, research into information sharing has broadened the concept of information behaviour to recognise that information acquisition can be regarded as an individualised activity, as well as one that may be collaborative in nature.

#### 2.2.4 Health information avoidance

A further research trajectory has examined a contrasting behaviour to those that examine people's acquisition of health information. This behaviour is referred to as 'information avoidance' and refers to an individual's tendency or reluctance to engage with information.

The concept of information avoidance has attracted research interest from a variety of disciplines. Case, Andrews, David Johnson and Allard (2005) note the phenomenon's lengthy history in literature emanating from the disciplines of communication science and psychology, while Sweeny, Melnyk, Miller and Shepperd, (2010) and Sairanen and Savolainen (2010) acknowledge disciplines including organisational behaviour, health sociology and medicine. According to Sairanen and Savolainen (2010), information scientists have shown considerably less interest in the issue of information avoidance compared to other information behaviours. Case, Andrews, David Johnson and Allard (2005) similarly concur with this assertion by noting how within literature regarding information seeking the idea of avoiding information is seldom discussed.

There is a notable absence in the literature of a unified definition for information avoidance. Sairanen and Savolainen (2010) contend that the lack of cohesive definition is attributed to the fact that information avoidance is a "multi-faceted phenomenon that defies exact definition" (p. 2). As an illustration of this point, Case, Andrews, David Johnson and Allard (2005) fail to provide a precise definition of information avoidance, but note its relationship with concepts such as selective exposure, ignorance, cognitive consistency, fear appeals, uncertainty reduction, uncertainty management, coping, and monitoring and blunting behaviours. An exception to this is Sweeny, Melnyk, Miller and Shepperd (2010) who

provide a recent review of literature examining information avoidance. In this review they define information avoidance as "any behaviour intended to prevent or delay the acquisition of available but potentially unwanted information" (p. 341).

Sweeny et al. (2010) also provide further elucidation concerning information avoidance. They suggest that information avoidance is a behaviour that can be either active or passive in nature, because it can encompass requesting that someone not reveal information as well as avoiding posing questions that will reveal information. Information avoidance is also a behaviour not solely limited to avoiding information about one's self, in that people may also turn away from information that relates to partners, close family members and friends. Furthermore information avoidance may be temporary or enduring as an individual may shun away from information at a certain point in time, but then revisit it at a later date, or they may avoid information altogether.

There are two distinct research trajectories that have investigated people's avoidance of health information. These trajectories include the different motivations underlying why individuals choose to avoid health information; and the different conditions under which avoidance behaviour towards health information is likely to occur, (Sweeny et al., 2010). The following sections present a brief discussion of each trajectory.

Research to investigate why people choose to avoid health information has identified two distinct motivations underlying this behaviour. First, that information may be avoided because it will necessitate an undesired action such as a behaviour change. Second, that information may also be avoided when people believe that choosing to learn particular information, or that the actual information itself may result in unpleasant emotions, or reduce a pleasant emotion (Sweeny et al., 2010).

The study by Vargas (2001) provides an illustration of research that has shown how people may avoid health information in situations where it may necessitate an undesired action. In an investigation of commercial sex workers and their clients in South Africa, results revealed that one reason cited for failing to undergo screening for HIV was the fact that a positive test result would necessitate behaviour change in sexual practices. Research by Ajekigbe (1991) similarly revealed that a primary reason for women delaying a visit to a general practitioner regarding a suspicious lump in their breast was their concern that they may be required to undergo a mastectomy. More recently in 2012, the study by Barbour, Rintamaki, Ramsey and Brashers found that people reported avoiding health information if it would interfere with habitual or enjoyable activities, even when certain habits or behaviours were known to be unhealthy.

Research has also shown that people may choose to avoid health information in order to avoid or mitigate experiencing unpleasant emotions. Studies following this line of enquiry have often investigated avoidance behaviours in regard to learning information about particular medication conditions such as breast and ovarian cancer (Thompson et al., 2002); leukaemia (Friis, Elverdam & Schmidt, 2003); Alzheimer's disease (Cutler & Hodgson 2003) and Huntington's disease (van der Steenstraten, Tibben, Roos, van de Kamp & Niermeijer, 1994). Studies of this kind have shown that a myriad of emotions may motivate information avoidance such as anger, disappointment, embarrassment, fear, guilt, sadness and shame.

The second trajectory of research enquiry has examined moderators of information avoidance, in other words, different situational factors that increase the likelihood of avoidance behaviour. Sweeny et al. (2010) suggest that situational factors include perceived control over the consequences of information; resources to cope with the information; ease of obtaining or interpreting the information; and expectations about the content of information.

Studies exploring people's perceptions regarding perceived control over the consequences of information have frequently shown the tendency for people to avoid information if they cannot control the consequences. For example studies by Dawson, Savistky and Dunning (2006) and Yaniv, Benador and Sagi (2004) both showed that people were more interested in undergoing testing for a severe disease if it was portrayed as treatable rather than untreatable.

The degree to which individuals perceive they can cope with information can equally moderate information avoidance. A study by Melnyk and Shepperd (2012) examined the role of coping resources in regards to women's decisions to avoid breast cancer risk information. Their results showed that women who perceived they had fewer coping resources were more likely to avoid learning about personal risk. Similarly, the study by van der Steenstraten, Tibben, Roos, van de Kamp and Niermeijer (1994) showed people's perceived ability to cope with news of a positive test result for Alzheimer's disease influenced their decision to undergo testing. As a final example, an early study by Klepac, Dowling and Hauge (1982) found that an individual would avoid dental examinations if they perceived themselves as unable to withstand dental pain (1982).

Information avoidance is also moderated by the effort required to acquire and interpret information. Research along this line of enquiry has revealed that avoidance is more likely to occur when an individual perceives obtaining access to information will be challenging, or if

the information itself will be too difficult to understand. For example Afifi and Weiner's study (2006) discovered that people's interest in information concerning their partner's sexual health corresponded with their perception of the degree to which their partner was able to provide accurate and complete information.

The final moderator proposed by Sweeny et al. (2010) was people's expectations about the content of information. This moderator refers to risk judgements that people make about the potential content of information. They comment that the influence of expectations on decisions to avoid information was an area that required further clarification and understanding.

Drawing on the review and evaluation of information avoidance literature by Sweeny et al. (2010), several comments can be made. First, there has been a tendency to research singular instead of multiple motivations concerning information avoidance. Second, that significantly less research has explored information avoidance that is motivated by potentially undesired actions or unpleasant emotions. Third, that the different situational moderators of information avoidance have also received disproportionate research attention. Finally, similar to information seeking, information avoidance is often perceived as an 'all or nothing' phenomenon, however research has suggested that similar to information seeking, human behaviour to avoid information often manifests itself in varying degrees. In summary Sweeny et al. (2010) acknowledged the absence of an overarching theoretical model that conceptualises why and when people avoid information. They concluded that as a phenomenon, information avoidance lacks comprehensive understanding, and that further research was necessary to examine this in a theoretical and systematic manner.

#### 2.2.5 Summary

In summary, health information behaviour research has examined the various processes and dynamics through which individuals acquire information. Although this field recognises that an array of information behaviours exist, to date research has unquestionably afforded information seeking the majority of attention compared to more passive or less purposeful behaviours such as scanning or sharing. As such further research is needed in this field to develop greater understandings about the different actions that constitute the complement of health information behaviours.

In addition, a notable observation of information behaviour research is its tendency to study a single specific behaviour as opposed investigations of the spectrum of behaviours an individual may engage in to acquire (or not acquire) health information. Consequently there is a need for research that investigates people's interactions with health information using

methods that will provide more comprehensive or holistic accounts of this phenomenon. Finally, research concerning people's health information behaviour has most commonly focused on investigating this phenomenon within the context of a specific illness. Therefore, it can be said that further knowledge is needed with respect to people's acquisition of health information in the broader management of their health (e.g. diet, exercise).

The following section moves to the second key body of research that has investigated consumer health information: health literacy. It begins with an overview of the emergence of this field and the various understandings and definitions that have been developed. Subsequent sections are then devoted to a discussion of research that has been undertaken to investigate health literacy including the development of instruments for measuring health literacy, the impact of health literacy on health outcomes, and investigating approaches to communicating health information.

## 2.3 Health literacy: Reading and understanding health information

Health literacy is a comparatively recent concept that first appeared in health care literature in the early 1990s (Schnitzer, Rosenweig & Harris, 2011). According to Peerson and Saunders (2009), the term health literacy reflects an intersection of the health and literacy fields, while Berkman, Davis and McCormack (2010) suggest that health literacy embodies a new field of study that has emerged from research exploring relationships between low literacy, health status and health outcomes. As a relatively emergent construct various authors acknowledge that there are multiple understandings and definitions for health literacy present in the literature (Berkman et al., 2010; Ishikawa & Yano, 2008; Speros, 2005). In 2006 Baker commented on the lack of a shared meaning of this term, and highlighted that while attention to health literacy had rapidly expanded in the last decade, confusion and debate over the concept continued to prevail among researchers and experts. More recently the review of health literacy literature by Berkman et al. in 2010 concluded that the construct of health literacy was highly complex in nature, and as such it could be approached from a range of perspectives that provided varying interpretations.

There are three separate definitions that are most commonly cited in the literature to define health literacy. The first is a definition from the American Medical Association (developed by the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs) that describes health literacy as "a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health-care environment. Patients with adequate HL [health literacy] can read, understand and act on health-care information"

(1999, p. 553). Drawing on this interpretation, health literacy is regarded as a concept that relates to patients within health-care situations and their understanding of the information they receive from health-care professionals.

A more commonly utilised definition of health literacy is one that was developed by Ratzan and Parker for the National Library of Medicine in the United States. In their definition, health literacy was described as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (2000, para. 7). As such the definition provided by Ratzan and Parker can be seen as extending the idea of health literacy beyond patients in health-care settings, and conceptualises health literacy as something that is applicable to all individuals.

Finally the World Health Organisation (WHO) also provide a definition that describes health literacy as "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain health" (1998, p. 10). Whilst less frequently cited by authors in this field, the WHO definition provides a contrasting view of health literacy by referring to both cognitive and social skills, as well as motivation and ability.

However despite different nuances in interpretation, the varying descriptions of health literacy are essentially grounded in the concept of literacy within a health or health-care context. Therefore although health literacy is commonly related to reading proficiency, it also takes in other functional skills such as prose, numeracy and communication which enable individuals to complete health documentation (e.g., medical forms), calculate a correct medication dosage, comprehend advice and instructions from health care professionals, and participate actively and effectively as a consumer in health-care decisions and settings (Nielsen-Bohlman, Kindig & Panzer, 2004; Speros, 2005). In addition, the concept of health literacy is regarded as a construct that applies at an individual level, that is, it relates to a person's ability or capacity to undertake health-care related tasks. Finally, the concept of health literacy is considered to be a variable that exerts influence over health outcomes (Berkman et al., 2010; Speros, 2005).

To date research into health literacy has explored relationships between this concept and an array of health-related foci. In the following three sections of this chapter I discuss and examine research into health literacy that has investigated consumers or patients and skills that are considered necessary to access and use health information. This includes the development of instruments to measure health literacy, the impact of health literacy on health outcomes and investigating approaches to communicating health information.

#### 2.3.1 Developing instruments to measure health literacy

There has been considerable attention in health literacy research towards developing various instruments that are designed to measure people's levels of health literacy, or in other words, ways in which to test or examine an individual's skills or competencies with respect to health-related information. Two instruments that have been developed and are widely used as screening tools in clinical settings and in health literacy studies are the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993), and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams & Nurss, 1995).

The REALM is a test that measures an individual's word recognition and pronunciation skills, and was developed to assist clinicians in identifying patients at greatest risk of having limited literacy skills. The form of the test comprises a list of words common to patient direction and medical education. Words are ordered by difficulty and consist of terms with one to multi-syllables. The test requires individuals to read as many words as they can, with scored based upon the number of words that are spoken correctly. An individual's final score assigns their health literacy skills into one of four categories that represent grade-equivalent reading level (Davis et al., 1993).

In contrast, the TOFHLA was designed to measure two main constructs, namely an individual's reading comprehension and numeracy skills. The TOFHLA comprises a 50-item reading comprehension, and a 17-item numerical ability test that uses 'real-to-life' health care materials such as patient education information, prescription bottle labels, registration forms, and instructions for diagnostic tests. The final test score categorises individuals as having either inadequate, marginal or adequate levels of health literacy (Parker et al., 1995).

However while the REALM and TOFHLA are regarded as useful tools in clinical settings and been extensively validated through research, these instruments have similarly drawn criticism for failing to capture the complexity of health literacy. In this way, the REALM and TOFHLA are considered to confine the measurement of health literacy to particular domains (i.e. word recognition, reading comprehension, numeracy skills), rather than measure the full range of skills that are needed for health literacy such as oral communication, listening and writing (Peerson & Saunders 2009; Baker 2006). In recent years research has continued into the development of additional instruments that aim to provide more comprehensive measurements of health literacy. For example studies by Jordan et al. (2013) who developed the Health Literacy Management Scale (HeLMS), and Chinn and McCarthy's (2013) All Aspects of Health Literacy Scale (AAHLS) provide two

illustrations of contemporary research to assess a range of health literacy competencies that extend beyond functional literacy skills.

An example of seminal research to measure levels of health literacy within Australia was a 2006 study conducted as part of the Adult Literacy and Life Skills Survey by the Australian Bureau of Statistics. This study utilised the United States Health Activity Literacy Scale (HALS), and attempted to assess health literacy across five health-related activities including health promotion, health protection, disease prevention, health care maintenance and systems navigation. Proficiency scores were grouped into five skill levels, with Level 3 identified by survey developers as the minimum level needed to meet the present demands of everyday life. Findings from the 2006 survey showed that 43% of Australians aged 15 to 74 years achieved a health literacy level of Level 3 or above, with males and females overall achieving similar health literacy levels (Australian Bureau of Statistics, 2006). Survey findings also revealed that being employed, having a white-collar occupation, higher levels of income, higher educational attainments and living within a major city were associated with achieving higher health literacy scores (Australian Bureau of Statistics, 2006).

In summary, research to develop instruments for the measurement of health literacy has shown that it is a difficult and elusive concept to measure. Similarly, current assessment tools are still reported to neglect including oral communication or writing skills in their measurements, or examine an individual's health literacy across a range of different health contexts. Finally, it can also be said that the development of instruments to measure health literacy has also had to contend with ongoing debate concerning how the concept of health literacy is theoretically interpreted and conceptualised. In consequence there has been ongoing contention about the specific complex of skills and competencies that are considered to contribute to health literacy, and how to test and measure these accordingly.

#### 2.3.2 Impact on health outcomes

A second major focus of research enquiry into health literacy has examined the impact of health literacy on various health outcomes. Knowledge gained from research undertaken in this area has provided substantial evidence that a significant relationship exists between low levels of health literacy and a range of negative health outcomes. Low levels of health literacy have been frequently associated with higher incidence of hospitalisation, increased use of emergency care, and lower rates of participation in preventative health-care services. In addition, limited health literacy has also been shown to impact on understanding treatment, lower adherence to treatment regimes, poorer overall health and higher mortality

(Frisch, Camerini, Diviani & Schulz, 2012; Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011).

Research into the impact of health literacy on health outcomes has investigated this relationship through a range of different foci. This section however concentrates on two foci that particularly highlight the impact of health literacy on people's health-care skills, with regards to appropriate administration of prescribed medication, and interpreting health-related labels.

The study by Yin et al. (2010) provides an example of research into the impact of health literacy on people's health-care skills with respect to taking or administering medication. This study investigated the extent to which parents' health literacy affected the frequency and magnitude of liquid medication dosing errors. Parents were observed for dosing accuracy using a range of standardised instruments that included dosing cups, droppers, dosing spoons and oral syringes. The study findings showed that statistically health literacy was significantly related to dosing errors with cups and dosing spoons. Dosing errors most frequently occurred due to reported confusion about teaspoons vs tablespoon instructions (i.e. the similarity between 'tsp' and 'tbsp' markings), and assumptions about the cup as the unit of measure, in that a full cup of medication was the dose. Results confirmed that dosing cups were specifically associated with large overdosing errors for parents with low health literacy. Yin et al. (2010) concluded that future strategies to decrease the rate of dosage errors needed to consider medication instrument designs that placed fewer literacy demands on the population, particularly for persons with low health literacy.

Likewise the study by Waldrop-Valverde et al. (2009) provides another illustration that investigated the impact of health literacy on medication management capacity among HIV positive adults through testing both reading comprehension and numeracy skills. Their findings showed that low levels of health literacy posed a significant risk for inadequate antiretroviral medication adherence. They concluded that training patients in medication management at the start of antiretroviral therapy could mitigate instances of non-adherence due to misunderstandings emanating from low health literacy.

Studies have also investigated the impact of health literacy on people's skills in interpreting prescription medication and nutrition related labels. An example of research in this area is the study by Davis et al. (2006) that investigated interpretations of simple prescription labels among patients that were taking an average of three different prescriptions. Their findings revealed that patients with low levels of health literacy misinterpreted labels 3.4 times more often than average. In addition, results also reported that in many instances, patients'

interpretations of what they thought was required was the direct opposite of what the instructions actually directed.

Rothman et al. (2006) similarly provides a further illustration of the impact of health literacy on people's interpretations of health labels. In this study they examined patient comprehension of food labels to investigate the relationship of comprehension to literacy and numeracy skills. Their findings demonstrated that poor label comprehension was highly correlated with low-level literacy and numeracy skills. They concluded that persons with low health literacy were less likely to understand nutrition labels, and that changes were required to make food labels more accessible and comprehensible.

In summary, the outcomes of this area of research have confirmed that relationships exist between people's level of health literacy and health care-related skills. In consequence this recognition has been integral in progressing another trajectory in health literacy research to examine alternative strategies for informing and educating people within the context of health and health care.

#### 2.3.3 Investigating approaches to communicating health information

Another significant area of health literacy research has investigated ways of making health information more accessible, alternative approaches for communicating health information, and the impact of information modification on people's comprehension of health related materials. This area of enquiry has largely emanated from understandings and acknowledgement within the field that health literacy can be improved when information is more accessible, or that attention to the readability, presentation and format of health information can help mitigate the effects of low health literacy (Berkman et al., 2010; Nutbeam, 2009).

There has been considerable attention paid in health literacy research towards studies that have assessed the readability of health information. This theme is illustrated in a literature review undertaken by Rudd, Anderson, Nath and Oppenheimer (2007) of more than 800 published studies that had investigated the readability of health information materials. Their review of research in this area confirmed that the reading skills needed to understand health information frequently exceeded the reading skill level of the average high school graduate. They concluded that this disparity was of significant consequence to health consumers in terms of their ability and capacity to access health information materials that were easily understood.

The study by Hoffman and McKenna (2006) provides a specific example of research that has investigated the readability and design of written health materials. This study examined patients' reading ability following stroke in conjunction with the reading level, and the content and design characteristics of written information that was provided in a hospital acute stroke unit. Their results revealed that the average reading level of materials provided to patients was of an eleventh-grade level of difficulty, while the majority of patients reading ability was at either seventh or eighth-grade levels. Hoffman and McKenna concluded that future development and distribution of written information needed to be more conscious of patients' literacy skills, and be tailored to better meet their informational needs.

In a similar way, a more recent study by Rose, Worral, Hickson and Hoffman (2011) provides another illustration of research in this area that examined formatting characteristics that people with aphasia regarded as barriers and facilitators to reading printed educational materials. Their results revealed forty-five facilitators and forty-six barriers that could be classified into two categories that reflected either content characteristics or design characteristics of health education materials. These authors concluded that routine consideration of these barriers and facilitators were crucial to ensuring that written information for people with aphasia was more accessible. Overall, the outcomes of work in this area have frequently revealed that significant gaps exist between the difficulty levels of printed health information and the reading ability levels of the patients or broader population for whom it was intended.

However acknowledging that improvements to the readability of health information may still limit its accessibility for people with very low levels of literacy, research has also been undertaken to investigate alternative approaches to communicating health information. For example, the effects of pictures in improving the communication of health information was examined in a review of several hundred studies undertaken by Houts, Doak, Doak, and Loscalzo (2006). Their review reported that there was a marked increase in attention to and recall of health education information when pictures were closely linked to written or spoken text when compared to text alone. In addition, the use of pictures was also shown to improve comprehension of health information and impact positively upon adherence to health related instructions. They recommended and affirmed the importance of incorporating appropriate pictures to support key messages in health education materials, particularly for persons with low text-based literacy.

Continuing this idea, studies have also been undertaken to examine how modifications to health information impacts on people's comprehension. Illustrative examples of research in this area include a 2006 study by Trifiletti, Shields, McDonald, Walker and Gielen into the

development and evaluation of written paediatric injury prevention information for parents with low literacy skills. Their findings demonstrated significant improvement in parents' comprehension of this information after materials were redesigned using plain language guidelines.

In a similar way, studies by Wolf et al. (2010) and Kripalani et al. (2007) provide further illustrations of research that has explored the impact of information modification on people's comprehension of health related materials. The 2010 study by Wolf et al. evaluated whether patient comprehension of drug warnings could be improved through the use of 'enhanced print' warning labels. Patient's interpretations of the drug warnings were tested using examples provided in three formats: (i) standard text, (ii) simplified text and (iii) simplified text with icons. Findings confirmed that warnings with simplified text and simplified text with icons were more likely to be correctly interpreted compared to drug warnings with standard labels, and that the addition of appropriate icons was also of significant value for adults with low literacy. Kripalani et al. (2007) likewise reported similar outcomes in their evaluation of an illustrated medication schedule that also revealed significant improvements in people's understanding of medication management.

Overall the outcomes of this line of enquiry have influenced efforts to adapt health-related information to enhance accessibility and usability. This includes strategies such as the introduction of standards and guidelines regarding the development of consumer health information, and stratifying health information that attends to different levels of health literacy within the population (Berkman et al., 2010; Frisch, Camerini, Diviani & Schulz, 2011).

#### 2.3.4 Summary

In summary, health literacy is a field of enquiry that has investigated various skills that are considered to be fundamental for enabling people to access, read and use information in a health context. More specifically, the concept of health literacy has brought what could be considered as a 'literacy lens' to the broader field of consumer health information research. However to date studies into health literacy have largely attended to this construct by investigating reading literacy, that is the skill that is associated with comprehension of written information, and to a lesser extent skills that relate to numeracy. In this way it can said that although this field has provided considerable knowledge, a broader evidence base is needed to understand other skills that contribute to health literacy such as oral literacy (i.e. verbal comprehension), interactive literacy (i.e. social skills involved in negotiation and advocacy) and critical literacy (i.e. skills that facilitate critical engagement with health

information). Consequently further research is needed to provide more comprehensive knowledge and understanding of the wider complement of skills that contribute to health literacy.

The following section of this chapter turns to information literacy, a concept that originates from the discipline of information and library science, and will outline the various theoretical perspectives that comprise research and scholarship in this field. In the final section of this chapter I introduce health information literacy, and propose this as an alterative theoretical perspective for investigations into consumer health information.

## 2.5 Information literacy: Background

The term information literacy was first coined in 1974 by Paul Zurkowski, a former president of the Information Industry Association. Zurkowski made reference to the term in a proposal to the United States National Commission on Libraries and Information Science stating that an information literate individual was someone "who had learned to use a wide range of information sources in order to solve problems at work and in his or her daily life" (Grassian & Kaplowitz, 2001, p. 4). Zurkowski's proposal advocated the establishment of a national program in the United States aimed at accomplishing work-related information literacy. The timing of the proposal was significant, arising amid an era where there was growing acknowledgement about the potential that computers and networks posed for revolutionising information management and communication. In this way, Zurkowski argued that 'information literate' individuals would be better positioned to more fully exploit information resources.

The most commonly cited definition of information literacy is one provided by the American Library Association in 1989 who proposed:

To be information literate, a person must be able to recognize when information is needed, and have the ability to locate, evaluate and use effectively the needed information (p. 1).

However since its inception the concept of information literacy has been described in countless ways and an exact definition has been the source of ongoing debate and conjecture (Snavely & Cooper, 1997). According to Bruce (2000) this myriad of descriptions for information literacy emanate from differences in the way the concept is understood by various researchers, experts and scholars in the field. This point is similarly reflected in more recent literature by Limberg, Sundin and Talja (2012), who discuss how understandings of information literacy differ based upon the "theoretical lens from which it is approached" (p.

93). Continuing this idea, Pilerot and Lindberg (2011) also point out how literature of relevance to the information literacy movement may be distinguished by differences concerning how the concept of information literacy is both theorised and presented.

Nevertheless despite differences in the way information literacy is defined "there is agreement it is a problem solving activity that involves critical thinking and the ability to apply information to an individual's life" (Harding, 2008, p. 3). In the same way authors such as Eisenberg and Brown (1992) and Grassian and Kaplowitz (2001) note the many commonalities interwoven among definitions proposed over time. They identified a number of distinctive themes including critical thinking, problem solving, preparedness or a desire for lifelong learning, and the capacity to use information in all aspects of life.

Other authors have similarly drawn connections between concepts such as the information age, information society, knowledge-economy and information literacy. For example in 2000, Webber and Johnston comment that information literacy has been posited as a theoretical and practical response to cultural, social and economic developments connected with the information society. Later on in 2002, O'Sullivan also asserted the relevance of information literacy, posing it as "critical for social and professional empowerment in a knowledge-based economy" (p. 8).

Information literacy has also been regarded as an essential enabler for good decision-making in personal, professional and community contexts. Commenting on the difference that information can make to people's everyday lives Todd (2000a) emphasises that "having the knowledge and skills to connect with and interact with information can enable people to solve real world problems and address life concerns" (p.164). Todd affirms the importance of information literacy in enabling people to engage with information in meaningful ways, and to put it to purposeful use.

Likewise information literacy is often promoted for its capacity to provide personal empowerment, providing individuals with a means through which they can substantiate or contest information, and discern between fact and fiction (ALA, 1989). For instance, Owen illustrates the importance of information literacy in a discussion concerning community protests opposing construction of the Hindmarsh Island Bridge in South Australia (1996). Owen remarked that "what information literacy is ultimately about, [is] empowering real life, not just a set of skills enabling us to study more effectively for the rest of our lives" (1996, p. 122). In the same way, Todd alluded to the empowering nature of information literacy suggesting that "At the heart of information literacy are people being able to effectively engage with their information world: to connect with, interact with and use

information meaningfully and purposefully to get on with their lives. The outcome is not information literate persons per se, but people able to get the best out of, and contribute to living" (2000b, p. 29).

There have been a number of landmark moments in the history of the information literacy movement. Aside from Zurkowski's initial coining of the term, it is conceivable to suggest that the next landmark event for information literacy was the establishment of the American Library Association's Presidential Committee on Information Literacy, and publication of its 1989 Presidential Report on Information Literacy (American Library Association, 1989). This report profiled the importance of information literacy, declaring it as critical for dealing with exponential increases in the availability of information with the advent of the information age. It championed information literacy as the "new foundation" that would enable individuals to effectively function in the modern ever-changing environment, ensuring "productive, healthy and satisfying life" (para. 30). That same year also saw the National Forum for Information Literacy established under the auspice of the American Library Association (National Forum on Information Literacy, n.d.). This forum was tasked with the mission of disseminating the philosophy and practice of information literacy in education, business and government spheres, and for promoting information literacy at national and international levels.

Further moments promoting information literacy at an international level have also taken place. Two invitational meetings convened by the US National Forum for information Literacy, the US National Commission for Library and Information Science, and the United Nations Educational, Scientific and Cultural Organization (UNESCO) were devoted to raising international awareness and promotion of information literacy. Each of these meetings resulted in outcomes that have served to continue advancing the information literacy agenda, firstly *The Prague Declaration – "Towards an Information Literate Society"* in 2003, followed by *The Alexandria Proclamation on Information Literacy and Lifelong Learning* in 2005. These two outcomes fundamentally emphasised the sociocultural role of information literacy as a phenomenon that could empower individuals and citizenship, and associated information literacy with the human right to information.

Finally more recently in 2009, information literacy was thrust firmly into the spotlight once again when President Barack Obama issued a proclamation establishing October as National Information Literacy Awareness Month in the United States (The White House, 2009). The Proclamation emphasised the need for all Americans to be equipped to navigate the information age and highlighted that the significance of information transpired across all facets of daily life. President Obama called for increased awareness of information literacy

and declared that an informed and educated community was fundamental to modern democratic society.

Yet despite widespread appreciation of the importance of information literacy for everyday life in the information society, research into information literacy to date has predominantly focused on its application in library or educational contexts (Bruce 2008; Lloyd & Williamson, 2008). In more recent years the research territory for information literacy has broadended by extending investigations of information literacy into workplace or professional environments (eg: Lloyd, 2006, 2009; Sayyad Abdi, Partridge & Bruce, 2013). However research into information literacy within everydaylife or community contexts remains an emerging field of study, and has been identified by several authors as a significant gap for investigation (Lloyd & Williamson, 2008; Partridge, Bruce & Tilley, 2008).

# 2.6 Theoretical perspectives in information literacy scholarship

As already stated in a previous section of this chapter, there are a number of ways in which the concept of information literacy is understood. Ultimately this variation in understanding originates from the different theoretical perspectives that comprise information literacy scholarship. Furthermore, in addition to influencing how the concept of information literacy is conceptualised, these different theoretical perspectives have similarly influenced the objectives of research into information literacy, and the way in which information literacy education is conceived. The following sections detail the three distinct theoretical perspectives in information literacy scholarship. These perspectives include the behavioural, the relational and the socio-cultural perspectives.

#### 2.6.1 The behavioural perspective

The behavioural perspective is the conventional way in which information literacy has been defined, researched and understood. This perspective considers information literacy as particular attributes such as knowledge, skills or attitudes that an information user must exhibit or acquire. It focuses on describing the abilities, traits or qualities of the 'information literate' information user, and is underpinned by information processing and behaviourist paradigms (Bruce, 1997a).

One of the most frequently cited studies of information literacy from the behavioural perspective was conducted by Christina Doyle (1992). Doyle's study was commissioned by

the National Forum on Information Literacy in the United States, a group comprising representatives from 46 organisations drawn from business, government and education sectors who shared an interest or concern in information literacy. Using the Delphi technique, a panel of 56 experts developed a definition of information literacy along with attributes depicting the information literate person.

The resulting definition produced from Doyle's study defined information literacy as being "the ability to access, evaluate, and use information from a variety of sources" (1992, p. 2). Attributes of the information literate person were identified as being someone who:

- Recognizes the need for information
- Recognizes that accurate and complete information is the basis for intelligent decisionmaking
- Formulates questions based on information needs
- Identifies potential sources of information
- Develops successful search strategies
- Accesses sources of information including computer-based and other technologies
- Evaluates information
- Organizes information for practical application
- Integrates new information into an existing body of knowledge
- Uses information in critical thinking and problem solving (Doyle, 1992, p.2)

Doyle claimed that this list of attributes illustrated the process of information literacy and that these could be used as "potential rubrics for a checklist of skills" (p. 2). Along with the definition and attributes, Doyle's study also identified desired outcome measures for the process of information literacy. These measures reflect the attributes of the 'information literate person', and comprised a list of twenty-one skills or competencies against which information literacy could be evaluated, assessed or measured.

Historically this perspective has dominated information literacy scholarship along with curriculum approaches for information literacy education. The influence of the behavioural perspective is reflected in standards and models that have been developed for information literacy education by various organisations and institutions. Examples of standards for information literacy education include *The Seven Pillars of Information Literacy model* developed by the United Kingdom Society of College, National and University Libraries

(SCONUL) in 1999, *Information literacy competency standards for higher education* (ACRL, 2000) and the *Australian and New Zealand information literacy framework* (Bundy, 2004). Such standards also provide performance indicators and indicative outcomes that are focused on measuring or assessing an individual's competence or ability in information literacy.

Models for information literacy education include Eisenberg and Berkowitz's *Big Six Skills* (1990), and the *Information Search Process* model developed by Carol Kuhlthau in 1993. These models provide examples of a more process oriented approach to information literacy, where information literacy is conceived as a sequence of linear steps or phases individuals should follow or progress through when seeking information. However according to Bruce (1997a) such models are still founded upon notions of particular skills, attributes or knowledge that an information literate person will display or possess.

## 2.6.2 Limitations of the behavioural perspective

While the behavioural perspective of information literacy has provided insights and understandings that have helped to advance discourse and a research agenda, some limitations of this position are apparent.

For example Lloyd and Williamson (2008) comment on the dominant understanding of information literacy as referring to different skills and attributes, and argue that this perspective restricts information literacy to an individualised and principally text-based skill. Instead they advocate for broader understandings of information literacy and approaches to information literacy education that will enable people to "engage in information environments which are collaborative, complex and messy" (2008, p. 9). Bruce (1997a, 2008) has likewise noted limitations that are evident in the behavioural perspective. She contends that discussions about information literacy or education for information literacy are too often confined to a focus on just skills alone. Whilst Bruce agrees that such skills are necessary, she highlights that ubiquitous changes arising in the evolving information age will mean many information skills rapidly date. Instead she maintains that discussion about information literacy needs to broaden and focus on how people have to engage with information in order to learn (Bruce, 2008).

Another cited limitation or criticism of the behavioural perspective is its tendency to restrict understandings of information literacy to a concept that applies only in library or educational settings. Campbell (2008) describes this inclination as appropriating the concept of information literacy from broader society and then confining it to a small fragment of the entire information universe. In this way, Campbell argues the need for interpretations of

information literacy that will encompass more diverse forms of information and more extensive information environments.

However more extensive criticism or limitations of the behavioural perspective to information literacy can be observed in writings concerning its influence on standards and models developed for information literacy education. Referring to the *Information Literacy Competency Standards for Higher Education* developed by the Association Of College and Research Libraries (ACRL), Webber and Johnston (2000) argue the danger of a 'tick the box' approach to information literacy education because it reduces "a complex set of skills and knowledge to small, discrete units" (p.384). Purdue (2003) concurred with this view, and criticised the 'mechanistic' and 'utilitarian' ideals the ACRL standards portray, and their recurrent emphasis on the 'individual'. Instead Purdue argued for the need to teach information literacy within a community context if its potential to create an active and informed citizenry is to be fulfilled.

Continuing this idea Johnston and Webber (2003) provide criticism of the behavioural perspective to information literacy education, referring to the frequently cited model developed by Eisenberg and Berkowitz: the *Big6 skills*. They contend that the term 'Big6 skills' itself is problematic because it suggests a 'recipe' approach to information literacy. In addition the model also depicts information literacy as mechanistic, and that information literacy can be reduced to six distinct steps that will ensure "the golden pathway to information success" (p. 338).

Standards and models for information literacy education developed from the behavioural perspective have similarly been scrutinised in terms of their transferability to contexts outside of educational environments. Webber and Johnston (2000) assert that a single discrete set of skills tied to information discovery in an educational context cannot possibly adequately equip an individual to effectively engage or function in the ever-changing information society. They point out how technological developments in information communication continue to change the ways in which individuals access information, and that changes in an individual's personal life (e.g. ageing, changing careers) influences the types or kinds of information needed. For this reason Webber and Johnston insist that models and standards for information literacy should be adaptable to various changes that will occur throughout the course of life.

The cited limitations and criticisms of the behavioural perspective have been coupled with declarations calling for research into information literacy that was grounded in alternative theoretical frameworks. Cheuk (2000) illustrates this point when commenting on the

dominance of discourse where information literacy is privileged as being about the 'right' steps to follow in obtaining and using information effectively (p. 177). Instead Cheuk advocated the need for research adopting a more user-centred perspective, and a shift away from standards that have been developed and imposed by experts.

Recognising limitations that are inherent in the behavioural perspective to information literacy, other theoretical frameworks have emerged in this field. These are the relational and socio-cultural perspectives to information literacy. Each of these perspectives will now be discussed.

## 2.6.3 The relational perspective

The relational perspective of information literacy was first established in the late 1990s. This perspective was founded upon phenomenological and hermeneutic theories along with educational research that had investigated the various ways in which people experienced learning related phenomena (Bruce, 1997b). The relational perspective considers that the meaning of information literacy originates from the various ways in which people relate with information, or in other words, the different ways in which people interact with elements of their information world. Consequently the relational perspective considers that the phenomenon of information literacy may be understood from descriptions portraying the various ways in which it is experienced by the information user (Bruce, 1997b).

The first study to investigate the experience of information literacy working from the relational perspective was published by Bruce (1997a). Using phenomenography, a research approach that explores differences or variations in how people experience particular aspects of the world, Bruce's study sought to describe the experience of information literacy among people who use information. Conducted in the university sector participants included academics, librarians, learning advisors and educational developers. The results of Bruce's study identified seven different ways in which participants experienced information literacy and her work *The Seven Faces of Information Literacy* (1997a) remains the most commonly cited study to emerge from this line of research. As a result of her study Bruce described the information literate person as being "one who experiences information literacy in a range of ways, and is able to determine the nature of experience it is necessary to draw upon in new situations" (1997a, p. 169). Bruce's research was also the first study that portrayed the complexity of information literacy as a phenomenon. This point was acknowledged by the Association of College and Research Libraries who stated that it revealed information literacy was "far more fluid and complex than American standards and guidelines might suggest" (ACRL, n.d. para. 4).

The seven faces of information literacy as identified by Bruce (1997a) are outlined in Table 1 below.

Face	Information literacy is seen as
Category One: The information technology conception	Information literacy is seen as using information technology for information retrieval and communication
Category Two: The information sources conception	Information literacy is seen as finding information located in information sources
Category Three: The information process conception	Information literacy is seen as executing a process
Category Four: The information control conception	Information literacy is seen as controlling information
Category Five: The knowledge construction conception	Information literacy is seen as building up a personal knowledge base in a new area of interest
Category Six: The knowledge extension conception	Information literacy is seen as working with knowledge and personal perspectives adopted in such a way that novel insights are gained
Category Seven: The wisdom conception	Information literacy is seen as using information wisely for the benefit of others

Table 1: The seven faces of information literacy (adapted from Bruce, 1997a)

Based upon her study, Bruce developed what is referred to as the relational model of information literacy, which encompassed three aspects of information literacy scholarship: descriptions of information literacy, information literacy education and information literacy research (1997a). Central to the relational model however was its portrayal of information literacy as a complex of ways of experiencing information use, which provided a unique approach to describing and understanding information literacy by representing the views of information users rather than information experts. In addition, the relational model did not seek to measure information literacy and instead emphasised the relationship between users and information and the way they experienced the world (Bruce, 1997a).

More recently in 2008, Bruce introduced the concept of 'informed learning' as a means to promote "learner-centred, experiential, and reflective approaches to the information literacy agenda" (p. 5). In articulating the idea of informed learning, Bruce offered an expanded definition of information literacy as "experiencing different ways of using information to learn" (p. 5). The inclusion of the term 'learn' reflects the association that the relational perspective has with the phenomenographic research tradition, and studies that have explored the interdependence between using information and learning (Bruce & Hughes, 2010). In addition, in presenting the idea of informed learning, Bruce articulated a

pedagogical framework for enacting the relational perspective in information literacy education (2008).

Other studies that have drawn upon the relational perspective to investigate people's experiences of information literacy include Maybee (2006) who explored undergraduate students' experiences of information literacy, Boon, Johnston and Webber (2007) who examined English faculty academics' experiences of information literacy, and Williams and Wavell (2007) in a study on the experiences of information literacy among secondary school teachers. More recently in 2012, Andretta drew upon this same approach to investigate the experience of information literacy among postgraduate students studying Information Services Management.

While the above studies have explored the experience of information literacy in various educational settings, examples of research that has explored people's experiences of information in workplace and community or everyday settings are likewise reported in the literature. Illustrations of other research drawing upon the relational perspective to information literacy include Sayyad Abdi, Partridge and Bruce's (2013) study of website designer's experiences of information literacy, Gunton (2011) who explored the experience of information literacy in the church community, and Demasson, Partridge and Bruce (2011) in a study that investigated the experience of information literacy among heritage volunteers.

In summary, the relational perspective emphasises uncovering variation in how the information user experiences information literacy. Furthermore, by attending to the qualitatively different ways in which information literacy may occur, research into information literacy drawing from this perspective has provided wider interpretations and understandings of this phenomenon.

### 2.6.4 The socio-cultural perspective

The socio-cultural perspective is the third and most recent theoretical approach that has appeared within information literacy discourse and scholarship. This perspective draws upon a range of socio-cultural theories developed by researchers such as Vygotsky, Lave, Lemke, Rogoff and Wertsch (Wang, Bruce & Hughes, 2011).

Socio-cultural theories seek to explain relationships between human action and the context in which action takes place (e.g., cultural, institutional, historical) (Wertsch, 1998). Such theories recognise the social and cultural aspects through which knowledge is acquired, and consider that learning can be enhanced when knowledge is shaped not just by the individual, but by the activities and perspectives of a group of learners (Vygotsky, 1978). Wang

describes the socio-cultural approach to research as being "based on socio-cultural theories that emphasise the interdependence of social and individual processes in the co-construction of knowledge" (2010, p. 64). In this way this perspective also shifts the focus away from the individual and pays attention to the social and cultural contexts in which learning takes place.

The study by Lloyd (2006) to investigate the information literacy practices of firefighters provided the first illustration of research into information literacy from a socio-cultural perspective. Lloyd's research described workplace information literacy as a "way of knowing about a range of sites of explicit and tacit knowledge within the workplace landscape" (2006, p. 575). She discovered that the process of becoming information literate within the workplace involved learning about different information modalities in a particular environment, along with developing 'know how' that enabled people to form relationships with information and which facilitated experiencing information in meaningful ways. Lloyd's research concluded that the concept of information literacy could be described as a phenomenon that facilitated knowing about an information landscape (Lloyd, 2006).

Although the social-cultural perspective has been applied to investigate information literacy in educational settings (e.g. Lazarow, 2004; Wang, 2010), it is possible to suggest that its application to research in the workplace and everyday life has been instrumental in providing greater understanding and knowledge about the phenomenon of information literacy in settings beyond the academy. Examples here include Lloyd's (2009) study that investigated how information literacy was experienced by novice and experienced paramedics, the study by Bonner and Lloyd (2011) that examined the information literacy practices of renal care nurses, and studies that have explored the information literacy practices of refugees (Kennan, Lloyd, Thompson & Qayyum, 2011; Lloyd, Kennan, Thompson & Qayyum, 2013).

Collectively the findings from these studies have provided further evidence that illustrates the complexity of information literacy, and a dynamic practice that acts as a catalyst to learning in all situations. More specifically studies within workplace and everyday life trajectories have provided knowledge about how and why information literacy manifests itself in different contexts, affirmed the importance of discussing the phenomenon of information literacy within the context in which it is experienced, and revealed that different information modalities may exist within an information landscape (Lloyd, 2007, 2011, 2012).

Having presented a discussion of information literacy and the distinct theoretical perspectives that comprise research and scholarship in this field, the final section of this

chapter now turns to health information literacy. In the following section I introduce the concept of health information literacy, and outline research to date that has investigated people's health information literacy in everyday life.

# 2.7 Health information literacy

The first definition of health information literacy was developed by the Health Information Literacy (HIL) Taskforce, a working party established by the Medical Library Association (MLA) to assist with addressing issues concerning health information literacy in the United States (Shipman, Kurtz-Rossi & Funk, 2009). The description arose out of collective consideration of the term 'health literacy' as defined by the US Department of Health and Human Services and the American Library Association's definition of 'information literacy'. The working definition they produced defined health information literacy as:

... the set of abilities needed to: recognise a health information need; identify likely information sources and use them to retrieve relevant information; assess the quality of the information and its applicability to a specific situation; and analyse, understand and use the information to make good health decisions (MLA, 2003, para. 5).

Since this definition first emerged, interest in health information literacy has received rising attention in information and library science literature among researchers and practitioners alike. More specifically, the importance of health information literacy has been increasingly asserted and championed from a general population standpoint, in recognition of the integral role that information plays in health and health care.

To date the role that libraries and librarians could play in promoting or addressing health information literacy in the general population is one area of discourse that has captured considerable attention in the literature. For example, Burnham and Petersen (2005) and Hammond (2005) both provide illustrations of literature discussing initiatives undertaken as part of consumer health information services established within hospital precincts. They describe various activities designed to promote or develop health information literacy among the general public such as training in the use of medical databases; guides on evaluating medical information; listings of credible health websites; providing information resources such as medical dictionaries and encyclopaedias; public information events to promote awareness of specific health topics, and producing health information materials in conjunction with health professionals. In a similar way, Cullen (2005) provides a comprehensive list of objectives that would serve to develop consumers' skills in health

information literacy, and outlines various activities designed to help people locate, evaluate and use health information.

However, at present there is limited evidence of research undertaken to investigate health information literacy among the general population in everyday life. As such, knowledge about people's health information literacy within this context represents a nascent area of research in information literacy scholarship. The remainder of this section now turns to examining existing literature that has investigated this area.

A study by Marshall and Williams (2006) investigated one aspect of health information literacy, by examining whether and how people evaluated the quality of health information accessed through the Internet and in printed formats. Data was collected from thirty-two members of patient support groups through a variation of focus group methodology referred to as 'information review groups'. Participants were asked to discuss what they 'liked' and 'disliked' about a particular set of health information materials to ascertain if they identified 'quality' criteria, and to indicate features they considered as a cause for concern to explore issues regarding the 'reliability' of health information. Furthermore, within the information review groups participants were also asked to discuss health information more generally with respect to different aspects they regarded as indicators of either good or bad quality information. Data analysis revealed a total of fifteen different ways in which participants evaluated the quality and reliability of health information.

Based upon the study's findings, Marshall and Williams noted several areas of disconnect between commonly accepted features of information quality, and people's process of selecting health information to meet individual needs. They concluded that the study had revealed there were considerable complexities that were associated with people's evaluation of health information quality. In addition they also recommended that there was a need for education on evaluating health information to extend beyond the constraints of a standard quality 'checklist'. Instead Marshall and Williams advocated that education needed to focus on guiding people towards strategies for selecting health information that would adequately meet their particular needs and personal experience.

In addition, the literature also provides examples of research designed to measure or assess people's health information literacy (Eriksson-Backa, 2010; Eriksson-Backa, Ek, Niemelä & Huotari, 2012; Niemelä, Eriksson-Backa and Huotari, 2012). The study by Eriksson-Backa (2010) investigated health information literacy among persons aged over 65 years who belonged to a Swedish-speaking language minority in Finland. Using self-administered questionnaires, data was collected from forty-six persons. This study approached health

information literacy from a behavioural perspective, and thereby treated the concept as a set of abilities needed to recognise health information needs, to identify and use health information, and to evaluate, understand and use health information to make good health decisions. As such, Eriksson-Backa's questionnaire aimed to assess people's health information literacy through questions relating to their needs, seeking, use, and understanding of health information, preferences for sources of health information, and how they assessed health information quality. Findings revealed that people identified their information needs and sources of health information fairly easily, but recognised difficulties with understanding and assessing the quality of health information. Eriksson-Backa concluded that the assessment has shown that people's health information literacy "seemed sufficient in some respects, but weaker in others" (2010, p. 181). Eriksson-Backa considered that there was considerable scope for widening people's use of the health information environment, and raising awareness about health information that people could access and use with respect to their health (2010).

Similarly the study by Eriksson-Backa, Ek, Niemelä and Huotari (2012) examined the everyday life health information literacy of 281 Finnish seniors aged 65-79 years. Again using self-administered questionnaires, data was collected to measure people's health information literacy through questions about how they perceived their ability to identify a need for health information, and how confident people were in being able to find and use health information. In addition, Eriksson-Backa et al. (2012) also investigated possible relationships between demographic factors (i.e. education), people's interest in health information, current health status and their abilities to obtain, evaluate, understand and use health information. Findings revealed that there was significant relationships between education level, interest in health information, health status and people's needs, seeking and use of health information. In particular, they concluded that certain categories of elderly people were more vulnerable with respect to accessing and using heath information. These included persons with lower levels of education, people in a poorer state of health, and persons with low levels of interest in actively seeking health information.

Finally, the 2012 study by Niemelä, Eriksson-Backa and Huotari provides a further example of research that reports on empirical testing of a screening tool designed to identify people with difficulties in heath information literacy. Drawing upon a skills-based definition of health information literacy, they developed a 10-item tool in the form of a questionnaire to 'detect' people with problems relating to interest and motivation to find health information; confidence in ability to find, understand and use health information, and skills in evaluating health information. The questionnaire was administered to 217 students in a Finland upper

secondary school. Their findings showed that the screening tool could be used to classify people's skills in health information literacy into four groups: low, medium low, medium high and high. Niemelä, et al. (2012) concluded that everyday life health information literacy was a "complex construct to be operationalised for screening purposes" (p. 131). They recommended that future studies needed to further examine independent factors such as motivation, confidence and evaluation in investigations of health information literacy.

The recent study by Marshall, Henwood and Guy (2012) similarly provides another example of research into health information literacy in everyday life. Using surveys and focus groups, Marshall et al. (2012) investigated information use and information literacy among adults who were endeavouring to manage their weight. Data was collected to investigate people's 'information landscapes', their information skills and use of information and communication technologies in the context of weight management. The study defined information literacy as the ability to know where to look for information, to formulate a search question, to judge good and bad information, and who to ask for help to find information.

Findings emanating from the study revealed a number of key observations regarding people's information use and information literacy. First, findings revealed that people found and used information in ways that were far more complex to the mainstream portrayal of information literacy as a cycle of staged activity. They confirmed that within the context of weight management, people both encountered information as well as actively seeking it out, and that this process resembled a highly complex practice of interacting with information.

Second, findings also revealed that although people engaged in processes to evaluate health information, their experience was again more complex than conventional understandings of information evaluation. In this way, results showed that people naturally used many 'expert' defined criteria for evaluating health information, but were also more likely to appraise health information in terms of how it 'fitted' with their own existing knowledge and personal experience.

Third, the results of the study also illustrated information literacy as an activity that could be social or collaborative in nature. This was demonstrated by results indicating the role of 'slimming groups' in the context of weight management for information provision and information support, and challenged common understandings of information literacy as being a purely individual activity. Marshall et al. (2012) concluded that there was a need to increase understanding about people's real-life health information practices, and for broader approaches to information literacy to ensure greater alignment between the provision and use of health information within the context of consumer health.

In summary, research to date to investigate people's health information literacy in everyday life have theorised the concept of health information literacy from a behavioural perspective. As such these studies conceptualise health information literacy as a discrete set of information skills or abilities that people must exhibit or possess. In addition, studies to date have all drawn upon the original working definition provided by the MLA (2003), which implies that the act or process of health information literacy is operationalised as a cycle of staged activity.

In contrast, there has been a lack of research undertaken to date into health information literacy that has applied a relational perspective to examine the complex of ways in which people experience using information to learn about health. Consequently there is a lack of understanding about the various ways in which people experience health information literacy, or in other words, the different ways in which people as information users engage with health information. As such, this topic represents a gap in the existing body of knowledge, and presents a research question that denotes the focus of this current study.

## 2.8 Conclusion

This chapter has presented a discussion of literature concerning consumer health information research through an examination of studies from the two distinct lines of theoretical enquiry that have contributed knowledge in this field to date. First, it has discussed health information behaviour as an area of research enquiry that has investigated a combination of particular behaviours through which people acquire health information. Second, it has reviewed research into health literacy that has investigated the skills and competencies that support people's cognitive apprehension of health information.

This review has also identified information literacy, or more specifically health information literacy as an alternative theoretical perspective for consumer health information research that is of relevance to consumer health information scholarship. In particular the review found a current lack of research applying a relational perspective has been undertaken to examine health information literacy. As such it has proposed the need for research to investigate how people experience health information literacy, or in other words, how people experience different ways of using information to learn about health. In the next chapter, I describe the research methodology that was utilised for this study. More specifically I discuss phenomenography as the research approach that enabled examination of the various ways in which people experience health information literacy.

# **Chapter 3: Research Approach:**

# **Phenomenography**

## 3.1 Introduction

This chapter describes the research approach that was used for this study and is divided into eleven parts. It begins with an overview of the research paradigm in which the study was situated, and provides a rationale for the appropriateness of phenomenography as the chosen research approach. Then, in parts three to seven, I provide a description of phenomenography, a discussion of the key philosophical assumptions underlying this research approach, an explanation of the phenomenographic knowledge interest, and the outcomes that arise from this type of research enquiry. Details regarding the research design and implementation of the study are presented in part nine, along with the analysis process I followed to produce descriptions of the qualitatively different ways in which the participants of the study experienced health information literacy. The final parts of the chapter are devoted to a discussion and examination of how the study's outcomes can be evaluated, and commentary concerning ethical considerations that were adhered to in conducting the research.

# 3.2 The interpretivist paradigm

This study is positioned within an interpretivist paradigm, a research tradition that fundamentally is concerned with understanding the world of human experience. As a paradigm for research inquiry, interpretivism developed in response to arguments concerning the need for distinctive and appropriate methods of investigation to study the social sciences, compared to methods that had historically been used to study the natural sciences (Hammersley, 2012).

The origins of interpretivism developed from two different intellectual strands of thinking. The first of these was hermeneutics, a scholarly practice initially concerned with deciphering the meanings of ancient texts, and later with the interpretation and understanding of social life. The second line of thinking originated from the phenomenological movement in philosophy, which was concerned with the study of subjective experience and consciousness (Mackenzie & Knipe, 2006).

The emergence of the interpretive research paradigm provided a distinct contrast to the long established theoretical frameworks of positivism and post-positivism, where the focus of research was concerned with prediction, control, explanation and making generalisations. In

comparison, the focus of research within the interpretive paradigm was concerned with exploring the beliefs, feelings and interpretations of human research participants, and to investigate social phenomena in natural settings (Pickard, 2007).

The interpretive research paradigm assumes that reality is constructed inter-subjectively by way of meanings and understandings developed collectively by human society and through individual experience (Denzin & Lincoln, 2005). Interpretivism rejects the notion of a single, tangible reality but instead regards reality as an 'individual' as opposed to a 'universal' construction. This assumption concerning the nature of reality according to interpretivism is referred to as a relativist ontology. Interpretivism also embraces a subjectivist epistemology which accepts that we are unable to separate ourselves from what we already know. In this way, all knowledge that we acquire is regarded as the result of the relation between the known and the knower (Denzin & Lincoln, 2005).

The interpretive tradition comprises an array of different approaches for research inquiry such as ethnography, discourse analysis, phenomenology, phenomenography and symbolic interactionism. Although each of these approaches is connected by overarching ideals, specific approaches also have particular characteristics that distinguish them from others in the broader interpretive paradigm (Mackenzie & Knipe, 2006).

# 3.3 Choosing phenomenography

This study selected phenomenography as its approach to research. Phenomenography is a qualitative, interpretive and descriptive approach to research that explores the qualitatively different ways in which people experience and conceptualise various phenomena and situations around them (Marton & Pang, 2008). Central to phenomenography is the emphasis it places on exploring variation in the ways people experience a particular phenomenon and providing experiential descriptions that reveal this variation.

There were two key reasons that underpinned the choice of phenomenography as the research approach for this study. First, the fundamental interest that phenomenography embraces to exploring variation in experience. Second, the demonstrated value of phenomenography as evidenced by previous studies that had explored the phenomenon of information literacy and phenomena in the health sciences using this approach.

In explaining the first reason, it is essential to acknowledge the central tenet of this research approach, which holds that individuals collectively experience and understand phenomena in a number of qualitatively different but interrelated ways. Accepting this premise, then gaining knowledge about these qualitatively different ways provides us with a lens through

which we can learn "how the world appears to others, ... what the world is like, and what the world could be like" (Marton & Booth, 1997, p. 13). Therefore in order to understand the various ways in which health information literacy may be experienced, phenomenography provided an approach that would emphasise exploring this variation and provide descriptions that revealed the spectrum of possibilities.

Additionally the application of phenomenography in a number of earlier studies similarly provided further evidence of its value and suitability as an approach to research. As already detailed previously in Chapter 2, phenomenography has been used in a number of studies to explore the experience of information literacy (e.g. Andretta, 2012; Lupton, 2008; Boon, Johnston & Webber, 2007; Williams & Wavell, 2007; Maybee, 2006; Bruce, 1997a). Likewise other investigations have used phenomenography to explore related or interrelated aspects of information literacy such as information seeking and use (e.g. Limberg 2000; Kirk 2002; Edwards 2006). Collectively knowledge gained from these studies has provided a deeper and richer understanding of the nature of information literacy and related phenomena. In particular studies exploring variation in the experience of information literacy have highlighted the critical role that context plays in understanding this phenomenon, as well as differences in the ways in which information as an 'object' may be perceived.

Similarly in the health sciences phenomenography has revealed its strengths as an approach to researching a range of health related phenomena (Barnard, McCosker & Gerber, 1999). In particular the application of phenomenography in two lines of enquiry was regarded as particularly relevant in informing its selection as an approach for this study, specifically studies that had used phenomenography to explore patients' experiences of their illness and patients' experiences of health education programs.

Phenomenographic studies exploring patient's experiences of illness have provided valuable knowledge about various issues that are integral to health care. These include recommendations for therapy, ways to improve or enhance patient support and treatment, facilitating knowledge transfer to patients in similar health situations, and ways to enhance communication between patients and health professionals (e.g. Fallsberg, 1991; Stenström, Bergman & Dahlgren, 1993; Backe, Larsson & Fridlund, 1996; Falk, Wahn & Lidell, 2007; Johansson, Swahn, & Strömberg, 2007). In the same way, phenomenographic research into patient education has provided valuable knowledge regarding different approaches for the design and delivery of health education, and the impact of health education on people's understanding of health issues or conditions (e.g. Göransson, Dahlgren & Lennerstrand, 1998; Ringsberg, Lepp & Finnström, 2002; Kärner, Göransson & Bergdahl's, 2002; Abrahamsson, Springett, Karlsson & Ottosson, 2005).

Collectively the application of phenomenography in these studies clearly illustrated its strengths in researching variation in experience, and therefore distinguished it as the most appropriate approach to explore the qualitatively different ways in which people experience health information literacy. Furthermore, recognising phenomenography's origins in pedagogical traditions it was also considered that this association may also engender outcomes that could be used to inform and suggest possible implications regarding health information literacy education.

# 3.4 Phenomenography: Background

Phenomenography emerged as a new approach to research in the 1970's and was primarily developed by educational researchers in Sweden (Marton, Dahlgren, Svensson & Säljö, 1977; Marton & Svensson, 1979; Säljö, 1979). Phenomenography emanated out of research led by Ference Marton to investigate variation in student learning outcomes. As a research approach, it has historically been concerned with exploring questions relating to learning and understanding, that is how people learn and how they see knowledge within a particular context (Marton & Booth, 1997; Svensson, 1997). Consequently, phenomenography's focus on learning and the experience of learning in different contexts has meant that learning related phenomena comprise the most typical experiences to utilise this research approach.

Phenomenography is most frequently described as a research specialisation that aims to map "the qualitatively different ways in which people experience, conceptualise, perceive, and understand various aspects of, and various phenomena in, the world around them" (Marton, 1986, p.31). It is underpinned by the notion that individuals collectively experience and understand phenomena in a number of qualitatively different but interrelated ways (Marton, 1986). As such phenomenography is therefore concerned with describing things as they appear and are experienced by people (Marton, 1994).

The aim of phenomenographic research is to investigate the central characteristics of difference and change in how individuals understand a particular phenomenon, instead of the cognitive processes associated with constructing these characteristics, differences and change (Barnard, McCosker & Gerber, 1999). This focus is described by Marton (1986) as an interest in "the content of thinking rather than the process of thought or perception" (p. 32). In focusing on individuals' understandings (i.e. their content of thinking) phenomenographic studies accordingly consider and treat all experiences of the phenomenon of interest as logical and valid.

Phenomenography is also considered to be a relational approach to research because the object (the phenomenon under investigation) and the research subject (the person experiencing the phenomenon) are not viewed or treated separately. Instead phenomenographic research focuses on exploring the relations formed between the research subject and the way they experience the object itself (Marton & Booth, 1997).

According to Marton (1988) the evolution of the phenomenographic research tradition saw three different lines of enquiry emerge. Two of these lines related to learning whilst the third line was associated with disciplines outside the educational domain. The first line of research focused on investigations of the qualitatively different outcomes of learning and approaches taken by learners. The second line however was concerned with the content of learning and students' qualitatively different understandings of ideas or concepts in a particular subject. The final line of research, often described as 'pure phenomenography', is concerned with exploring the qualitative differences in the way that people conceive or understand particular aspects of their world. It is this final line of phenomenographic enquiry where the current study is positioned.

Distinctions are also made in the literature between 'early' and 'new' phases of phenomenographic research (Marton & Pang, 2008). In early phenomenographic research, questions were directed towards exploring the different ways in which a particular phenomenon was experienced and how these different ways related to each other. Pang refers to studies exploring these types of questions as belonging to the "first face of variation" (2003, p. 146). In contrast the aim of new phenomenography involved characterising the different ways of experiencing a phenomenon and how the different ways of experiencing that phenomenon evolved (Marton & Pang, 2008). According to Pang (2003) this shift in emphasis represented an interest in answering theoretical questions concerning the nature of differences, rather than questions about how different ways of experiencing a phenomenon could be captured in a methodological sense. Describing the distinction between early and new phenomenography Pang (2003) considers this saw a move towards not only describing the difference in ways that something can be experienced, but to also describe "the variation in various aspects of the world" (p. 148). In this way, Pang (2003) proposed that new phenomenography represented the "second face of variation" (p. 146) due to its focus on how different dimensions of variation are experienced. Furthermore, the advent of new phenomenography also saw the emergence of variation theory to describe its foundational concept of variation in experience (Marton & Booth, 1997).

Phenomenographic studies can be conducted using various theoretical approaches. For example, in a review of literature since the early 1980's Lupton (2008) observed approaches

on a continuum ranging from positivist-objectivist to interpretivist-subjectivist. These differences in approach have influenced various aspects of study design as well as the process for data analysis. As noted in an earlier section of this chapter, this study is situated within an interpretive research paradigm and accordingly I embraced an interpretivist phenomenographic approach in undertaking this research.

## 3.5 Ontological and epistemological assumptions

In establishing knowledge about a particular aspect of reality all research approaches embrace certain assumptions regarding ontology (the nature of reality under investigation) and epistemology (the nature of knowledge) (Sandberg, 2005). According to Svensson (1997), phenomenography devised its own set of ontological and epistemological assumptions which while inspired from several related research traditions avoided concurring with any in entirety. Defining phenomenography as an empirical research tradition rather than an approach with an articulated metaphysical foundation, he asserted that assumptions made in phenomenography were connected to ideas about the nature of its object of study. Consequently the assumptions embraced by phenomenography regarding ontology and epistemology relate to the nature of experience (i.e. conceptions).

Phenomenography espouses a non-dualist ontology, which assumes that there is an inseparable relation between a person and something experienced (i.e. a phenomenon) (Marton & Booth, 1997). Describing phenomenography's non-dualist stance Marton claims:

There are not two worlds: a real, objective world, on the one hand, and a subjective world of mental representations, on the other. There is only one world, a really existing world, which is experienced and understood in different ways by human beings. It is simultaneously objective and subjective (2000, p. 105).

In a dualist ontology, the person and the phenomenon are viewed as two distinct entities, or in other words, as a "subject in itself and an object in itself" (Sandberg, 2005, p. 44). In contrast phenomenography's non-dualist stance does not imply a separation of research entities and instead sees them as "connected in a relationship" (Lupton, 2008, p.30). Consequently phenomenography's non-dualist position assumes that "the only world that we can communicate about is the world as experienced" (Sjöström & Dahlgren, 2002, p. 340). Reality in phenomenography is examined through the way in which people experience or are aware of it, and as such the central point of phenomenographic research is to explore the experienced relationship between person and phenomenon.

Phenomenography's epistemological position posits that the nature of knowledge is relational, it is "intentionally constituted" through peoples' experiences of their reality (Sandberg, 1997, p. 207). According to Marton and Pang (2008), the epistemological stance of phenomenography builds upon the principle of intentionality, which embraces a non-dualist view of human consciousness whereby experience is depicted as an internal relationship between human beings and the world. Consequently phenomenography considers that knowledge is constituted through internal relations between people and the world, it is conceptualised as a human-world relationship (Marton & Booth, 1997). Continuing this idea, knowledge in phenomenography is therefore seen to represent "ways of seeing, experiencing, thinking about the world", and is constituted through the internal relation between the 'knower' (person) and the 'known' (phenomenon)(Marton & Neumann, 1989, p. 35).

## 3.6 A second order perspective

A distinguishing feature of phenomenography is that it assumes a second-order perspective, whereby phenomena are investigated through the experience of the research participant rather than the experience of the researcher (Pang, 2003). Marton first distinguished between the 'first-order' and 'second-order' perspectives stating that while the former was concerned with "describing various aspects of the world", the latter was concerned with "describing people's experiences of various aspects of the world" (1981, p.171). In comparing these two perspectives, Marton characterised the first-order perspective as being "from the outside" and the second-order perspective as being "from the inside" (p. 177). It was this 'insider' perspective that Marton argued as being a distinguishing feature and strength of phenomenography, and providing a significant contrast to traditional first-order scientific research where the world is expressed as is (1981).

Continuing this idea, Marton and Booth (1997) also associated the first-order and second-order perspectives as being oriented towards different objects of research. Therefore the second-order perspective has influence on the way in which research questions are expressed in a phenomenographic study. Säljö (1988) explains how research questions from a first-order perspective attempt to make statements about reality, while a second-order perspective yields research questions concerning people's experiences of the world and how they interpret aspects of reality. To illustrate this point within the context of this study it will ask 'What are the qualitatively different ways in which people experience using information to learn about health?' (second-order perspective) instead of asking 'Why do people use information to learn about their health?' (first-order perspective).

Finally, the second-order perspective is also of relevance through all stages of a phenomenographic study including when research questions are devised along with the process of gathering and analysing data. Consequently, Marton and Booth (1997) insist that at all times the researcher must ensure they are endeavouring to see the phenomenon through the participant's eyes, and are oriented towards describing the individual's reflected understanding of the world.

# 3.7 The knowledge interest of phenomenography: Ways of experiencing

The knowledge interest in phenomenographic enquiry is concerned with revealing variation in human experience and awareness, and to provide experiential descriptions of this variation (Marton & Booth, 1997; Sjöström & Dahlgren, 2002). In the development of phenomenography as an approach to research, a number of terms have been used synonymously in the literature to represent its knowledge interest. These terms include conceptions, ways of experiencing, ways of seeing and ways of understanding (Marton & Booth, 1997). To alleviate confusion for the reader I will use the term 'ways of experiencing' to represent the phenomenographic knowledge interest throughout this thesis. Appropriately a relevant question to now consider and discuss is what indeed is meant by the term 'way of experiencing'?

A way of experiencing is described as "a way of being aware of something" (Marton 1994, p. 4426) and "the basic meaning structure of individuals' experiences of a particular aspect of their reality" (Sandberg, 1994, p. 52). In explicating the character of a way of experiencing something Marton (1981) expressed that it frequently denotes something that is implicitly or silently understood, or something that at no point in time has been the subject of reflection. Continuing this idea, it is not a primary interest in phenomenography to find out about what is not reflected on as "the structure and meaning of a phenomenon as experienced can be found both in prereflective experience and conceptual thought" (Marton & Booth, 1997, p. 116-117). It follows then that all the phenomenographer has access to and it interested in is people's ways of experiencing something, reflected or not. Finally, a way of experiencing is not "a mental representation or a cognitive structure", it is distinct features in the experience of a phenomenon which are shared by a group of individuals (Svensson, 1994).

There are a number of elements that are understood to influence a way of experiencing. These include past experiences, beliefs, values, education, culture and the historical context in which a way of experiencing is embedded (McCosker, Barnard & Gerber, 2004).

Continuing this idea, Sjöström and Dahlgren remark how a way of experiencing is contingent upon our personal history, as well as data interpreted from our senses. They affirm that "the only world we can report about is the world as we experience it", and in consequence there is logically several worlds that we can report about (Sjöström & Dahlgren, 2002, p. 340). The goal of phenomenographic research is therefore to reveal how these different worlds appear, along with the similarities and differences among them.

In reporting on the different worlds we may experience, it is fundamental to emphasise that investigating a way of experiencing a particular aspect of reality is not concerned with questions about something being true or false. Backe, Larsson and Fridlund affirm this idea and remark that it is crucial to comprehend the difference between "the naked reality of a thing, a factual happening, and how it is conceived" (1996, p. 287). For this reason the second order perspective embraced in phenomenographic research is of critical relevance, as its emphasis is directed to obtaining descriptions of people's perceptual worlds, or in other words, how different individuals perceive something to be.

Phenomenography considers that a way of experiencing something represents a relationship between subject and object (i.e. phenomenon) or in other words, an "internal relation between the experiencer and the experienced" (Marton & Booth, 1997, p. 113). This focus on the relations between a subject and object in phenomenography is illustrated in the diagram shown below:

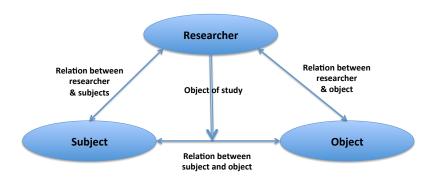


Figure 1: The object of study in phenomenography (Bowden, 2005, p. 13)

Therefore a way of experiencing something is considered to be "as much an aspect of the object as it is of the subject" in that it encompasses both (Marton, 2000, p. 105). Consequently, ways of experiencing are considered to be relational, due to their dependency on human activity and the world or a reality that is external to the individual. In addition, the position of the researcher in a phenomenographic study is a point that requires comment. In a phenomenography, the researcher's role is to investigate the relationship between the

research subject and the object of study. This idea and how it was applied in undertaking this study is explicated in subsequent sections of this chapter.

Marton and Booth (1997) posited that a way of experiencing something comprises both meaning and structure. They argued that in order to experience something, that 'something' must be discerned from its surrounding environment. Discerning something from a context requires perceiving its structure, which comprises the 'whole' of that 'something' as well as its constituent parts. However to discern 'something', it must also be perceived as a particular thing, that is, it must be assigned a meaning. Accordingly Marton and Booth (1997) explained that the 'anatomy' of a way of experiencing something could be characterised as comprised of two components: the referential and structural elements of experience. The referential component concerns the overall or global meaning that is assigned to the experience of the phenomenon. Marton and Pong (2005) described this as "a particular meaning of an individual object," and "anything delimited and attended to by subjects". The structural component concerns the "combination of features discerned and focused on by the subject" and consists of two elements (Marton & Pong, 2005, p. 336). First, how the phenomenon is discerned as a whole, including how it is discerned from and related to its context. Second, how the phenomenon's constituent parts are discerned, along with their relationship to each other and to the whole. Furthermore, in experiencing something (i.e. a particular phenomenon), it is said that these two components, that is the referential and structural aspects of experience, are intertwined and occur in a simultaneous manner (Marton & Booth, 1997).

In further explicating the structural aspect of experience, Marton (1996) described a way of experiencing something in terms of a person's awareness or consciousness. He expressed the idea of awareness as relating to a person's total experience of the world at any given point in time, and that two key features were present in human awareness. The first of these is that a person's awareness is layered, because one cannot be aware of all things simultaneously. The second feature Marton identified is that we are all aware of everything at the same time, but not in the same way.

In elucidating the concept of awareness, phenomenography was influenced by phenomenology and drew upon the work of Gurwitsch (1964). Gurtwitsch developed the idea of a field of consciousness to represent and describe what individuals are aware of and how they are aware. Consequently the way in which the term 'awareness' is used in phenomenography is critically different to its common application in that the usual "dichotomic sense of the term" (i.e. awareness as opposed to unawareness), is instead replaced by the idea of a "structural differentiation of awareness" (Marton, 2000, p. 109).

Phenomenography regards awareness as structured and thematised according to a 'figure-ground' arrangement. Following this idea phenomenography posits that certain aspects of an experience are in 'focus' at a certain point in time in a person's awareness, or in other words a particular aspect is explicit and has attracted the individual's attention. In contrast, other aspects of the experienced world reside in the 'background' of a person's awareness. These aspects are related to the focus of the experience and the context in which it is embedded. Finally, there are aspects that reside in the 'margin'. These aspects are unrelated to the focus of the experience, but are "temporally and spatially coexistent" with it at that point in time (Marton, 2000, p. 110). Indeed a diagrammatic representation of the ideas presented to this point concerning phenomenography's knowledge interest (i.e. a way of experiencing something) would appear as follows:

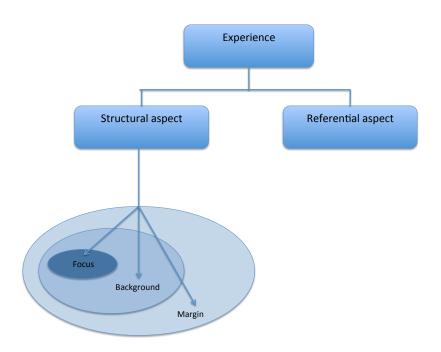


Figure 2: A way of experiencing something (Marton & Booth, 1997, p. 88)

Further illustration of the referential and structural components that comprise a way of experiencing can be provided by drawing upon an example from Marton and Booth (1997, p. 86-87). Imagine that while walking through a park, you notice a bird sitting in a tree. Firstly, to see the bird at all you need to distinguish it from the surrounding trees and the broader environment. In this experience, the bird itself is in 'focus', it is the aspect that has attracted our attention. In addition, the 'background' of this experience comprises the various parts of the bird's body (e.g. pointy beak, colourful plumage) and the particular pose in which the bird is sitting in the tree. Also present are aspects that belong to the margin of the

experience, for example, the person jogging on the pathway beside you, or the group of children playing in the distance on the playground equipment.

Together all of these elements (i.e. focus, background, margin) comprise the *structural* aspect of the experience whereby there is "discernment of the whole from the context on one hand and discernment of the parts and their relationships within the whole on the other" (Marton & Booth, 1997, p. 87). Furthermore the bird also has to be seen or identified as a bird by the person experiencing it. Hence the bird itself needs to be assigned a meaning and our prior experiences of birds assist us to recognise what it represents. This is the meaning or *referential aspect* of the experience. In this instance the meaning of the bird may be represented by the particular kind of bird we understand it to be, for example, a rainbow lorikeet. However as already mentioned, these two aspects of the experience, the structural and referential aspects are closely related and experienced in a simultaneous manner.

## 3.8 The outcomes of phenomenographic research

In phenomenographic research the outcomes or results are termed as categories of description and an outcome space. In the next two sections of this chapter I explain and discuss the outcomes that arise from phenomenographic enquiry. Following this, I then detail a further element of relevance in the outcomes of phenomenographic research. This element is termed 'dimensions of variation'.

## 3.8.1 Categories of description

In phenomenographic research categories of description are used to describe variation in the critically or qualitatively different ways in which people experience a particular phenomenon. Marton (1981) referred to phenomenographic categories of description as 'abstract instruments' (p. 196), or in other words, a particular form that is used to characterise and express different ways of experiencing the object of study.

There are four key qualities that underpin categories of description. Marton describes these qualities as relational (the subject-object relation that comprises a way of experiencing); experiential (based on the experience of participants in the study); content oriented (focused on the meaning of the phenomenon under investigation); and finally qualitative (descriptive in nature)(1988, p. 181).

Furthermore it is important to understand the distinction between categories of description as an outcome of phenomenographic research, and how they relate to ways of experiencing as the knowledge interest and object of study in phenomenography. Johansson, Marton and

Svensson describe that ways of experiencing comprise phenomenography's 'unit of analysis', that they 'refer to whole qualities of human-world relations', and the qualitatively different ways in which a particular aspect of reality is understood. In endeavouring to describe these ways of experiencing, they explain that phenomenography utilises categories of descriptions, which are not identical with the ways of experiencing, but are used to 'denote' them (1985, p. 249).

Continuing this idea, Åkerlind (2003) discusses how categories of description comprise a descriptive collection of the key aspects of an experience, as opposed to a description of the experience itself. Therefore in forming the categories of description only the critical or qualitatively different aspects of an experience are represented, while the non-critical aspects are discarded. Accordingly the nature of the descriptions provided is considered to be a reduced or 'stripped' description of the phenomenon (Marton & Booth, 1997, p. 114).

A further distinction between ways of experiencing a phenomenon and categories of description is the shift in focus from the individual to the collective (Sandberg, 1997). Marton and Booth (1997) explain this difference in focus stating:

When we talk about 'a way of experiencing something' we usually do so in terms of individual awareness ... When we talk about 'categories of description' we usually do so in terms of qualitatively different ways a phenomenon may appear to people of one kind or another. Thus categories of description refer to the collective level (p. 128).

Therefore, although a way of experiencing a phenomenon derives from an individual, a category of description combines the experiences of multiple individuals. Marton and Booth illustrated this point by acknowledging that in phenomenography "individuals are seen as the bearers of fragments of different ways of experiencing that phenomenon" (1997, p. 114). However through incorporating the experiences of multiple individuals into descriptions at a collective level "individual voices are not heard" (Marton & Booth, 1997, p. 114). Indeed through combining the 'voices' of many individuals it has been suggested that categories of description can be considered to 'transcend' the individual (Lupton, 2008, p. 32).

A principle assumption of phenomenography is the belief that there are a limited number of critically or qualitatively different ways in which people experience a phenomenon (Marton, 1988). In other words phenomenography considers that within a certain group of people within a certain context there will be a finite number of ways that a particular phenomenon will be understood. A phenomenographic study therefore seeks to map these critically or qualitatively different ways into categories of description. These categories are delimited

from one another by variation in key aspects of the experienced phenomenon, which enable it to be discerned from other phenomena in the world.

However it must also be emphasised that the categories of description produced will not necessarily denote the total range of possible ways of experiencing a certain phenomenon, as indeed this may be limitless. Instead, the resulting categories of description communicate the meaning of the phenomenon within a certain context that was experienced by a participant group (Barnard, McCosker & Gerber, 1999).

Each category of description is described in terms of its referential and structural components as previously illustrated in Figure 2. In detailing the 'structure of awareness' within each category the structural component is subdivided into the different layers of awareness. These layers describe aspects that are in 'focus', that is in the foreground of awareness, aspects that are in the 'background' of awareness, and aspects of awareness that are marginal (i.e. the 'margin').

### 3.8.2 Outcome space

The end result of phenomenographic research is an 'outcome space', which comprises the set of interrelated categories of description for the specific phenomenon investigated (Marton & Pang, 2008). The outcome space constitutes a picture of the phenomenon, which symbolises the total range of potential ways in which the participant group experienced the phenomenon at any one point in time (Åkerlind, 2003). Marton described the outcome space in phenomenographic research as a "synonym for 'phenomenon'", and is the "logically structured complex of the different ways of experiencing an object" (2000, p.105). Similarly Säljö (1988) suggested that the outcome space reflected a "map of a territory" interpreting how people conceive of a particular aspect of reality (p. 44).

The outcome space portrays the logical relationships between the categories of description, or in other words, an empirical representation of how each category relates to each other. In the same way, the outcome space similarly depicts the 'space of variation', by describing variation in the qualitatively different ways in which a particular phenomenon is experienced (Marton & Pang, 2008). Through revealing the relationships between the different ways of experiencing a phenomenon, Åkerlind claims that the outcome space offers a means of examining the holistic meaning of the phenomenon, despite that phenomenography's research emphasis is to identify different meanings (2003).

Laurillard distinguished three different types of outcome space that reflect various ways in which the relationships between the categories of descriptions may be viewed. First, an

inclusive or hierarchical outcome space where categories that are higher up in the hierarchy take in preceding or lower categories. Second, an outcome space where the different categories relate to the history of the interviewee's experience of the phenomenon, instead of each other. Third, where the outcome space denotes a "developmental progression", in that the ways of experiencing represented by some categories of description have greater "explanatory power" than others, and therefore may be seen as "better" (1993, p. 45).

However, irrespective of the type of outcome space to emerge Marton and Booth (1997) stress that the set of categories comprising the outcome space must conform to three criteria: (i) each category expresses a critically or qualitatively different way of experiencing the phenomenon; (ii) each category should be logically related with one another; and (iii) the set of categories should be "parsimonious", namely that as few categories should be used as practical to describe the critical variation that is evident in the data (p. 125).

#### 3.8.3 Dimensions of variation

An additional feature that may also appear in the presentation of phenomenographic results concerns a further layer of awareness that is referred to as dimensions of variation. Dimensions of variation are recognisable themes or common threads that traverse each category of description. However although a dimension of variation may appear in each category, the character of this dimension changes across each category, or in other words, it is experienced in a qualitatively different way from one category to another (Åkerlind, 2005b).

Pang (2003) reported that the dimensions of variation represented a "second face of variation" and denoted a shift in the primary focus of phenomenographic research from answering methodological to theoretical questions. This shift referred to a move from describing different ways of experiencing a phenomenon towards endeavours to answer questions such as "what is a way of experiencing something?" and "what is the actual difference between two ways of experiencing the same thing?" (p. 147). In other words the development of dimensions of variation represented a shift in the emphasis of phenomenographic research to exploring theoretical questions concerning the nature of the differences between ways of experiencing something.

However Åkerlind (2005b) remarks that there is a degree of ambiguity in the original explanation provided by Marton and Booth (1997) concerning what constitutes a dimension of variation, which has resulted in differences concerning how this feature is interpreted. Recognising this situation, some researchers have drawn upon different terminology to represent this feature when reporting phenomenographic results. As an illustration, both

Åkerlind (2003) and Lupton (2008) used the term 'themes of expanding awareness' to denote a further layer of awareness in addition to the 'structure of awareness' that comprises the focus, background and marginal aspects of an experience.

In elucidating her use of the term 'themes of expanding awareness' Åkerlind (2003) stated that this still represented dimensions of variation, but that they were of a "more complex nature" than was generally implied (p. 90). As a result she described the themes of expanding awareness as "representing structural groups of dimensions of variation" that emphasised the structural relationships that were present between different dimensions (Åkerlind, 2005b, p. 122).

However it is conceivable that the ambiguity in Marton and Booth's original explanation also avoided definitional interpretations that might constrain comprehensive understandings of different phenomena. In this way, the absence of a 'rigid' definition preserved the emphasis on interpretation, or more specifically, to adhere to the principle of allowing each particular phenomenon to unfold or reveal itself.

## 3.9 Research Design

This section focuses on the design of the proposed research study. It provides details on participant selection, approach to sampling and the use of semi-structured interviews as the data gathering tool. The approach to undertaking data analysis in phenomenographic research is also discussed.

#### 3.9.1 The participants

Phenomenographic research frequently uses a purposive sampling approach whereby participants are intentionally selected because they meet particular criteria (Bowden, 2000a). Likewise Barnard, McCosker and Gerber (1999) similarly explain how data collection in a phenomenographic study is frequently based upon a specific group of people and their connection to a phenomenon in a particular context.

I elected to select a specific age cohort as the participant group for this research. My decision to choose a specific age cohort for this study was informed by a 2003 report entitled 'Promoting Healthy Ageing in Australia' published by the Prime Ministers' Science, Engineering and Innovation Council (PMSEIC). This report discussed how when considering issues pertaining to health or ways to improve health, it was valuable and useful to recognise the different needs, priorities and expectations as they applied to distinct generations of Australians.

Accordingly I elected to investigate a significant and distinct generation within the Australian population that is commonly referred to as the 'Baby Boomers'. The term Baby Boomers refers to persons born between the years 1946 to 1965, and as an age cohort they encompass a significant percentage of Australia's population (Australian Bureau of Statistics, 2005). For instance in Queensland alone persons born during 1946 to 1965 comprise nearly one third (29%) of the state's total population (Australian Bureau of Statistics, 2005).

As noted by the PMSEIC (2003) this sizeable cohort are presently in 'mid-life', and are establishing the health and lifestyle trajectories that will accompany them into old age. For this reason investigating how persons within this group experienced health information literacy was identified as being a worthwhile focus for research attention. Furthermore it was also considered that knowledge about this experienced phenomenon could be used to inform agencies involved in the design, delivery and implementation of health information resources, services, programs and policy.

At the time of conducting this study the Baby Boomers generation was aged between 45 to 64 years and accordingly year of birth provided the overarching criterion for inclusion in the research sample. However I was also mindful that the primary goal of a phenomenographic study was to explore variation and therefore participant selection needed to consider different characteristics that might capture diversity in experience. According to Ashworth and Lucas (2000) this can be achieved through selecting participants with potentially different 'lifeworlds', however caution must similarly be exercised in making assumptions about the ways of experiencing among certain 'types' of individuals, as these may be incorrect.

Being attentive to these requirements I continually monitored the research sample composition when recruiting participants in three ways. First, I ensured that both male and female participants were included and endeavoured to achieve as close to equal numbers of both sexes as was possible. Second, that there was a variation in the age distribution of participants between 45 to 64 years in the research sample. Third, I also asked potential participants to disclose details concerning their current occupation. In instances where people indicated they were no longer participating in paid employment (i.e. they were retired) I asked them to identify their former primary occupation.

It is important to reiterate that my purpose in monitoring the research sample was to exploit the variety of perspectives encountered, and not an endeavour to achieve statistical rigour (Bowden, 2000a). In fact Ashworth and Lucas (2000) contend that the notion of statistical

sampling in phenomenography is illogical, because it is inconceivable to suggest that experience may have 'parameters' in a mathematical sense (p. 302). Instead at all times my attention or emphasis was directed to sampling for variation, or in other words, to attain different experiences of the phenomenon.

Although there is no prescriptive sample size for a phenomenographic study it is acknowledged that this generally comprises between 15 and 30 participants (Sandberg, 1994; Bowden 2005). Bruce (1997a) considers that the number of participants needs to be of a size that is sufficient to gather suitably rich descriptions of people's varying ways of experiencing a phenomenon. Bowden (2005) similarly agrees and also stresses that the size of the research sample should not make it problematic in terms of managing the resulting data for analysis.

The research sample for this study comprised 23 people, which contained 14 females and 9 males. Participants were aged between 47 to 64 years of age (56 years average). To minimize the need and expense of travel all research participants were recruited from the greater Brisbane area of Queensland, Australia.

I recruited participants via direct email invitations to a range of community organisations that supported adult leisure or hobby interests (e.g. gardening, music, car rally driving, sport). I also made direct approaches by distributing recruitment flyers to groups that were either targeted specifically to persons aged over 45 years, or where persons in the desired age range were likely to be found. This included a 'seniors' group for people aged over 55 years, two support groups for particular health conditions and a community 'Mens Shed'. Finally, I also encouraged interviewees to distribute recruitment invitations within their own networks (physically or electronically) and a couple of participants in the sample were sourced in this way.

In recruiting participants the main difficulty I encountered was the considerably higher number of females that expressed interest in taking part in the study compared to males. As a response to this situation I consciously started to target avenues where I considered that I might have greater success in accessing males. For example, I approached a leisure related automobile club for persons with 4WD vehicles and some adult male sporting teams. The other challenge I encountered was attracting participants aged between 45-50 years and I endeavoured to respond to this issue in two ways. First, I amended my recruitment flyer to reflect that persons aged 45 to 50 years was the group I was looking to interview, and second, by a direct approach to the parents and friends association of a secondary school. Finally, although several measures were taken to capture variation, possible limitations of

the sampling and recruitment approaches taken must be acknowledged. This point is further discussed in Chapter 5 of this thesis.

#### 3.9.2 Data collection: Interviews

In this study, I carried out face-to-face interviews which is the most commonly utilised approach for data collection in phenomenographic research (Ashworth & Lucas, 2000; Bruce, 1997a; Marton, 1994). Svensson (1994) suggests that preference towards the use of interviews arises from the nature of conceptions (i.e. way of experiencing something) as the object of interest in a phenomenographic study. A way of experiencing something signifies the experienced meaning of a phenomenon, and while this can be communicated in different ways, Svensson considers language as the form through which these are most accessible. Continuing this idea Säljö similarly disscusses the use of 'talk' as empirical data in phenomenographic research (1997). Commenting on how "language, culture and human experience are inextricably intertwined, Säljö notes the suitability and frequent use of interviews as a method for collecting data in phenomenographic research (1997, p. 177).

Bruce (1994) describes the phenomenographic interview as a "specialised form of the qualitative research interview" (p. 49). Referring to the work of Kvale (1983), Bruce identifies several characteristics that are distinctive of the phenomenographic and qualitative research interview. These qualities are:

- they are centred on the interviewee's life-world
- they seek to understand the meaning of phenomenon in the interviewee's life-world
- they are qualitative, descriptive, specific and presuppositionless
- they are focused on certain themes
- they are open to ambiguities and change
- they take place in an interpersonal interaction
- they may be a positive experience (1994, p. 49)

A number of distinctive characteristics similarly distinguish the phenomenographic interview from qualitative research interviews. This includes the aim and purpose of the interview, the interview focus and how the interview itself is designed and conducted. The following paragraphs further elaborate on each of these characteristics.

The aim of a phenomenographic interview is to explore how a particular aspect of the world (i.e. a phenomenon) appears to a person. Bruce (1994) emphasises how the aim of the

phenomenographic interview is fundamentally entwined to the aim of the research approach itself, that is, "mapping of the qualitatively different ways in which people experience, conceptualise, perceive, and understand various aspects of... the world around them" (Marton, 1988, p. 178-9). As such the specific purpose or objective of the phenomenographic interview is to identify and explore variation in how the interviewee sees, experiences or understands the phenomenon of interest.

The focus of the phenomenographic interview provides a further aspect of distinction. In a phenomenographic interview the focus is on the relation between the interviewee and the phenomenon, instead of on the interviewee or the phenomenon of interest itself. In addition the interview focus is also directed to exploring differences in how that relation is experienced by a single individual, and how it is experienced among individuals (Bruce, 1994).

Phenomenology, or rather phenomenological theory has also exerted influence on the approach to conducting a phenomenographic interview. This influence is a regimen known as the 'phenomenological reduction', and comprises three rules. The first of these rules is the rule of the epoche, also referred to as 'phenomenological bracketing', whereby any preconceptions about the phenomenon are cast aside. The second rule is the rule of description, which places emphasis on description rather than explanation of the phenomenon. Finally, there is the rule of horizontalisation, which refers to treating all descriptions or experiences as equally significant (Bruce, 1994).

The design of the phenomenographic interview is commonly described as being semi-structured in form (Bruce, 1994; Marton, 1988). In a semi-structured interview an interview guide provides an outline of topics for discussion as well as suggested questions. However unlike the structured interview, the specific questions used and their sequence in the semi-structured interview is not always predetermined (Kvale & Brinkmann, 2009). Defending the adoption of the semi-structured approach in phenomenographic interviews, Marton explains that this emanates from a preference to "standardize the type of outcome instead of the procedure" (1988, p. 197).

Trigwell (2000) describes the technique of conducting a phenomenographic interview as "exploring at greater and greater depths of thinking without leading" (p. 68). Continuing this idea Marton (1994) maintains that interviews be conducted in a dialogic form where "experiences and understandings are jointly constituted by the interviewer and interviewee" (p. 4427). Ashworth and Lucas (2000, p. 302) likewise concur and consider that the practice

of the phenomenographic interview is a 'conversational partnership', where the interviewer supports a process of reflection.

The style of questions used in phenomenographic research is distinctively open-ended. Säljö (1988) identifies two styles of open-ended questions that are characteristic of phenomenographic research. The first of these asks the interviewee to describe in their own words what they see as significant experiences in a certain context. The second style of question asks the interviewee to describe a particular situation that prompted these experiences. This style of question is used in the phenomenographic interview as it allows the interviewee to select the dimensions of the question that they wish to answer (Marton, 1994) and to also remain true to their thought processes (Marton & Booth, 1997). Booth (1997) also comments how the open structure of questions in phenomenographic research enables the interviewer to pursue anticipated lines of reasoning that may lead to new reflections.

Phenomenographic research makes limited use of pre-determined interview questions, with interviewees commonly asked to respond to one or two broad key questions (Ashworth & Lucas, 2000; Bruce 1994; Marton, 1994). The use of broad questions is designed to orient the interviewee to the phenomenon under study in general terms, and to identify elements of the phenomenon that enter their immediate awareness (Marton & Booth, 1997). Bruce maintains that the intent behind interview questions must be to "tap the lived experience of the interviewee" (1994, p. 51), to direct them to elicit how they see, experience or understand the phenomenon of interest. Furthermore, recognising that the aim of phenomenographic research is focused on revealing qualitatively different ways of experiencing a phenomenon, interview questions must likewise be successful in eliciting variation (Bruce, 1994).

In discussing the design of the phenomenographic interview Marton (1994) emphasises how the majority of interview questions should follow on in response to what the interviewee highlights or describes about their experience of a phenomenon. To achieve this, phenomenographic research makes considerable use of unstructured probing questions to follow up or further investigate the interviewee's responses (Åkerlind, Bowden & Green, 2005). Typical examples of this type of question include "What do you mean by that?" or "Can you tell me more about that?", which allows the interviewer to obtain more detail and clarify meanings that interviewees attribute to a particular phenomenon.

#### 3.9.3 Interview approach

It is evident that contrasting methodological approaches can be embraced in phenomenographic research and these differing approaches similarly influence the way in which interviews are conducted (Bowden 2005; Åkerlind, 2005b). Lupton (2008) contrasted methodological approaches in phenomenographic research as being positioned on a continuum between positivist-objectivist and interpretivist-subjectivist approaches. In this study I have taken an interpretivist-subjectivist approach and as such my conduct of the interviews was consistent with that approach.

In preparing for interviews, I was mindful of the need for interviewees to clearly understand the focus of the study (Francis, 1993). For this reason I endeavoured to establish a *community of interpretation* to ensure that communication between myself as the researcher and the interviewee referred to the same object of study (Sandberg, 1994).

Prior to each interview, I explained the intent of the study on three separate occasions. First, the recruitment flyer distributed as part of the participant recruitment process provided initial details of the research and its purpose (refer Appendix A). Second, when approached by prospective participants I took the opportunity to further discuss the study by both email and phone, and by providing a copy of the Participant Information Sheet (refer Appendix B). Finally, at the point of interview I read a standard introduction (refer Appendix C) that again explained the intent of the research, outlined how the interview would be conducted, and ethics considerations such as confidentiality, anonymity of responses provided and the participant's right to withdraw from the process.

I supplied each participant with a copy of the interview questions two days before the arranged interview time. Participants were advised that reflecting on these questions prior to the interview was entirely at their discretion. My rationale for deciding to supply participants with a copy of the interview questions beforehand was informed by three factors. Each of these factors will now be discussed.

First, it is well accepted that phenomenographic interviews can potentially cause discomfort and frustration for participants (Åkerlind, Bowden & Green, 2005; Bruce 1997a, Trigwell, 2000). As a result I was influenced by Åkerlind's (2005b) position that as the researcher I was ethically responsible for creating an environment that was as pleasant as possible for the interviewee. For this reason, supplying questions to participants prior to their interview time was intended to alleviate or minimise any potential stress or discomfort that might occur.

Second, I was aware that the focus of the research, that is, the qualitatively different ways that people experience health information literacy meant that potentially sensitive information could be revealed during the interview process. This was also a concern raised as part of obtaining ethical clearance with respect to the potential for participants to experience embarrassment or discomfort when disclosing instances of when they had used information related to their health. Supplying questions prior to the interview time was deemed to be a practical strategy to mitigate this concern, because it gave participants the opportunity to select experiences to discuss during the interview process that they felt comfortable to disclose.

Finally I was mindful that the phenomenographic interview is often challenging for the interviewee, as "they invite [the interviewee] to reflect deeply or attempt to integrate issues that they have often not reflected on or attempted to integrate before" (Åkerlind (2005b, p. 115). This was coupled with an awareness that the phenomenon of information literacy was abstract in nature, and that previous research had recognised it as a phenomenon that was often challenging for interviewees to reflect upon (Bruce, 1997a; Lupton, 2008; Yates, Partridge & Bruce, 2009). In this way, the opportunity for interviewees to reflect on the phenomenon prior to the interview was intended to be helpful.

In choosing an interview setting I was aware of the importance of finding a location that is quiet, has minimal distraction and that the interview setting may influence the quality of responses received. Furthermore, I was similarly conscious of the need for a location that offered privacy as considering the context and focus of the study it was possible that potentially sensitive information could be revealed during the interview process.

Recognising all of these factors my approach was to ask each interviewee where they preferred to be interviewed. In the majority of instances interviewees' chose to conduct the interview at their place of residence. On a few occasions I also conducted interviews at the person's place of work or in a quiet corner of a café. The duration of interviews ranged from 24 to 59 minutes. The average length of all interviews was 44 minutes.

I commenced each interview with an open question that was designed to orient the interviewee to the phenomenon of health information literacy. In the majority of instances the open question posed at the start of each interview was "Can you describe a time when you used information to learn about your health?". The purpose of posing an open question was to provide interviewees with the opportunity to concentrate on instances of using information to learn about their health, which they identified as being significant (Åkerlind, 2003). Sandberg refers to this practice in phenomenographic interviews as "taking social

praxis as the point of the departure" (1994, p. 80). According to Sandberg this guideline for interviews stems from the belief that meaning is tied to specific social contexts. In this way asking interviewees to describe a time where they had used information to learn about their health served the purpose of better understanding the context in which that had taken place. Furthermore it also provided a starting point for discussions and to assist the interviewee in reflecting on the experience itself.

While all interviews commenced with the same opening question they often followed quite dissimilar paths. This divergence ensued from directing the conversation to further explore specific points or aspects that the interviewee had raised. Moreover, differences in the paths followed during a phenomenographic interview stems from their purpose that involves directing the interviewee to the phenomenon of interest, and then exploring variation in terms of the experienced relationship between the interviewee and that phenomenon (Marton, 1981). For this reason variation in the course each interview takes is a feature that is commonly reported in phenomenographic literature (Åkerlind, 2005b; Marton, 1986).

Similar to Åkerlind (2005b), aside from the opening question, the specific order in which I posed subsequent questions and the phrasing I used varied across interviews. This approach was consistent with the interpretivist stance I adopted (while an objectivist approach would have insisted on adherence to the same phrasing and sequencing being used). However it must also be emphasised that the approach I took towards question phrasing or sequence in no way reflected what Åkerlind termed "random variation" (2005b, p. 113). The central aim underlying my approach was grounded by the desire to create a comfortable interview atmosphere, to ensure the experience of the interview itself was more conversational in nature for the interviewee, and to allow for in-depth discussion. Furthermore, despite any variations in the way in which the interview was conducted, at all times I was mindful of the necessity to ensure interviewees were discussing the phenomenon of health information literacy.

At various points during the interviews, I used prompt questions to elicit further information from interviewees about their responses, and to explore the meaning of particular phrases or key words that they used. The type of prompts I used typically took the form of direct requests such as 'Can you tell me more about that?', 'What do you mean by that?' or 'Can you give me an example?'. Similar to Åkerlind (2005b), my experience of using prompt questions often proved to be more significant than pre-determined questions in obtaining the underlying meaning of particular points raised by the interviewee. In addition, I also used prompts that took the form of actions such as a nod of the head, or short verbal responses

such as 'Yes' or 'Okay' that were likewise intended to encourage the interviewee to continue their conversation.

I also drew upon other techniques to encourage rich descriptions, reflection and further elaboration from interviewees (McCosker, 1995). For example I used active listening by restating or paraphrasing parts of the interviewee's dialogue which was effective in eliciting further elaboration on their experiences. In addition I paid attention to the interviewee's body language, for instance observing people's eye movements to see whether they were looking down or away, and other actions that might indicate people were still in a state of reflection. Finally I was also mindful that moments of silence during the interview process are often enlightening for the interviewee (Kvale & Brinkmann, 2009). In this way I avoided posing prompt questions too quickly, and used silence as a technique for assisting reflection.

During all interviews I was careful to avoid leading questions that might influence the interviewees' account of their experience (Francis, 1996; Bowden, 2000b). Furthermore I was mindful not to raise ideas in the interview that the participant had not expressed (Åkerlind, Bowden & Green, 2005). In instances where more detailed dialogue was required to continue the conversation I ensured I used the interviewee's own words to avoid inferring an interpretation that was not correct (Dall'Alba, 2000).

All interviews were audio recorded in two separate formats: through an audio tape recorder and using QuickTime Player software on a laptop computer. I chose to make two recordings of each interview in order to safeguard against the risk of losing interview content due to equipment failure.

I personally transcribed each interview into text transcripts. Audio recordings of each interview were destroyed once the transcript was produced to preserve the interviewees' anonymity and confidentiality. The interviewee's privacy was further assured through the use of pseudonyms (e.g. Participant 1) and that any other persons or locations mentioned by name were removed and replaced with text such as [name of husband] or [location].

Following the advice of Lupton (2008) I made minor edits to the transcripts to remove expressions such as 'um', 'ah', or 'you know'. I similarly removed the introductory 'small talk' at the start of each interview and any false starts to sentences. As noted by Lupton (2008) this process was effective in producing transcripts with considerably greater clarity, and ultimately aided the analysis process.

#### 3.9.4 Pilot study

Phenomenographic literature emphasises the benefits of conducting a number of small pilots prior to the main study (Dahlgren, 1993; Frances, 1996). This practice is understood to assist with question formulation and refinement to ensure the data collection instrument best captures the phenomenon of interest.

This section outlines the different phases involved in designing the study's data collection instrument. The pilot study for this research consisted of three phases, and involved interviews with 9 participants. I discuss each of the three phases in turn, detailing revisions made to the schedule of interview questions, and my rationale for these.

#### Phase 1

Phase 1 of the pilot study consisted of interviews with three participants.

In devising an initial set of questions I began by reviewing phenomenographic literature to develop an understanding of the style of questions commonly used in this research approach (e.g. Ashworth & Lucas, 2000; Bowden, 2000a; Bruce, 1994; Marton 1994). Furthermore I also examined a number of phenomenographic studies that had explored the phenomenon of information literacy (e.g. Boon, Johnston & Webber, 2007; Bruce, 1997a; Lupton, 2008; Williams & Wavell, 2007), and studies that had investigated related or interrelated aspects such as information seeking and information use (e.g. Limberg, 2000; Kirk, 2002; Edwards, 2006; Parker, 2006). These studies were useful in providing me with an appreciation of terms or phrasing that had been used to investigate various information literacy and related phenomena.

However in reviewing previous information literacy research it was evident that using the term itself in interview questions had sometimes proved problematic. In particular the challenge of using the term 'information literacy' was expressed by Lupton (2008) in devising questions to explore the experienced relationship between information literacy and learning in undergraduate students. Lupton noted that although research conducted among educators frequently used this term in interview questions (e.g. Bruce, 1997a; Boon, Johnston & Webber; 2007; Williams & Wavell, 2007), other researchers exploring the phenomenon among student populations had discovered that the term held no meaning for this participant group (e.g. Maybee, 2006, 2007).

I too considered that this issue was likely to apply to an exploration among citizens in everyday life, and therefore alternative wording that captured the meaning of information

literacy would be necessary in devising interview questions. Consequently similar to Lupton (2008) I chose to use terms such as 'used information', and 'using information' as a substitute for information literacy in the initial set of interview questions developed.

The questions used in the first phase of interviews were as follows:

- 1. Can you describe a time when you used information to stay healthy?
- 2. Describe your experience of using information to learn how to stay healthy.
- 3. What kinds of information have you used in learning how to stay healthy?
- 4. Can you tell me about using information to help other people to stay healthy?

At the conclusion of Phase 1, I reviewed reflections that I had documented at the end of each interview, as well as the interview transcripts. In doing so I decided that several revisions were necessary.

The first revision entailed changes to the phrasing for Question 1 by replacing the words 'stay healthy' with 'to learn about your health'. The rationale for this decision was based on four factors. First, that the intent of the research was to explore the qualitatively different ways people experience health information literacy, and this was irrespective of health status (e.g. present, former or future). In this way, changes to phrasing were designed to be more inclusive of people's experiences of using with information in regards to health.

Second, Phase 1 interviews had shown that the phenomenon of interest was both abstract and complex in nature. For this reason, the phrasing of the opening interview question needed to be crafted in such a way that it gave the participant a concrete platform to commence the conversation and effectively oriented them to the phenomenon. In this way it was considered that including the term 'learn' would help to make the question less vague.

Third, that use of the term 'learn' was also thought to hold good potential for common understanding, and therefore an appropriate choice for research with citizens in everyday life. Finally, amendments to question phrasing were also deemed appropriate in order to more adequately reflect the theoretical model of information literacy framing the study, where information literacy is viewed as experiencing different ways of using information to learn (Bruce, 1997a, 2008).

The second revision entailed changes to phrasing for Question 2, which was intended to explore the overarching nature of people's experiences of health information literacy in a wholistic sense. Based upon my reflections of these interviews and a review of the

transcripts, it was clear that all three participants experienced difficulty in providing a response, and appeared to find the phrasing too vague.

Rather than abandon this question, I decided to trial a revision to phrasing and accordingly reworded this to 'Describe your experience of being a health information user'. Furthermore, I also opted to change its placement in the interview schedule and re-positioned it as the concluding question. Here I considered that by posing this question in the latter stage of the interview participants would have already reflected extensively on their experiences of the phenomenon, and therefore be potentially more able to describe this at a 'meta' level.

The wording for Question 3 was similarly altered to reflect phrasing changes made to Question 1 to become 'What kinds of information have you used to learn about your health?'. Building on Question 1, this question was designed to further explore what participants constituted as information that they used to learn about health. Again here I acknowledged that the study's focus was on people's experiences of using information concerning their health, and that question phrasing needed to be open and inclusive of all situations and contexts.

Finally, it was also recognised that Question 1 and Question 4 could be used interchangeably as data gathered from both questions did not appear to yield a significantly different response. Consequently it was decided that future interviews would only draw upon this question in situations where a participant was unable to reflect upon a personal experience of using information in a health context.

#### Phase 2

Phase 2 of the pilot study consisted of interviews with three participants.

The questions used for Phase 2 were as follows:

- 1. Can you describe a time when you used information to learn about your health?
- 2. What kinds of information have you used to learn about your health?
- 3. Describe your experience of being a health information user.

Similar to Phase 1, at the conclusion of Phase 2 I followed the same process of reviewing reflections I had noted after interviews along with the transcripts. Once again I considered that further refinements were required to the questions.

The first change was to introduce an additional question to follow Question 1 which was ''Can you tell me about a time when you used information for your health in general or for living a healthy lifestyle? In reviewing participant's responses to Question 1 from Phase 1 and 2, it was evident that these typically elicited instances where the participant had experienced a health issue or concern. However given that this study was interested in exploring health information literacy in a wholistic sense, a question was needed that would explore experiences of this in everyday life, or in times when illness or disease were not a present or ongoing concern.

Furthermore, the second change also involved introducing an additional question to follow Question 2 which was 'Is there anything else that informs you when you are learning about your health?'. Responses in both Phase 1 and Phase 2 revealed that participants often seemed constrained by the term 'information', or tentative about how to conceptualise it. Therefore by introducing an additional question using the phrase 'informs' rather than 'information' I considered this may assist participants to reflect or draw upon forms of information that were perhaps more abstract in nature.

Finally, Question 3 continued to prove problematic in terms of its understanding among participants and difficulty in generating a response. I elected to test another alteration to the phrasing for this question using 'What is it like using information to learn about your health?'. It was hoped that this change would prove to be more successful than previous attempts.

#### Phase 3

Phase 3 of the pilot study consisted of interviews with three participants.

The questions used for Phase 3 were as follows:

- 1. Can you describe a time when you used information to learn about your health?
- 2. Can you tell me about time when you used information for your health in general or for living a healthy lifestyle?
- 3. What kinds of information have you used to learn about your health?
- 4. Is there anything else that informs you when you are learning about your health?
- 5. What is it like using information to learn about your health?

Once again I adhered to the same process used in the previous two phases by reviewing reflections noted after interviews along with the transcripts. I concluded that Questions 1-4

were performing well in terms of orienting participants towards the phenomenon of interest and in eliciting variation. In contrast the phrasing used in Question 5 was again unsuccessful in achieving its intention. Recognising that this had now been revisited a number of times, I decided to abandon any further testing and discarded this line of questioning.

#### 3.9.5 Main study

Being satisfied that the interview questions were effectively orienting participants to the phenomenon as well as eliciting variation, I commenced recruiting additional participants for the study.

However at this point in time I also deliberated on the often-vexed question in phenomenographic research of whether to include or discard data I obtained during the pilot study. Bowden (2005) insists on discarding pilot interviews, asserting that these are 'tainted' by potential errors made by the interviewer in their questioning, and by the 'shifting focus' of questions while they are refined (p. 19). However in reviewing various research studies it was evident that some researchers had elected to incorporate data from a pilot process into the main study (e.g. Lupton, 2008).

Feeling uncertain about the best way to proceed, I discussed this matter with members of my supervisory team. It was collectively agreed that aside from one line of questioning that I had decided to abandon, the revisions to all other interview questions were not considered radical. The various versions of these questions had all directed participants to their experiences of health information literacy, with alterations merely serving to provide the best possible orientation to the phenomenon and to elicit variation. Consequently it was decided that data obtained from the 9 pilot interviews could be incorporated into the main study.

I conducted a further 14 interviews thereby reaching a total of 23 interviews for study's sample.

The questions used to conduct the final 14 interviews were as follows:

- 1. Can you describe a time when you used information to learn about your health?
- 2. Can you tell me about time when you used information for your health in general or for living a healthy lifestyle?
- 3. What kinds of information have you used to learn about your health?
- 4. Is there anything else that informs you when you are learning about your health?

The purpose of Question 1 was to provide people with the opportunity to concentrate on particular instances they identified as being significant in terms of using information to learn about health. Question 2 was similar in its purpose however the choice of phrasing was intended to assisting participants with reflecting on their engagement with information in a more comprehensive manner. The intent of Question 3 was to explore what people constituted as information that they used to learn about health. Question 4 was similarly intended to explore this same point, but again used particular phrasing that enabled participants to reflect upon objects of information that they may have considered as more abstract in nature.

Furthermore throughout all interviews (including those which comprised the pilot study), I used a set of generic probe questions. The phrasing of these questions was characteristic of generic probe questions in a phenomenographic study (Bowden, 2000a). These were as follows:

- Could you explain that further?
- Can you tell me more about that?
- What do you mean by that?
- Could you please give me an example?
- Can you explain that in a different way?
- Is there anything else you would like to say about this?

During interviews I used these questions to elicit further information from participants, and to obtain greater clarification about responses they had provided.

# 3.10 Describing ways of experiencing health information literacy

The purpose of this section is to describe general principles that underlie data analysis in phenomenographic research, and to outline the process I followed in this study. First, I detail the general principles. Second, I explain the different steps that I undertook to find and describe the qualitatively different ways of experiencing health information literacy.

#### 3.10.1 Data analysis: Overview

Svensson (1997) explains how phenomenography's research orientation is primarily concerned with identifying and describing critical variation in the ways in which a particular

phenomenon is experienced. Accordingly the aim of data analysis in a phenomenographic study is to uncover these qualitatively different ways, and to provide experiential descriptions that capture this variation.

There is no single process or technique prescribed for the analysis of phenomenographic data and indeed an array of approaches are reported in the literature. Although the absence of a distinct approach or set of techniques has frequently drawn criticism (Ashworth & Lucas, 2000; Francis, 1996; Säljö, 1997; Uljens, 1996), it has also been argued that given the nature of this type of research a prescriptive 'formula' for analysis is neither possible or desirable (Bruce, 1997a; Johansson, Marton & Svensson, 1985; Prosser, 2000; Säljö, 1988).

However despite the absence of a methodological algorithm for undertaking data analysis in a phenomenographic study Åkerlind (2003) argues that three common principles of practice exist. First, the researcher must maintain an open mind during analysis by limiting any predetermined views or drawing conclusions too quickly about the nature of the categories of description. Second, the researcher must ensure that a focus on the collective experience is maintained by viewing the transcripts and the emerging categories of description as a set, rather than individual transcripts and categories of description. Finally, there is a search for meaning or variation in meaning across interview transcripts as well as the structural relationships between these meanings.

To contend with criticism regarding variation in the approach to phenomenographic data analysis, Ashworth and Lucas (2000) stress the importance of the researcher to clearly document the process followed. Ashworth and Lucas (2000) consider that providing a detailed trail of evidence concerning the procedures utilised to develop the categories of description provides transparency for the process, and enables scrutiny regarding the trustworthiness of research findings.

However, for those unfamiliar with phenomenography, possibly the most eloquent explanation describing the process of analysis is provided by Fallsberg (1991), where she compares this to sorting a deck of playing cards. At first glance it is clear that all the cards in the deck are different and that they could be separated into 52 variations. On closer inspection though it is also possible to discern other ways in which to divide the cards as a way of comparing them. For example the cards may be divided into four groups of different suits (i.e. aces, spades, hearts, diamonds), while another possibility may be to divide them into thirteen groups based on denomination. However, in this example it is relatively simple to discern the different groupings of cards that may be possible, as generally most people are familiar with a deck of playing cards, and therefore know it is comprised of different suits

and denominations. Conversely, in phenomenographic analysis the researcher is required to sort a number of different dialogues, except unlike a deck of playing cards, the researcher is not previously aware of particular categories that they can apply to the sorting process. Instead in phenomenographic analysis the researcher's task is to discover different categories of meaning that are expressed in these dialogues, and to then group and describe them accordingly.

#### 3.10.2 Data analysis: Process followed

My approach to undertaking data analysis drew upon descriptions of the process provided by Bruce (1997a), Lupton (2008), Sandberg (1994) and Åkerlind (2003). I also followed the advice of Lupton (2008) in keeping a series of notebooks throughout the process. In these notebooks I detailed the different steps and various iterations that were involved in drafting the categories of description. I also used the notebooks as a space for recording my reflections throughout the process and for documenting the emerging research findings.

Descriptions provided by other researchers concerning their experience of carrying out phenomenographic data analysis frequently emphasise the iterative nature of the process. My experience of undertaking data analysis similarly concurred with this description, and indeed resembled a more recursive rather than liner process. In fact in reporting on the procedure followed perhaps the greatest challenge for a phenomenographic researcher is to provide an account that does the process involved justice, and which truly reflects the endeavour to disentangle what at first appears to be total dialogic chaos.

The way in which I implemented the process of data analysis is best described as a series of six different phases. These phases included: familiarisation with the data; searching for meaning; concentrating on meaning rather than words; searching for structure; drafting the categories of description; and discovering the dimensions of variation. The remainder of this section now turns to a discussion of each of these phases.

#### Familiarisation with the data

In this first phase of analysis my primary aim was to reach a basic level of familiarisation with the transcripts and to begin immersing myself in the data. To achieve this I read all of the 23 transcripts four times each in an open-minded manner. In the first reading my main purpose was to simply reacquaint myself with each interview. For the second and third readings of transcripts I chose to do this by reading each interview out loud. This proved to be an effective strategy as it prevented me from skim reading the transcripts and enabled me to 'hear' as well as 'see' the data. At the end of my fourth reading of the transcripts I also

wrote a summary paragraph for each interview. These summaries contained my overarching observations and reflections on the data contained in each transcript.

#### Searching for meaning

In the second phase of analysis I began looking for the different meanings being attributed to ways of experiencing health information literacy (i.e. referential aspect). Borrowing the example provided by Bruce (1997a) I applied the following questions to the data during this phase: "Health information literacy is experienced as ..." and "Using information to learn about health is experienced as ...". I wrote these two phrases on a piece of paper, which I kept in front of me while working with the transcripts. Its purpose was to remind me that the objective of this phase was to focus only on meaning.

Based on researchers' accounts of undertaking analysis, I also chose to commence looking for different meanings by working with a subset of 4 transcripts. This strategy is recognised as a common practice among many researchers working with phenomenography, and is designed to assist the researcher with the challenge of managing the large amount of data requiring interpretation (Prosser, 2000; Trigwell, 2000; Åkerlind 2005a; Lupton 2008).

In instances where I identified a meaning I wrote statements to express this on separate coloured sticky notes. I also recorded the participant number, the transcript page and paragraph number that related to each statement. The purpose of this system was to ensure that I could easily refer back to the transcript at a later point in time. When I had completed writing meaning statements for each transcript I placed the collection of coloured sticky notes on a large piece of white paper and wrote the participant number at the top of the sheet (refer Appendix D). I followed this same process for each of the 4 transcripts.

I discussed the meaning statements I had identified in all 4 transcripts with a member of my supervisory team who had also read through the same transcripts I had worked with. This proved to be very helpful in 'testing' my interpretations of the data as it provided an opportunity for me to debate and reflect on the meaning statements I had devised with another person. Furthermore, it also helped me to gain confidence and reassurance that I was analysing the data in accordance with the phenomenographic approach.

I repeated the same process of working on additional subsets of four transcripts until the total amount of transcripts I was working with equalled 16. During this time I also met on two occasions with a member of my supervisory team and went through the same process of discussing and debating the meaning statements I had devised. However after completing

meaning statements for 16 transcripts I started to feel overwhelmed by the amount of data I was trying to manage, and sought advice from my supervisors as to the best way to proceed.

We agreed that I would set aside the remaining 7 transcripts and continue the analysis process using a preliminary set of 16. These remaining transcripts were eventually introduced into the analysis process at a later point in time when tentative categories of description had been developed. In this way reserving some transcripts provided an opportunity to test and check the soundness of the categories that had been developed, and again is another practice frequently utilised in phenomenographic research (Åkerlind, 2005a).

I then commenced a process of grouping meaning statements where I had used a similar language expression. Each group of similar meaning statements were placed on a separate large piece of paper (refer Appendix E). At the end of this process I had 11 different groups of meaning statements, and another group of assorted statements that I termed 'miscellaneous' as they did not appear similar to others.

#### Concentrating on meaning rather than words

In the third phase I began working with each group of statements to ensure that the meanings underlying these were similar. In this way I was mindful of phenomenography's emphasis of needing to distinguish the difference between participants "underlying intentional attitude towards the phenomenon being described" rather than purely linguistic differences in the particular words used to express this (Åkerlind, Bowden & Green, 2005, p. 87).

Using the numbered coding on each sticky note, I then returned to the transcripts and started to concentrate closely on the meanings behind each statement as opposed particular words the interviewee had chosen to use. On some occasions I found that statements I had used to represent sections of the data did not accurately reflect the intended meaning, or were not similar to other meaning statements in that same group. In instances where this occurred I endeavoured to see if the statement could be incorporated into another grouping. When this wasn't possible however the statement was allocated to the 'miscellaneous' grouping I described in the previous section.

By examining the similarities between different meaning statements in each group this third phase denoted the first shift from an individual to a collective focus in the analysis process. It also marked a point at which critical variation in the ways of experiencing health information literacy between the groups began to appear, even though these differences could not be entirely discerned.

#### Searching for structure

Following the recommendation of Ashworth and Lucas (2000) I shifted the focus of analysis in the fourth phase from looking for meaning towards looking for structure (i.e. the structural aspect). Again here I borrowed the approach taken by Bruce (1997a) and applied the following question to the data: 'What are people focusing on in order to experience health information literacy in this way?'.

Consequently in this phase of the analysis I started to look for the most crucial structural aspect, or in other words the collective focus within each group. During the course of this process it became evident that not all 11 groups were exhibiting critical variation in experience, and in fact that some groups were sharing the same focus. After continuing to work closely with the data in an iterative manner between meaning and structure, and both within individual groups and across groups it eventually became apparent that 7 distinct groups were present in the data.

I presented these 7 groups to my supervisory team, discussing both the essential meaning and the distinct element that appeared to be in focus for each. In addition I also sought confirmation as to whether I could consider these as preliminary categories of description and guidance on the next step to take. This was affirmed and accordingly the next step recommended was to commence the process of drafting categories of description.

#### Drafting the categories of description

Having identified some preliminary categories of description, the fifth phase then involved starting to write descriptions of each category in terms of their referential and structural aspects.

During this part of the process I also started to discern other elements that were present in each category's structure of awareness (i.e. background and marginal aspects). In some instances these elements 'jumped out' at me in reading through the relevant data for that group. However in other instances these elements only became visible as I worked across other categories and could start to see differences between them.

It is important to emphasise that the process of drafting the categories of description was intensely recursive. It involved numerous iterations during which I continued to draw upon the transcripts for the purpose of revising and refining each category.

At this point in the analysis I also began to use coloured sticky flags to denote data relating to different categories within the transcripts themselves. This strategy proved immensely

useful in providing immediate access to different excerpts of data at all times, and also ensured that my interpretations of the data were continually grounded within the context in which they had been expressed (refer Appendix F).

In addition, it was also during this phase that I introduced the remaining 7 transcripts that had been reserved in an earlier stage of the process. As already explained these were used to test the stability of the tentative categories as it enabled me to play 'devil's advocate' between these transcripts and the descriptions I had produced. In a similar way, I also revisited the group of 'miscellaneous' meaning statements that arose from work undertaken in an earlier phase of the process. Again here this provided me with another opportunity to scrutinise the categories of description devised, and to ensure that the process of analysis had been comprehensive.

#### Discovering the dimensions of variation

Finally, another distinct phase in the analysis process was the discovery of different dimensions of variation that were present across the categories of description. In writing on this point however it is important to acknowledge that this discovery although presented here as a 'phase' occurred in what is perhaps best described as a parallel manner with some of the earlier phases I have already discussed. In reality, I first began to detect the presence of different themes running through all the categories in the initial search for structure. These themes then continued to emerge with greater clarity as I started work on drafting the categories of description.

While working on the structural aspect of each category (i.e. the different elements that comprised the structure of awareness), I also found myself making notes across each category about information and learning. In addition I also observed that in some categories there appeared to be a particular 'role' that people 'took on' when experiencing health information literacy in that particular way.

However once I began working more closely with the notes I had written around information and learning, as well as with the transcripts, I realised that these were in fact multi-faceted and comprised of several different aspects. For example within the theme of 'information' I could discern differences in 'what' was experienced as information in each category, as well as differences across each category in 'how' the act of using information was experienced.

Consequently I then began to 'unpack' the dimensions of information and learning into these different aspects I could discern, and similar to developing the meaning and structure of each category, the process of 'discovering' the dimensions of variation was one of working within

and across the categories. In some instances, particular aspects were easily discerned, while on other occasions articulating a particular dimension only came after I had looked at that same dimension across each of the categories, and reflected upon whether or how it was similar to or different from the others.

# 3.11 Evaluating phenomenographic inquiry

An essential question when evaluating knowledge claims produced from research endeavours is the trustworthiness of the research process and its outcomes. In addressing this question I have chosen the criteria proposed by Sandberg (2005), which concern knowledge claims produced using interpretive research approaches.

In evaluating interpretive enquiry, Sandberg asserts that the notion of validity concerns whether "our interpretations are truthful to the lived experience within the theoretical and methodological perspectives taken", while reliability concerns "the process for achieving truthful interpretations" (2005, p. 58). Accordingly he recommended communicative and pragmatic validity together with reliability as interpretive awareness as the most appropriate criteria for evaluating the trustworthiness of interpretive research.

In the following sections I introduce the three criteria proposed by Sandberg (2005) and outline how each of these were established for this study. I also conclude the section with some commentary concerning the replicability and generalisability of the outcomes from phenomenographic research.

#### Communicative validity

According to Sandberg (2005) there are three phases in the research process where communicative validity can be substantiated: (i) data collection, (ii) analysis; and (iii) reporting results.

First, at the point of gathering empirical data communicative validity can be confirmed through dialogue between the researcher and the research participant. This process enables the researcher to determine whether a community of interpretation has been established, or in other words, that a shared understanding between the researcher and the research participant is achieved (Apel, 1972). Prior to commencing each interview I conversed with the participant where I reiterated details about the research project. In addition I also reminded them that the interview's purpose was to explore their lived experience of health information literacy. This process served to ensure there was presupposed understanding of the research project and the interview objective between both parties involved. Furthermore, during each

interview I made extensive use of follow-up questions such as "Can you explain that further?" or "What do you mean by that?". By posing questions of this kind I was able to continually check that my understanding of each participant's interpretation was correct.

Second, communicative validity can also be established in the analysis phase where the researcher is required to engage with the 'text' (i.e. the empirical data) to attain faithful interpretations of the research object (Sandberg, 1994). In reading the interview transcripts I continually shifted my focus from analysing individual transcripts to analysing across multiple transcripts. Once I had identified different ways of experiencing health information literacy, I compared participants who understood this in a similar way within that group and then between the various groups. Using this process enabled me to constantly check my interpretations of the phenomenon and to establish communicative validity (Sandberg, 2005).

Similarly I also followed the example of Bruce (1997a) by retaining the interview transcripts as a 'whole' throughout the analysis process, that is, I refrained from physically dissecting excerpts of sections until writing the categories of description. This meant that at all times the sections of text I drew upon in formulating the descriptions were faithful to the context in which the statement had been made, and to the transcript as a whole. In the same way I relied extensively on quotes sourced from interview transcripts as evidence to support each category. This likewise served to ensure that the analysis remained true to the data, and that the participants' 'voices' were used to communicate each category.

Finally, communicative validity can also be ascertained through discussing research findings with other individuals who have knowledge and interest in the same area. Drawing upon an assertion by Gadamer, Sandberg (2005) maintains that the notion of truth, to a substantial extent, is achieved through discourse between individuals. In this way, Sandberg contends that intersubjective judgement plays a fundamental role in determining the ultimate truth value of the researcher's knowledge claims. I consider that communicative validity of the research and its outcomes was established in two primary ways. The following paragraphs provide comment on each with respect to this study.

First, during the course of data analysis I engaged in an ongoing process of discussion and debate with different members of my supervisory team. By having myself as well as a supervisor read the same selected transcripts I was able to test and challenge my interpretations of the data. Likewise I also engaged in a similar process during the formation of the categories of description by presenting various draft descriptions to my supervisors and colleagues for scrutiny.

Second, throughout the course of the research process I have taken several opportunities as outlined below to check the communicability of the study and its results through avenues such as conference presentations, seminars and publications.

## Conference presentations

- Presentation of pilot findings, The International Federation on Ageing 10th Global Conference, Melbourne, Australia, May 2010
- Presentation of results, EARLI SIG 9 Phenomenography and Variation Theory Conference, University of Jönköping, Sweden, August 2012

#### **Seminars**

- Confirmation seminar, Queensland University of Technology, Brisbane, July 2010
- Presentation of results, research seminar hosted by Professor Ference Marton, Göteborg University, Sweden, August 2012
- Presentation of results, research seminar hosted by the Swedish School of Library and Information Science, University of Borås, Sweden, August 2012

#### **Publications**

- Yates, C., Partridge, H., & Bruce, C. (2009). Learning wellness: how ageing Australians experience health information literacy. *Australian Library Journal*, 58(3), 269-285.
- Yates, C., Stoodley, I., Partridge, H., Bruce, C., Cooper, H., Day, G., & Edwards, S. (2012). Exploring health information use by older Australians within everyday life. Library Trends, 60(3), 460-478.

Finally, on a number of occasions I was invited to deliver presentations about the study to postgraduate students at QUT. Guest lectures on either the project itself, the pilot findings or final results were delivered to students enrolled in *Information Literacy Education* (2009, 2010, 2011 & 2012) and *User Experience* (2010, 2011 & 2012).

In the early stages of the research these activities enabled me to incorporate feedback that served to enhance the communicability of the research. Conversely in the latter stages of the research where I presented my findings, the feedback I received confirmed the communicative validity of the study's results.

#### Pragmatic validity

The concept of pragmatic validity relates to testing knowledge produced in action (Kvale, 1989). Sandberg (2005) posits that the most comprehensive way to ascertain whether pragmatic validity has been achieved is through the application of research findings into practice. Typically this would involve conducting a separate study where the findings are "recontextualised into the practice investigated" (Sandberg, 1994, p. 64). Although this possibility was initially considered, conducting an additional study to investigate this was eventually deemed unfeasible due to time constraints associated with doctoral research programs.

However, in Chapter 5, I propose how the results from this study may be applied to practice in areas such as health communication and health information literacy education. In this way I consider that identifying possible application of the research findings into practice provides partial evidence that demonstrates pragmatic validity.

#### Reliability as interpretive awareness

Sandberg (2005) insists that the principle of reliability in interpretive enquiry relates to procedures followed during the research process to achieve truthful interpretations. Emphasising that researchers "cannot escape their interpretations", Sandberg asserts the importance of exercising "perspectival subjectivity", which requires researchers to be aware of, and explicitly deal with their subjectivity throughout the research process (2005, p. 59). In this way, the researcher's ongoing awareness of how they may be affecting the process, and also demonstrating how interpretations have been controlled and verified becomes a strength rather than a risk to attaining reliable results.

To ensure the researcher maintains 'interpretive awareness', Sandberg proposes entering into the 'phenomenological reduction', which involves the suspension or 'bracketing' of any preconceived assumptions or biases throughout the research process (2005). In other words this requires the researcher to set aside their views of the phenomenon, and not presume that the experience of others will be similar in any way. While Sandberg acknowledges the challenges of striving to achieve this, I concur with the assertion expressed by Lupton (2008). Accepting phenomenography's essential interest in investigating other people's experiences, Lupton stated that in selecting this approach the phenomenographic researcher was inherently and perpetually mindful to not impose their own 'worldview' upon the study (2008).

More specifically however the phenomenological reduction also comprises several points that serve as interpretive guidelines concerning the researcher's role as interpreter in the research process. This involves:

- an orientation to the phenomenon and how it appears
- describing the phenomenon rather than explaining or surpassing the experience
- treating all aspects of the phenomenon in equal importance, a process known as 'horizontalisation'
- searching for structural features, that is the basic meaning structure of the phenomenon (Sandberg, 2005, p. 60-61)

I now comment on how the principles of the phenomenological reduction were applied in this study.

The study's primary research question "What are the qualitatively different wasy in which people exeprience health information literacy?" was overtly oriented towards exploring the various ways in which people experienced the phenomenon of health information literacy. In addition the pilot study enabled me to test the style or phrasing of interview questions, and thereby ensure that the final data collection instrument provided the best orientation to the phenomenon and eliciting different ways in which this was experienced.

I strove to ensure that the study's focus was centred on 'describing' rather than 'explaining' the phenomenon. This was achieved through the use of interview questions that were designed towards generating descriptions rather than explanations of the ways in which health information literacy was experienced. Similarly in developing the categories of description I was mindful of the need to ensure that these were concerned with descriptions of how the experience was constituted.

I endeavoured to abide by the rule of horizontalisation in both the collection and analysis of data through treating all responses as equally important.

As suggested by Sandberg (2005, p. 61), I embraced the principle of "free imaginative variation" by adopting different interpretations in the analysis process to uncover the phenomenon's basic meaning structure. This continued until the overall structure stabilised, and I have extensively detailed the process I undertook in an earlier section of this chapter.

#### Replicability and generalisability of research outcomes

A further question often posed concerning the results of phenomenographic research is whether a different researcher would produce the same categories of description if they were studying the same data. Marton (1986) attends to this question using the example of a botanist studying previously unknown species of plants on a remote island, and explains how the discovery of a new species necessitates devising a new plant classification. Similar to identifying new plant species, Marton contends that identifying the categories of description in a phenomenographic study represents a form of discovery and that "discoveries do not have to be replicable" (p. 35).

In other words, once a new species has been classified, it has been 'discovered' and there is no requirement for another researcher to independently classify the same species in the exact same way. To further explicate this point Marton draws the distinction between inventing an experiment and carrying it out and states "nobody would require different researchers independently to invent the same experiment" (1986, p. 35). Accordingly Marton asserts that this same premise is applicable to the categories of description arising from phenomenographic research.

However while Marton considers replication of the categories of description is unreasonable, he insists that once a category is identified it must be described in such a way that it can be recognised and understood by others. In other words, Marton stresses the need to achieve "a high degree of intersubjective agreement" concerning the presence or absence of the categories of description to ensure other researchers are able to use them (1988, p. 183). As already mentioned in a preceding section I have discussed how intersubjective agreement can be used to establish the communicative validity of research findings, and outlined how it was achieved in this study.

In addition, another question often presented concerns the extent to which research outcomes are generalisable beyond the population represented in the research sample. Marton and Booth (1997) assert that results arising from phenomenographic enquiry are generalisable to groups that would share similar characteristics to the research sample. Continuing this idea, Åkerlind (2003) insists that research findings could also be generalised to groups that shared less similarities with the research sample, but notes that this is likely to be a less inclusive representation of the range of experiences that may be possible. Accordingly I consider that the results from this study, or in other words the range of experiences identified can be expected to correspond with persons who share similar characteristics to the research population investigated.

# 3.12 Ethical considerations

Full ethical clearance of the research tool and data collection process was obtained from the QUT Ethics Committee (QUT Ethics Approval Number 0800000684).

Matters concerning the anonymity of participants and confidentiality of information provided were achieved in following ways:

- Audio recordings were destroyed once a written transcript was produced;
- Any potentially identifying information was removed from transcripts (e.g., reference to the locality in which a participant resided).

All research participants were informed about complaint procedures in the event of concerns regarding the conduct of the research. This information was communicated prior to the commencement of each interview, and similarly outlined in the Participant Information Sheet.

Prior to the start of each interview participants were informed that all responses were confidential and anonymous. They were similarly advised that the process was entirely voluntary and that they were free to withdraw from the interview process at any time. All participants were asked to sign a Consent Form before commencement of the interview process.

#### 3.13 Conclusion

This chapter has presented phenomenography as the research approach that was selected for this study. It has outlined the key features of phenomenography and detailed how the approach was implemented in the study. In the following chapter I present the study's findings. These findings provide descriptions of the various ways in which people experienced the phenomenon of health information literacy.

# Chapter 4: Findings: Ways of experiencing health information literacy

#### 4.1 Introduction

This chapter presents the findings of this study and is divided into three parts. In the first part, I provide a summary of the study's findings and outline the way in which its results will be presented and examined. The second part of the chapter consists of seven separate sections. These sections articulate the categories of description that describe the critically and qualitatively different ways in which people experienced health information literacy. In the final part of this chapter I present the outcome space for the phenomenon of health information literacy, which depicts the relationships between the categories of description.

# 4.2 Summary of findings

Altogether data analysis uncovered seven qualitatively different ways in which health information literacy was experienced. Taken together, these seven categories constitute the phenomenon of health information literacy. For this study, people experienced health information literacy as:

- Building a new knowledge base (Category 1)
- Weighing up information (Category 2)
- Discerning valid information (Category 3)
- Paying attention to bodily information (Category 4)
- Staying informed about health (Category 5)
- Participating in learning communities (Category 6)
- Envisaging health (Category 7)

It is important to emphasise that not every participant in the study experienced health information literacy in each of the seven ways that are presented. Instead these seven categories present the critically and qualitatively different ways of experiencing health information literacy that were identified among the collective group. Furthermore, it must again be emphasised that each category of description refers to the collective level, and is regarded as an aggregation of the experiences of multiple individuals. As such the categories

denote groupings of a particular way of experiencing health information literacy, rather than groupings of people.

In addition, through the process of data analysis eight dimensions of variation were also uncovered. These eight dimensions are explicated in the table below:

Dimension of Variation	Explanation
Experienced nature of information	This dimension describes 'what' people experienced as 'information' in each category. In other words, it details the way in which information 'appeared' or what was perceived as being 'informing'.
Experienced object of information	This dimension describes 'how' people experienced the 'object' of information in each category. In other words, it describes the way in which 'information' as an 'object' was experienced.
Experienced act of using information	This dimension describes 'how' people experienced the act of using information. It describes the process experience of information use.
Experienced outcome of using information	This dimension describes 'what' people experienced the outcome of using information as. Similar to the experienced act of using information, this dimension also relates to the process experience of information use.
Experienced object of learning	This dimension describes 'what' people experienced as the content of learning in each category.
Experienced act of learning	This dimension describes 'how' people experienced the act of learning in each category. It denotes the way in which learning happens.
Experienced outcome of learning	This dimension describes 'what' people experienced the outcome of learning as. It denotes what ensues as a result of learning.
Experienced role	This dimension describes the primary role that people experienced playing or taking on when using information to learn about health.

Table 2: Dimensions of variation in the phenomenon of health information literacy

It should be acknowledged here that use of the term 'experienced' denotes how each dimension was experienced by people in this study (i.e. the participants). This is in keeping with the second-order perspective that phenomenography assumes, whereby phenomena are investigated through the experience of the research participants, instead of the experience of the researcher. A summary table that portrays each dimension of variation across all seven categories of description is provided in Appendix G.

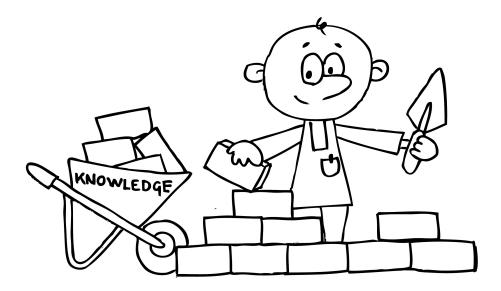
In the following seven sections of this chapter I present and explain each of the categories that were identified in turn.

Within each category I describe the way in which health information literacy was experienced in terms of its referential and structural components. In the preceding chapter I explained that the referential component concerned the overall or global meaning that was assigned to the experience of the phenomenon. For each category presented here, the referential component is collectively described by the category's label (i.e. Building a knowledge base) and the summary statement provided at the beginning of each section.

The structural component is captured through the structure of awareness within each category. It describes the different layers of awareness that are present in each way of experiencing health information literacy, or in other words, the focus, background and marginal aspects of experience. The structural component will be presently directly after the referential component in each category.

The final element presented within each category illuminates the dimensions of variation. These dimensions represent a further layer of awareness that takes the form of recognisable themes or common threads that traverse each category of description. In addition, a summary table that outlines the referential and structural components, and the dimensions of variation is included at the conclusion of each section.

# 4.3 Category 1: Building a new knowledge base



In this category, people experience health information literacy as building a new knowledge base. People's need and desire to build a new knowledge base emanates from becoming aware that an aspect of their health is a matter of concern or needs greater attention. As such

people are actively researching and pursuing information to equip themselves with new knowledge that is considered necessary to contend with or respond to a particular health context. Building a new knowledge base is about gathering information for a new knowledge foundation and developing a comprehensive understanding of a particular health matter.

The following quotation illustrates the meaning associated with this experience:

I'm thinking of a particular instance when I had a bone density test and it was borderline so the doctor suggested that I take Phosomax to stop the loss of bone. So I did quite a bit of research on the Internet about that. I suppose all I really did was Google it and come up with articles about Phosomax and Osteopenia which was what I had rather than osteoporosis. I found articles by medical practitioners, mostly in the US and there were some radio interviews I found from the ABC I think. But I used all that to put together what I thought was some sort of opinion about it. And then I spoke to my friends who were medical practitioners to see what they thought. So I suppose that would be one of the times when I've had to go and do a bit of research about medical issues relating to myself. [Participant 4, p. 1]

#### Structure of Awareness

When experiencing health information literacy as building a new knowledge base people's attention is directed towards a specific health topic, for example a particular medical condition or disorder, or a health related matter such as nutrition or exercise. The focus of this experience towards an explicit health topic is illustrated by the following quotation:

I suppose when I was going through menopause. I sort of looked up to find out what was going on because my peers to whom I am closest to are on the other side of the world, they are overseas. So the ones that I really wanted to talk to are over there. I mean like you can get on the phone and have a bit of a natter or send each other emails but it's not quite the same as sitting face to face. And although I've got good friends here, I didn't have the same ease with them as with people that I had grown up with. So I resorted more to books and the Internet than direct chat. And as my friends have caught up with me cause I'm a little bit older than some of them and some of them have been later than me, then we've talked more. [Participant 9, p. 1]

The background of awareness for this category is comprised of two elements: (i) a particular health context; and (ii) personal presence.

Awareness concerning context refers to the way in which people are experiencing the focus of this category, that is, what the health topic signifies to them. For some situations, this context may be described as 'illness', where people are using information relating to a medical condition or disease they have been diagnosed with, or a medical disorder they are experiencing. Similarly the health context may be described as 'wellness', where people are using information relating to a health matter they wish to focus on in order to improve their health. Examples to illustrate the context of wellness would be topics such as improving diet and nutrition or achieving weight loss.

Similarly, personal presence is also situated in the background of awareness for this category. People are aware that the focus of this experience is pertinent to their personal health. In other words it means 'something' to them and is connected to their health as a human being in some way. As such people are aware of themselves, or rather their presence as an individual in this experience. However, both of these elements, that is the particular context and people's personal self, 'sit behind' the category's focus and as such form the background of awareness.

People's prior knowledge concerning the particular health topic is not an essential part of this experience. Therefore while people may have some prior knowledge about this topic, it is not regarded as being appropriate or relevant for the particular context or situation that people are contending with. In this way, prior health knowledge pertaining to this topic is not seen as being sufficient or useful, and is located in the margin of awareness.

Figure 3 below depicts the structure of awareness for this category:

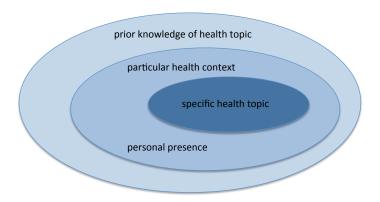


Figure 3: Structure of Awareness - Category 1

#### **Dimensions of Variation**

#### Experienced nature of information

In this category information is described as sources that people can draw upon to obtain information about health. Sources of information include physical, digital or audio-visual forms of information as well as other people. Physical information sources include printed materials such as books, brochures or magazines while digital information sources are described as being various websites that people can access through the Internet. Audio-visual information sources comprise resources such as DVD's and the video-sharing website YouTube. Finally, people are also described as being sources of information and include health professionals such as general practitioners, specialists and allied health professionals. Similarly people that are non-health professionals such as family members or friends are similarly perceived as a source of information in this experience.

Furthermore, the way in which information appears as an object in this experience can be described in two distinct ways: facts and experiences. Information in the form of facts is described as clinical or medical details about a particular health matter, while in contrast, information in the form of experiences are other people's stories, vignettes, or case studies describing that same health matter. However while information may appear in two distinctly different ways, people recognise that both may appear through the same source of information. For example information accessed via the Internet may encompass clinical information about a particular medical condition, but may also include a blog written by a person that is similarly affected by the same condition.

A distinguishing aspect in this category is the diversity of sources that people describe as being information. In other words many things are seen as being information that can be used to build a new knowledge base. Similarly people also draw upon many sources of information in order to build a new knowledge base. This point is illustrated by the interview excerpt shown below:

... in 2005 before I had my first stent put in, I've had four stents put into my heart. I used written information from the doctor's office and also the Internet. My wife got on the Internet and looked it up about stents and heart disease. And that was how I found out about it. And I saw a video about it at the hospital before I had it done which is not real good cause all it does is scare the hell out of you. [Participant 11, p. 1]

Similarly, in the following quotation this interviewee describes various sources of information they drew upon after being diagnosed with mental illness:

The books, one was psychological, it described why people become anxious and what impact that has on them and on their ability to be able to concentrate, think straight, read, relax and do other things. One of the other brochures I got was more psychiatric where it was talking about serotonin uptake inhibitors, things that happen in your head. And it was trying to explain that just because this has happened, doesn't necessarily mean that it is permanent. It was trying to explain chemically why this had happened and how medication might help. But the videotapes were really trying to just see people's experience and go through different sorts of experience where people had been able to improve. Sometimes that was by using medications, other times by physically doing things, exercising, how you exercise, how you eat, how you sleep, all sorts of things. [Participant 14, p. 4]

#### Experienced object of information

When people experience health information literacy as building a new knowledge base information is experienced in a layered or staged manner. In other words, this category highlights how using information to learn about health may span over time as the process of building a new knowledge base unfolds. The unfolding nature of building a knowledge base may be due to the health matter itself in the sense that additional information is needed before greater understanding can be achieved. However it may also refer to the prolonged timespan over which the construction of a new knowledge base concerning a health matter may occur.

The unfolding nature of how information is experienced in this category is illustrated in the passage below. In this example, the interviewee mentions using the Internet on several occasions in regards to lumps they had discovered on their back:

In the past week or so, the past several weeks I have used the Internet several times, I had a couple of suspicious lumps on my back but before I went to the GP I sort of did some preliminary research, basically a Google search you know 'lumps on back' and did some searching about what that could be and what it couldn't be. [Participant 17, p. 1]

When prompted to further explain using the Internet several times about this health matter they then state:

Well it is like different layers isn't it. So initially it is see what it might be in terms of right across the whole plethora of things. So you've got a lump, well what might a lump be. Well the lump could be this or it could be that. And then you go to the doctor and

they say well it can't be that but it could be this. And then you go back [to the Internet] and you look up this. But this could be a, b or c... So each time I went back to the Internet I was refining my search, my Google search. It was a guided refinement of my Google search. [Participant 17, p. 1]

Likewise the following quotation further reveals how people may engage with information about a particular health matter over a protracted period of time. For this example, interview dialogue that reflects the aspect of time is highlighted in bold:

I think probably the very beginning of this was back around about 1983 when I had massive problems with endometriosis and the doctor put me on these special tablets and said the chances that are you're going to put on weight because you are on these and it was the last thing I wanted to do. And I actually immediately said to the doctor what should I do to stop this from happening. He basically told me to cut out sugar and just stick to only 2 slices of bread a day. At that stage I didn't think much about carbohydrates or anything like that. And I did very well actually, I went from 9 and a half stone to 8 stone 3. But I had no intentions of losing weight to that extent I just took what he said so literally that I really started watching what I was doing. But a little bit after that, after I was married and I had (my son), I found those little books about counting calories and things like that. And so I used to follow that for awhile and I looked at how much of things I ate and all the rest. [Participant 2, p. 1]

Furthermore, when people experience health information literacy as building a new knowledge base information is experienced in a kaleidoscopic manner. In building a new knowledge base people engage with a rich and diverse array of health information sources. These sources of information are experienced kaleidoscopically in the sense that they are subject to constant change and highly complex in composition.

## Experienced act of using information

In this category the act of using information can be described as coming to understand a specific health topic in a richer or more comprehensive manner. It is about seeking explanations to answer questions such as 'What is this?' or 'What does this really mean?' or 'What do I need to do?'. To achieve this deeper level of understanding people draw upon and engage with multiple sources of information. These various sources of information help facilitate clarity about the particular health topic or may also further illuminate certain aspects that have previously been explained.

The idea of coming to understand a certain health matter in greater depth is reflected in the interview excerpt shown below. In this example, the interviewee describes using information that their wife accessed online in relation to heart stent surgery and coronary heart disease:

But yeah my wife looked up some information and it just cleared up some questions that maybe the doctor hadn't explained fully to me or the brochures he gave me didn't fully explain. And for some things it just explained it in a different way that I could understand. Just a bit better in terms of what was going to happen in the procedure. [Participant 11, p. 1]

Similarly, this next interviewee's comment also illustrates how the act of using information is experienced as coming to a better understanding of how to improve diet and nutrition:

Well it's not a plan like a menu plan as such, I guess it is just information that I have pulled together that just looks at different food groups, the amounts of those food groups that you should be eating. And also foods to be avoiding. So there is a lot of information there from the Internet and recipes and things that I have been able to use it to follow a reasonably set menu. It's led me to understand better what I should be eating and what I shouldn't be eating. [Participant 15, p. 3]

As a final example, the interview quotation below likewise illustrates how people experience the act of using information. In this example the interviewee's comments reveal how their engagement with multiple sources of information was critical to achieving a more complete understanding of a particular health matter:

Well you hear things and see things and different parts of your brain respond to different things. So there were things that he [a health specialist] talked about where I thought 'Oh yeah I think I understand that', but when I saw the YouTube clip it was more like 'Oh yes I do understand that'. So it's just further reinforcement. [Participant 8, p. 2]

#### Experienced outcome of using information

In this category the experienced outcome of using information can be broadly described as answering people's questions about a particular health topic. However the experienced outcome of information use is also related to the particular context that people perceive the health topic represents.

For example in instances where the health topic reflects a situation of 'illness', that is people are aware that they are 'unwell' in some way, the experienced outcome of information use may be described as coping with or managing the situation. This idea is reflected in the following quotation by an interviewee who describes the experienced outcome of using information in regards to menopause:

I think mostly to put my mind at rest. So saying 'Oh yeah okay it's happening to others'. That's all I wanted to know, that I was going roughly in the same direction as others. The normal direction, if there is such a thing as normal. You've always got a bit of variation within every stage of life but I was wanting to know whether I was within those 'lines'. And that was what that information I got was giving me. [Participant 9, p. 2]

Similarly, this interviewee comments on the experienced outcome of information use following a diagnosis of fibromyalgia:

Well basically at the time I was using information to be able do things that didn't give me pain or to help with the pain, to avoid having pain or stress on the body, changing the whole way that you did things, your attitude towards doing jobs or normal daily living. [Participant 1, p. 1]

Conversely, in instances where the context reflects a state of 'wellness', that is people are looking to improve their health in some way, the experienced outcome of information use can be described as assisting people to strive towards a personal goal. This next interview excerpt illustrates this point. In this example the interviewee refers to the experienced outcome of information use with regards to achieving weight loss:

What I did to start with was I actually set myself out a week's timetable and I did, I wrote down everything I ate through the day. And actually did count up the calories for a day. To see approximately where the amount I was eating came. I think it said a steady diet was about 1200 calories. I actually counted how many calories I was getting for probably about 2 weeks and started cutting down bits here and there and so forth. And it gave me an idea of which foods I was eating did have masses of calories or only a few and things like that. [Participant 3, p. 2]

# Experienced object of learning

In this category, people are learning content that will provide them with comprehensive understanding of a specific health topic. Learning content refers to learning specifically what health topic 'x' is, and the many different aspects or facets that pertain to it.

In other words, when people experience health information literacy as building a new knowledge base the object of learning could also be portrayed as deep or rich knowledge, as opposed to general awareness. This idea could be illustrated as the difference between learning that diabetes is a disease concerning high blood sugar, compared to learning detailed information about this disease, medications used for treatment and related information about disease management with respect to lifestyle or diet.

The idea of developing richer and deeper understanding about a specific health topic is reflected in the interview excerpt below. In this example, the interviewee describes what they were learning when using information in relation to morning sickness during pregnancy:

Well basically what I was trying to achieve was getting most of my minerals and vitamins from my food, not an outside source. My thinking was that I didn't want to live my life getting what I needed from supplements. If you can't get what you need from the food, then there is something wrong with the food you are eating... So it was really about learning about foods, I learnt a lot about food. So I learnt about different nuts and beans and legumes. About different combinations of foods and meats and oils and what they supply you as far as minerals and vitamins. [Participant 16, p. 2]

#### Experienced act of learning

In this category the way of learning can be described as the practice of researching. In other words learning happens through actively investigating and exploring various sources of information to learn about a specific health topic.

The notion of learning through doing research is reflected in the interview excerpt below. Here the interviewee's comments reflect how they explored a variety of information sources in order to learn about a particular health matter:

You see when you first find out it hits you pretty hard. So that extra information helped me handle it. I was never in denial or anything and I've handled it my way. And the more information you have about anything, the better informed you are, the better you

can handle it. That's the same for any situation whether it is a medical thing or anything else. So I just got all the information I could from the internet, newspaper articles and the doctor's surgery and talking to my GP and my oncologist. [Participant 11, p. 5]

Furthermore, while the way of learning in this category occurs through actively researching information, learning may also happen in a serendipitous manner. That is, in the process of investigating and exploring various sources of information people may come across other information that relates to the same health topic of interest. This aspect of serendipity is illustrated in the quotation below:

So when you are kind of searching for something you often end up coming across people who are the same, you filter into streams where other people are also interested in that type of thing. So because I was looking for something to help me with that I happened to come across people who were informative. People who told me that I had to have a combination of potassium and magnesium and to make sure you are eating when you are taking these things because you need other types of vitamins for those types of vitamins to be absorbed. [Participant 16, p. 2]

## Experienced outcome of learning

In this category, the experienced outcome of learning can be described as the construction of a new knowledge base relating to a specific health matter. This knowledge base represents a new foundation of health information that provides people with a comprehensive understanding of specifically what health matter 'x' means.

Furthermore, in creating a new knowledge base people become aware of different information sources they can draw upon at a future point in time if or when further information is needed about this same matter. For this reason, awareness of information sources can also be described as an experienced outcome of learning in this category.

### Experienced role

In this category, people's experienced role when engaging with information for building a new knowledge base is being a researcher. In order to build a new knowledge base people are aware of needing to pursue information that will help them to achieve this. For this reason people perceive themselves as researchers that are gathering information and identifying information sources that will bring about a new body of health knowledge.

This point is illustrated by the interviewee's statements shown in bold below:

I've actually had some cardiac problems, I'd been to a cardiac specialist, and I subsequently found out that his bedside manner and social skills weren't really good. So I find it really hard to talk to the guy and ask him information and he was very reticent But he told me to take these particular pills, which I started taking and they made me feel terrible. So obviously the first thing I wanted to do was find out and research why I was taking this medication, what it was supposed to do, what the side effects were and what would happen if I stopped taking them. So I went onto the internet and just did a Google search on the name of the drug and also some investigation on the condition itself. So I found all sorts of interesting information ... and there's always links to something else, so you can spend hours trawling and researching by following links and things like that. [Participant 12, p. 2]

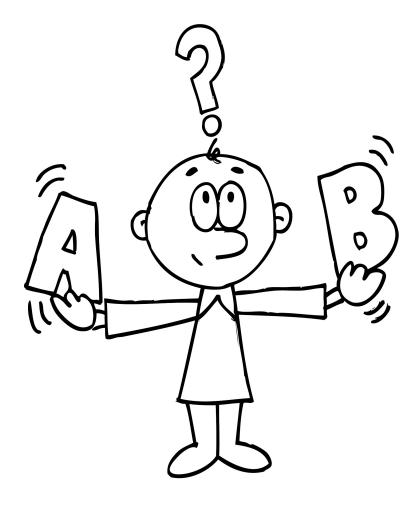
# Summary

Table 3 provides a summary of Category 1, where health information literacy is experienced as building a new knowledge base.

	Category 1: Building a new knowledge base				
Key quote	I'm thinking of a particular instance when I had a bone density test and it was				
	borderline so the doctor suggested that I take Phosomax to stop the loss of bone. So				
	I did quite a bit of research on the Internet about that. I suppose all I really did was				
	Google it and come up with articles about Phosomax and Osteopenia which was				
	what I had rather than osteoporosis. I found articles by medical practitioners, mostly				
	in the US and there were some radio interviews I found from the ABC I think. But I				
	used all that to put together what I thought was some sort of opinion about it. And				
	then I spoke to my friends who were medical practitioners to see what they thought.				
	So I suppose that would be one of the times when I've had to go and do a bit of research about medical issues relating to myself. [Participant 4, p. 1]				
Meaning	Using information to learn about health is about gathering information to build a				
	new knowledge foundation and coming to a more comprehensive understanding about a particular health matter.				
Structure of	Focus	specific health topic			
Awareness	Background	particular health context; personal presence			
	Margin	prior knowledge of health topic			
Dimensions of	Variation				
Information	Experienced nature of	information sources; facts and experiences			
	information				
	<b>Experienced object of</b>	layered or staged manner; kaleidoscopic			
	information				
	Experienced act of using	developing comprehensive understanding			
	information				
	<b>Experienced outcome of</b>	answering questions; contextually dependent			
	using information				
Learning	Experienced object of	comprehensive content about a particular health topic			
	learning				
	Experienced act of	the practice of researching			
	learning				
	<b>Experienced outcome of</b>	construction of new knowledge base; awareness of			
	learning	information sources			
Role	Experienced role	Experienced role researcher			

**Table 3: Category 1 Summary** 

# 4.4 Category 2: Weighing up information



In this category, people experience health information literacy as weighing up information. People are aware of needing to make a decision that concerns treating or attending to a specific health matter. For this reason people are using information to learn about different options available to care for this aspect of their health, along with the associated costs, risks, benefits and potential outcomes. Weighing up information is therefore about using information to consider what options are available for health care, and to choose a particular path or approach to follow.

The following quotation illustrates the meaning associated with this experience:

Probably when I had my knee operation. Obviously I asked a lot of questions of the doctor. I didn't think he gave me enough and I didn't really have a lot of time to make a decision. I looked on the Internet. I also asked a friend because I knew her sister had had the same operation as well...Basically to find out if it was going to be worthwhile or is it going to be something that you pay a lot of money for and go through a lot of trauma but get little results in the end. [Participant 2, p. 1]

#### **Structure of Awareness**

When experiencing health information literacy as weighing up information people's attention is directed towards becoming aware of the different options available for dealing with a particular health matter. The focus of this experience towards various options that may be available is illustrated by the quotation shown below:

Well they pretty much knew what it was straight away. They just x-rayed it and basically checked it. Did an ultrasound on it to check that what they thought it was, was actually what it was. That was basically it. And then after that I got some treatment for it, which was like cortisone injections over a period of about 4 or 5 months. It's still not 100%, but it's a heck of a lot better than what it was. And I was also offered some other options, like having it operated on. But I decided to go for the simpler options first, like operation as a last resort. [Participant 15, p. 1]

The background of awareness for this category comprises two elements: (i) personal presence; and (ii) the quality of information and the quality of the information source.

Awareness of personal presence refers to people's understanding that their engagement with information is connected to care or treatment of a personal health matter. As such there is an awareness of self in this experience whereby people recognise there will be a resulting impact on their wellbeing that arises from information use.

In addition, people are aware of the quality of information and the quality of the information sources they are engaging with. People are mindful that information is being used to make a decision relating to their personal health care, and for this reason they are aware that both aspects need to be considered in terms of whether they are perceived as trustworthy and authoritative for the purpose of decision-making.

However each of these elements reside behind the focus of this category, that is, health care options, and therefore form the background of awareness.

People's existing knowledge about the particular health matter resides in the margin of awareness for this category. Existing knowledge concerning a specific health matter provides contextual understanding for engaging with information that relates to options for treatment or resolution of that same matter. Therefore while knowledge about the specific health matter is necessary for the purpose of making a decision, it provides a background of understanding against which other kinds of information are considered. For this reason it is located in the margin of awareness.

Figure 4 below depicts the structure of awareness for this category:



Figure 4: Structure of Awareness - Category 2

#### **Dimensions of Variation**

## Experienced nature of information

In this category the experienced nature of information can be described in two distinct ways: facts and experiences. In other words, information appears as an object in either a factual or experiential way. These two kinds of information are synergetic in the sense that both are essential when people experience health information literacy as weighing up information.

The idea of combining two different kinds of information is illustrated in the following quotation:

The information from the doctor – the diagrams and things like that, it didn't really make it clearer about the effect it would have on my wellbeing I suppose. The doctor just tells you the clinical side or technical side of what they were doing, rather than how I would feel after. Like he told me that I wouldn't be in as much pain, but that doesn't tell you whether you'll be able to walk. Like I asked the doctor if I would be able to play sport or tennis again, and he really just shrugged that off and said we would have to wait and see. But I wanted to know what I was going to be able to do after, whether my lifestyle was going to change. He really just gave me the information about the operation itself rather than the type of lifestyle I could expect after. [Participant 2, p. 3]

Facts are described as information that is technical, clinical, statistical or monetary information. Technical information is perceived as the 'hard facts' of a particular health procedure as shown in the interview excerpt below:

I suppose it is more to do with the nitty gritty of what they are going to do to you. I suppose I just like to know pretty clearly, specifically what they are going to do. [Participant 2, p. 2]

While clinical information is described as results from medical tests:

... I went and saw [name] down at Hearwell. He did a test and confirmed there was a problem. [Participant 13, p. 1]

In other instances factual information appears in a statistical form, such as the success rate for a particular surgical procedure, or the percentage of operations where complications are encountered. Evidence of this point is highlighted in bold type below:

I also used information once when I had to have a medical procedure and I wanted to find out what the success rate of the procedure was like, or what the problems could be in doing the surgery, the complications. [Participant 17, p. 5]

Finally, monetary information is another type of factual information that appears in this experience. When weighing up information people need to consider costs that may be connected with different options that are available. For this reason, details concerning the financial implications of different decisions are seen as being another way that information may be constituted in this experience. This idea is reflected in bold type below:

Like a few years ago, I started suffering from vertigo. And after a lot of trials and we couldn't work out what was happening he [the doctor] suggested strongly that I have this device implanted in my chest. But he didn't insist I do this and it having this device implanted was going to cost us some money. And in the end I decided yes based on the amount my health fund would pay, I could not have afforded to do it without that sort of backing... And if I have a choice then that choice will be based on money as well as costs and benefits. [Participant 14, p. 10]

Conversely the character of information in this experience may also be experiential in nature. This kind of information is constituted as other people's stories about a particular option they chose for treating or resolving a health matter. An example of this would be listening to people's experiences of undergoing a particular surgical procedure to learn about possible side effects, their views on whether they experienced a beneficial outcome, and if this had been a good decision for their health care. This point is reflected in the interview excerpt below:

Well the Internet was very clinical but talking to someone else was more about personal experience. Because not everybody has the same reaction to the operation or the same benefit. It was good to talk to someone who had had it done [knee surgery] but also to know how much she was allowed to do after and when she was allowed to start exercising or walking. And 6 months down the track what she was like. [Participant 2, p. 2]

Although the previous quotation illustrates that this type of information appears in an oral fashion through conversation, the next quotation shows how experiential information may also be accessed in textual form via the Internet:

...if you know specifically what an operation is you can type it straight in and see the risk factors and the benefits and read up on some of the people who have written in later about what their experience has been. [Participant 2, p. 2]

## Experienced object of information

When people experience health information literacy as weighing up information, information is experienced in a reflective manner. In other words, people examine and contemplate information in an introspective way to ascertain what it may mean for their own personal situation.

The following quotation is provided to illustrate this point. In this example, the interviewee is discussing using information in regards to making a decision concerning knee surgery. The statement shows how information is reflected upon in an 'inward-looking' way, to consider what it meant for personal wellbeing, and whether to proceed with surgery at a particular point in time.

The main thing was whether I wanted to go through 6-8 weeks of not being able to stand up. That's not something that you do lightly. So I thought do I just live with this for the short term and go for a major operation later on. Or do I have this operation and give myself another 10 years before I have the big major knee replacement. So I guess it did help me make the decision to do it sooner rather than keep waiting. [Participant 2, p. 2]

## Experienced act of using information

In this category, the act of using information is experienced as weighing up different pieces of information to contemplate various options available for treating or resolving a health matter. By weighing up information, people's understanding about what each of these options means for their personal health and wellbeing deepens, as does their awareness of what the advantages and disadvantages of each option may be.

The idea of weighing up information and considering the advantages or disadvantages of different options is evident in the interview excerpt below. In this example, the interviewee refers to a conversation with their general practitioner about the 'pros' and 'cons' of surgery as an option for treating shoulder pain. In this instance the interviewee decides to pursue a non-surgical response, however their statement reveals how this decision was based on consideration of other options that were available, and the potential consequences of that choice:

Well it was based on what he [doctor] told me, all the pros and cons for and against surgery. So like we could do the surgery and it might not work. We could nick something and it might cause further damage. You would have to have your shoulder strapped up for twelve months. So basically it was try these cortisone injections and they might just work. [Participant 15, p.2]

## Experienced outcome of using information

In this category the experienced outcome of using information can be described as informing a decision-making process. That is it assists in helping people determine what decision to make with regards to different options or choices to deal with a particular health matter.

This point is illustrated in the interview excerpt shown below. In this example, the interviewee's response illustrates the experienced outcome of information use to inform a decision regarding surgery for carpal tunnel syndrome:

**Researcher:** And thinking about all the different sources you have talked about, talking to friends, talking to the specialist, YouTube and things you found on the Internet. Can you think of a way to describe how you actually used all of the information?

Interviewee: It helped me to determine whether I would proceed with the procedure. That was it. It was part of my decision making process as to whether I would go ahead and have the operation done or whether I would just put up with the tingling fingers for the rest of my life. [Participant 8, p. 3]

Similarly in the next example, this interviewee's statements in bold collectively shows the experienced outcome of using information as helping to inform the choice of surgeon to undertake a particular medical procedure:

And I used that information to inform myself so I could ask the surgeon that I was planning to get to do my surgery what their history in doing this type of procedure was like... I suppose it was like a "What's your score, how well are you travelling on this son?" type of question. [Participant 17, p. 5]

In the same way, the experienced outcome of information use may also help reinforce or confirm a particular path people are considering for a health matter. The interview passage shown below illustrates this point:

**Researcher**: In making that decision around the hearing aid – you mentioned that you had looked online – can you tell me a bit more about that?

Interviewee: I did that after I went to see the audiologist. And he recommended the Unitron, but he told me the names of a few others and told me to look at them on the Internet. So I looked at them using Google.

**Researcher**: So can you describe how you used that information you found on the Internet?

Interviewee: Well I supposed it reinforced what he said, and the brochure he gave me in terms of what the hearing aid did. There was more information about that particular brand on the Internet so I could look at it and confirm that it would meet my needs. The information I got from the web and from him reinforced my decision and that this was the way to go. [Participant 13, p. 2]

As a final example, this interviewee's statement in bold also provides evidence of the experienced outcome of information use as reinforcing a decision regarding treatment or resolution of a health matter. In this instance, the interviewee mentions conversing with another person who had undergone the same type of surgical procedure they were considering having performed:

So it probably made me feel a little more confident that I'd chosen the right way to go. Someone like her – I didn't really know her but she was really friendly and open. So that really gave me confidence that I'd made the right decision and I knew it was up to me to help myself as well, not just expect it all to happen without me putting in some effort as well. [Participant 2, p. 2]

### Experienced object of learning

In this category people are learning about the costs, risks, benefits or potential outcomes that relate to different options for treating or resolving a particular health matter. In other words, when people experience health information literacy as weighing up information, they are

learning about answers to questions such as 'What are the costs involved?', 'What are the risks?', 'What are the benefits?', 'What are the potential outcomes?', 'How will doing this make me feel?' or 'Will this meet my needs?'.

Therefore, in this experience people are learning details that are associated with a health matter, rather than about the health matter itself. For example, rather than learning about hearing loss and what causes hearing loss, people are engaging with information to learn about different options for treating hearing loss. This might include learning about different types of hearing aids that would suit their needs, the financial costs of each, and specific advantages and disadvantages of particular brands or models.

The idea of learning details that are associated with a health matter is illustrated in the quotation below. In this example, the interviewee makes a distinction between information concerning heart disease compared to details regarding risks or potential side effects of surgery for heart disease. The text shown in bold particularly emphasises this point:

Well I had to go and see the [heart] specialist and he had a whole pile of literature to read about the procedure that was going to happen. And you had to virtually read all of that. I think from memory there was some that I had to read and actually sign that I had read them. Not the information ones but the ones that tell you about the risks and the side effects from the procedures you were having done. [Participant 11, p. 1]

In the same way this next example provides another illustration about the content of learning in this experience. For this interviewee, the content of learning concerns details of a surgeon's success rate in performing a particular operation along with complications they had previously encountered in undertaking the procedure.

So I was asking them about their success rate in doing this procedure and what complications they had encountered. [Participant 17, p. 5]

As a final example, this quotation shows how the content of learning may also relate to the potential outcome of a certain option. Here the interviewee makes reference to a conversation with their doctor about the potential outcome of surgery for varicose veins, discussing the degree of improvement that may be experienced, and the likelihood of less successful or unsuccessful outcomes:

So the information I guess I took on board was hoping that that would be the final outcome. He said [the doctor] that if I had these veins done in 50% of cases they find a huge improvement. And I thought 'Well let's hope I'm in that 50%' kind of thing. So the

information that he gave me I guess I took on board what he said but I also wasn't going in there thinking 'This is what he said and everything is going to be fantastic.' I didn't believe everything he said and that I'd be in that percentage where everything would be rosy. So I took on board what I hoped but also was aware that I may be somewhere different at the end of the operation, or have a different outcome. [Participant 2, p. 8]

## Experienced act of learning

In this category the way in which people are learning can be described as contemplating various details and reflecting on what they signify for people's personal wellbeing. In other words, people are considering information that pertains to different health care options and thinking about the potential impact of each of these for their personal self.

The following passage illustrates this point where the interviewee is discussing the statistical risks relating to heart stent surgery. This statement reveals reflection upon the probability of the surgical procedure encountering complications, as well as whether consent to undergo the procedure itself should be given:

You know if you read the risks and you believe them, you wouldn't have it done. You wouldn't because you would think 'that's just scary'. Like with the stents, 1 in 1000 patients die, 1 in every 500 have a stroke, 1 in 300 have a heart attack. And I'm thinking, 'When was the last bloke, am I patient 300 or am I patient 1?', 'Are we starting again?'. If you read it and you start to believe it you think 'oh no'. But then you think 'I've got to have it done'. [Participant 11, p. 1]

### Experienced outcome of learning

In this category the experienced outcome of learning can be described as making a decision to select a particular option for treating or resolving a health matter. The decision is the result of learning about the costs, risks, benefits and potential outcomes of options available and then collectively contemplating these details and reflecting on their significance for personal wellbeing. In other words, people's experienced outcome of learning could be described as 'choosing to do x'.

### Experienced role

In this category people's experienced role when engaging with information is being an empowered and informed health care consumer. That is when weighing up information for

making decisions about choices for health care, people are aware of their need to be informed, and are therefore engaging with information so as to participate to the best of their ability.

The idea of being an empowered an informed health care consumer is reflected in the interview quotation shown below:

I think information is a powerful thing. It can be frightening but it also empowers you with knowledge that you didn't have prior to accessing that information. And you are able then to better inform yourself if you have got to go to a doctor or you've got to go back to a specialist or you've got to undergo surgery. You know that saying 'God helps those who help themselves'? If you don't turn around and investigate and make those enquiries, you owe it to yourself to investigate and ask questions. [Participant 21, p. 6]

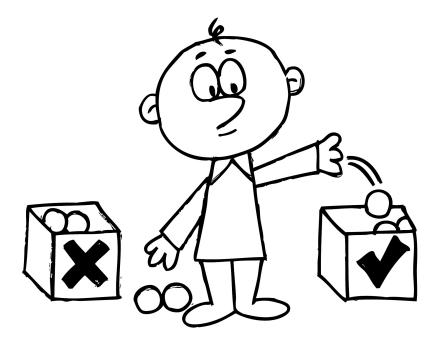
# Summary

Table 4 provides a summary of Category 2, where health information literacy is experienced as weighing up information.

	Category 2: Weighing up information				
Key quote	Probably when I had my knee operation. Obviously I asked a lot of questions of the				
	doctor. I didn't think he gave me enough and I didn't really have a lot of time to				
	make a decision. I looked on the Internet. I also asked a friend because I knew her				
	sister had had the same operation as wellBasically to find out if it was going to be				
	worthwhile or is it going to be something that you pay a lot of money for and go				
	through a lot of trauma but get little results in the end. [Participant 2, p. 1]				
Meaning	Using information to learn about health is about considering what options are				
	available for health care and choosing a particular path or approach to follow.				
Structure of	Focus	health care options			
Awareness	Background	personal presence; quality of information; quality of			
		information source			
	Margin	knowledge of specific health matter			
Dimensions of V	Dimensions of Variation				
Information	Experienced nature of	facts and experiences			
	information				
	Experienced object of	reflective or introspective manner			
	information				
	Experienced act of using	weighing up information to contemplate various			
	information	options			
	<b>Experienced outcome of</b>	informing a decision-making process			
	using information				
Learning	Experienced object of	costs, risks, benefits and potential outcomes of			
learning		available options			
	Experienced act of	contemplating various details; reflecting on			
	learning	significance for personal wellbeing			
	<b>Experienced outcome of</b>	making a decision			
	learning				
Role	Experienced role	empowered and informed consumer			

**Table 4: Category 2 Summary** 

# 4.5 Category 3: Discerning valid information



In this category people experience health information literacy as distinguishing 'useable' or 'real' information that they can use to learn about health. People understand that not all information is 'equal', that is they recognise that there can be different biases or motivations underlying information about health. In the same way people appreciate that information will not always express the same viewpoint or provide the same advice, and that there can be inconsistencies or conflict between different pieces of information. Discerning valid information is therefore about sifting or filtering information, that is, understanding what is 'real' or 'authoritative' information and to differentiate this from information perceived as 'rubbish'.

The following quotation illustrates the meaning associated with this experience:

So how authoritative it is, is probably how I go about working through whether or not what they are saying makes sense. If I go to look it up on the Internet, I don't just go to the first place. It doesn't matter if that first place says Bayer or Wikipedia or whatever. Because you don't always know what is behind it. Whether it is well-intentioned nonsense, absolutely stupidity or somebody trying to make some money. You know there are a lot of well-intentioned idiots and some of them write very well. So I am looking for recognised people coming from recognised places. Things that are reputable. [Participant 14, p. 11]

#### **Structure of Awareness**

When experiencing health information literacy as discerning valid information, people's attention is simultaneously directed towards the quality of information and the quality of the source through which information appears. Collectively people are focussed on these two aspects to perceive whether (i) it represents good quality information and (ii) it is personally usable information.

The following quotation is provided to illustrate the focus of this experience:

Well first of all, the articles that you find using Google, you've got to make some sort of assessment on where the information has come from. Like the Mayo Clinic I've found is a reputable website. But if you just find some article that's not attributed somewhere, well you've have to take that with a grain of salt and give the reputable sources more weight than the disreputable ones or the non-attributed ones. [Participant 4, p. 1]

The background of awareness for this category is comprised of two elements: information overload and information bias.

In regards to information overload, people recognise that they live in an information rich world and while the abundance of information relating to health is considered an asset, people are aware they cannot take in or use the total amount of information that exists. Furthermore people understand that not all information will express the same viewpoint or provide the same advice and therefore differentiating between different pieces of information is imperative when using information to learn about health.

In the same way people are mindful of information bias, that is they are aware of needing to consider different motivations that may be present within or underlie information relating to health. Together these two elements provide a situational understanding that enables the category's focus to be discerned. For this reason they form the background of awareness in this category.

People's personal health knowledge, that is, what they already know about health is in the margin of awareness. In this instance, people's existing knowledge about health helps to facilitate their understanding of new information. However their attention is more heavily directed towards awareness of information overload and information bias as part of contending with their information world.

Figure 5 below depicts the structure of awareness for this category:

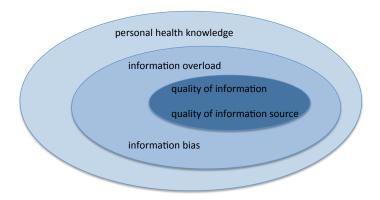


Figure 5: Structure of Awareness - Category 3

## **Dimensions of Variation**

# Experienced nature of information

In this category, people describe information as something that exhibits or comprises particular qualities. People characterise these qualities in various ways using labels such as reputable, real, right, accurate, authoritative or valid.

This idea is illustrated in the interview quotation shown below. In this example the interviewee discusses using information in relation to carpal tunnel syndrome:

...so I got on the Internet and looked up all the stuff. There seemed to be two major sources on the website – one from the UK and an American based one. And they both looked fairly authoritative in their field. There's lots of funny things on the web but those I could identify as being fairly authoritative. [Participant 8, p. 1]

In the same way, the above quotation also reveals how some information may be perceived as 'funny' in the sense that it is information people regard as 'poor', 'bad' or even 'rubbish'. This next quotation similarly illustrates how people distinguish information by different qualities that they consider it displays:

But in my current job, ... I work [in IT] and our database is shared with the hospital. So if I wanted to know something about rubella, unlike everyone else who has to look it up on the internet and then try and work out what of this is real and what of this is rubbish, I get to jump straight in to the same info that the doctors get. And although I might not understand all the background, at least I am not going to get what is fundamentally an ad, or some lunatic's view. This is going to be pretty much along the same lines as the

doctor who would be treating me. So it is likely to be right even though it is not information that is as easy for other people to get. [Participant 14, p. 7]

Information is also seen as being something that has to be suitable for people's needs and situations. In other words people recognise that information can be 'true' or 'correct' but not appropriate for their particular circumstance. The interview excerpt below provides evidence of this understanding:

Interviewee: Like if I had a bung knee or arthritis – well I'd probably have a look on the Internet and have a bit of a think about it. But then I'd also think that I really needed some information, some genuine or positive information from a specialist.

**Researcher:** Can you think of a way to explain that further for me?

Interviewee: Probably because I trust them more and trust that the information they give me is the right stuff. There's a stack of stuff on there [points to computer] and it might be true, but it may not suit my needs or situation. [Participant 13, p. 2]

Finally, people also describe information in this category as something obtained from a source they perceive as trustworthy. This idea is reflected in the following interviewee's statement where they discuss receiving a recommendation for a particular surgeon from one of their friends:

And then of course there was the recommendation I got from a friend to a surgeon. So I took that name to my GP and he looked into that name for me and confirmed that the surgeon was good. He also told me that they had a long waiting list. And the surgeon recommendation itself from my friend, well it was someone that I trusted. So it was the standing of the friend that made the information they gave me important and valuable. [Participant 8, p. 2]

## Experienced object of information

When experiencing health information literacy as discerning valid information, information is experienced in a filtered or sifted manner. People are aware there is an abundance of information they can use to learn about health, but equally that it is not possible for them to 'know' or 'take on' every piece of information. For this reason, people contend with the reality of living in an information rich world by filtering and sifting information about health. In other words, people are mindful that they need to be aware of what health information they 'take on board'.

The passage below provides evidence of how the object of information is experienced in this category:

Some information you get about any illness you have to take with a grain of salt. You know that saying, you've got to learn how to sift the chaff from the hay. You've got to learn to make up your mind about whether you believe everything you hear, but you can't believe everything you hear or you'd go nuts. You learn to sift it out a bit. Like that's feasible, that's rubbish or that sounds really good. And you sort of just in your own mind you tend to work it out. You can't believe everything. [Participant 11, p. 7]

# Experienced act of using information

In this category people experience the act of using information as taking notice of the background behind health information and being mindful of any biases that may be present. In other words, people recognise that health information can have a 'hidden agenda', particularly when information is embedded with promotion or marketing for a health related product or service.

The following quotation provides evidence of people's understanding of how information relating to health may be biased by motivations to sell a particular product or service and consequently not always provide the 'true' story. In this example the interviewee's comments to reflect this point are shown in bold:

But it worries me that sometimes they promote certain brands like Swisse Multi – it seems to be this big thing on the TV at the moment I'm finding and I'm thinking 'Oh I don't know, I've taken multi-vitamins before for 12 months and it's done nothing - I don't feel like I'm going to jump out of my skin or anything'. So I'm getting very sceptical of these sorts of things now. But then I think well maybe I should go and see a nutritionist or the dietician would that be better. But then I think no, I think we lead a balanced lifestyle. So I sort of absorb it, but then I throw a lot of it out. And I often think 'Oh yes, I think they are just trying to sell the product'. [Participant 5, p. 3]

In addition people also recognise that information relating to health may not provide the 'full' story and so they need to be mindful of ascertaining information that may be withheld or hidden. This idea is reflected in the interview excerpt below where the interviewee is discussing information relating to the proclaimed results of following a particular diet. In this example dialogue to emphasise this point is highlighted in bold:

The confusing ones are ones where for instance like as I said they put these menus up and show you this person that used to look like this and now looks like this. And you look at them and you say yeah okay and she's got make up on and everything now and a she's bought a nice dress and the whole bit so that really helps her. But the confusion is they don't give you a background to what else has to be happening for this to be successful. So they're giving you some of the information and not all of the information. [Participant 2, p. 5]

However in contrast people also recognise that information relating to health may not always be embedded by motivations to market particular products or services, in other words, health information may also be provided for purely altruistic reasons. This understanding is evident in the example shown below. In this instance the interviewee's comments refer to various websites they discovered that provided information for treating a particular health matter:

A lot of them were just selling products. And that wasn't what I was after, I was after real information. And some of the sites seemed to be sponsored by medical associations of some form or other and I find that they are very useful. So there were a couple that I found which seemed to be written by medical specialists, who knew what they were talking about instead of someone who was trying to sell something. So they provided some information but then said things like 'see your GP for further information' so I didn't get the sense that I was trying to be sold anything. It was just information. [Participant 8, p. 3]

Finally people also recognise that information may also be influenced by different philosophies or approaches to health and health care. This point is demonstrated in the next passage where the interviewee is discussing health information concerning treatments for menopause. This statement reveals awareness and understanding of wanting information that is grounded by scientific evidence and evaluation:

I'm a bit of a sceptic about a lot of these weird sort of, well that's a bad word, alternative health practices that aren't scientifically based. The one I am thinking of in particular is natural hormone replacement therapy that hasn't been scientifically evaluated. So I suppose what I would be tending to look for was finding out information for health outcomes that are scientifically based and that can be properly evaluated. [Participant 4, p. 8]

# Experienced outcome of using information

In this category people experience the outcome of information use as distinguishing information that is valid and useable. In other words, people perceive certain information to be 'true' as well as relevant to their personal needs and situation.

Furthermore the 'use' or 'application' of information is experienced in a contextually dependent way. That is in some instances people may use or apply information in an immediate or imminent sense, however it may also be something that people 'take on board' to use at a future point in time.

# Experienced object of learning

In this category people are learning about evaluating information. This could also be described as learning to understand particular qualities that make information 'good' or 'bad' or 'usable'. Therefore the content of learning in this category refers to learning how to ascertain the value of information, as well as different aspects to consider or be aware of when using information about health.

### Experienced act of learning

In this category the way in which people are learning can be described as comparing and contrasting information about health. In other words, people are examining different pieces or items of information to consider what is trustworthy and authoritative.

This idea is reflected in the interview quotation below. In this example the way in which learning occurs is reflected in the interviewee's comments as they discuss engaging with health related information on the Internet:

Well, trying to understand the information and trying to get a sense of how valid it is I suppose. So you'd look over a range of websites to see if you can get corroboration, get a thread running through it that seems to have some validity, because you never know what you're going to read on the Internet. I suppose you read some really outlandish claims, so you want to get a sense that there is some validity to some of that, some of those claims. So I suppose if you get something that seems to have more of a scientific bend to it you might find that's more valid than just individual anecdotes. [Participant 10, p. 7]

As a further example this next quotation similarly provides evidence of the way in which learning occurs in this category through comparing and contrasting information:

There's a lot of repetitive information out there, you can look up a particular subject and there's just masses, huge amounts of information, but very repetitive. But I guess if you find that it is repetitive it's probably right rather than finding some site that tells you something and then not having it confirmed in other places. There's an awful lot of rubbish out there on the Internet as well as good factual information. If something is reiterated on 3 or 4 sites then you'd probably find it is reasonably accurate.

[Participant 12, p. 2]

[1 articipani 12, p. 2]

# Experienced outcome of learning

In this category the experienced outcome of learning can be described as the adoption or dismissal of information that is used to learn about health. People identify or determine that certain information is valid and can therefore be 'taken on board'. In contrast, information that is not perceived as valid is discounted or dismissed. The following interview excerpt illustrates how the outcome of learning is experienced when discerning valid information:

But I've also learnt over the years to look at these things, throw out what you don't like, or what you don't think is appropriate, take hold of the stuff you do, maybe some of it the next time you go to your doctor or your physio say 'Look I've read this information what you do reckon about this or would it help me in any way?'. So I think I've probably been a person that's done that. [Participant 3, p. 5]

Continuing this idea, the following quotation also reveals how certain information may be discarded if it is not seen to be valid or true. In this example the interviewee mentions a particular speaker's presentation at a health related support group meeting:

So like there was this one time at a meeting where we had this person who came and talked about this drink they made with herbs and things in it. And I just thought 'I don't believe you', because if it worked, everyone would be kicking your door in. So I just took that with a grain of salt. [Participant 11, p. 7]

# Experienced role

In this category people's experienced role when engaging with information to learn about health is akin to an analyst. When discerning valid information people are aware of the need to inspect information about health in order to contend with the quantity and perceived variation in information quality that is present in their information world. For this reason people regard themselves as analysts that are scrutinising information to ascertain what information they will 'take on board' for learning about health.

This idea is reflected in the two brief interview excerpts provided below:

I like to look and find what I feel is the real information. And all of the cushioning around it I like to just peel away and forget. [Participant 9, p. 6]

I'll have a look at a range of views and see whether there are any coincidences of views or opinions. And where there is a coming together of the ideas, where there is a common thread, I'll form a view that is based on that. [Participant 19, p. 5]

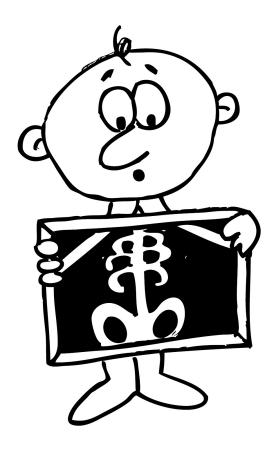
# Summary

Table 5 provides a summary of Category 3, where health information literacy is experienced as discerning valid information.

Category 3: Discerning valid information				
Key quote	So how authoritative it is, is probably how I go about working through whether or			
	not what they are saying makes sense. If I go to look it up on the internet, I don't just			
	go to the first place. It doesn't matter if that first place says Bayer or Wikipedia or			
	whatever. Because you don't always know what is behind it. Whether it is well-			
	intentioned nonsense, absolutely stupidity or somebody trying to make some money.			
	You know there are a lot of well-intentioned idiots and some of them write very			
	well. So I am looking for recognised people coming from recognised places. Things			
	that are reputable. [Participant 14, p. 11]			
Meaning	Using information to learn about health is about sifting or filtering information,			
	understanding what is 'real' or 'authoritative' information and differentiating this			
	from information that is 'rubbish'.			
Structure of	Focus	quality of information; quality of information source		
Awareness	Background	information overload; information bias		
	Margin	personal health knowledge		
Dimensions of '	Variation			
Information	Experienced nature of	something that exhibits or comprises particular		
	information	qualities; suitable for needs and situation; obtained		
		from a trustworthy source		
	Experienced object of	filtered or sifted manner		
	information			
	Experienced act of using	being aware of the background or biases in health		
	information	information		
	Experienced outcome of	distinguishing information that is valid and useable		
	using information			
Learning	Experienced object of	evaluating information		
	learning			
	Experienced act of	comparing and contrasting information		
	learning			
	Experienced outcome of	adoption or dismissal of information		
	learning			
Role	<b>Experienced role</b> analyst			

**Table 5: Category 3 Summary** 

# 4.6 Category 4: Paying attention to bodily information



In this category, people experience health information literacy as paying attention to bodily information. People become aware of changes within themselves in either a physical or psychological sense, which represents information that a particular aspect of their health may need attention. In the same way, changes in how people are feeling may serve to help guide, explain or reinforce how they are using their body. Paying attention to bodily information is therefore about observing and listening to the body to learn about its health.

... when my daughter was small I managed to rip the calf muscle in the back of my leg. I had had twinges two or three days before but had the idea if I just did things gently this would go away. This worked for two or three days until I decided to play a game of tennis, and I lasted about five minutes and then spent the next few weeks on crutches. I know now that over the years that if I stretch properly before I start, the right kind of exercises, well if something starts to hurt, I need to stop and listen to my body. [Participant 3, p. 8]

#### **Structure of Awareness**

When experiencing health information literacy as paying attention to bodily information people's attention is directed towards information from their body. In other words people are focussed on what they perceive as bodily information, which is constituted in different ways.

The focus of this experience towards information from the body is illustrated by the following quotation:

The symptoms for me started at about midnight one night after doing a lot of work out in the yard... But at midnight I got up to go to the toilet. And I'm sitting there and I've got a small pain in my back where your kidneys are. And I'm just thinking that I've pulled a muscle or something because I had been working fairly hard. And I had this feeling about whether I wanted to have a pee or a poo. I wasn't sure as the mind and the body weren't getting along well. And within five minutes I'm on the floor of the toilet and I'm screaming in pain. [Participant 21, p. 1]

The background of awareness for this category is comprised of two elements: (i) prior knowledge of self; and (ii) personal health knowledge.

Prior knowledge of self refers to people's awareness of how the body ordinarily feels as well as people's past experiences with their body that have occurred throughout life. Awareness of this element enables people to distinguish the focus of this experience (i.e. information from the body) as being 'different' in some way to how it is normally experienced.

In addition, people's personal health knowledge also forms part of the background of awareness in this category. This element represents people's accumulated understandings of what they have learnt and experienced in relation to health during the course of life.

Together these two elements provide contextual understanding that enables the category's focus to be discerned and as such they form the background of awareness.

Figure 6 below depicts the structure of awareness for this category:

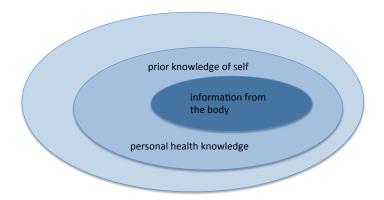


Figure 6: Structure of Awareness - Category 4

## **Dimensions of Variation**

## Experienced nature of information

In this category information is described as physical or psychological changes. Physical or psychological changes signify information about people's present state of health or how a particular aspect of their health may currently be.

There are several different ways in which information may appear in this experience. This includes unpleasant physical sensations such as pain or discomfort; changes in people's physique or a particular aspect of their physique; bodily reactions that are perceived as being different or unusual; and changes in how people are feeling in a psychological sense.

The idea of information as unpleasant physical sensations is illustrated in the interview excerpts shown below. In each instance these statement shows how pain or discomfort represents the experienced nature of information in this category:

I noticed pain in my shoulder. I couldn't recall hurting it at any stage or doing anything to it. But I initially I thought that I had probably just pulled a muscle, something like that. [Participant 15, p. 1]

Aches and pains weren't right. They weren't the same as they used to be. So physically the aches and pains that I was getting were changing, they were getting more intense. Headaches. I could really pick when I was going to get a headache, and I'd never really had major headaches. [Participant 18, p. 1]

Similarly changes in people's physique may also be a form of information in this experience. In this example, the interviewee's comment illustrates how clothing that no longer fits or is becoming tight on the body is characterised as information in the form of physical changes:

It's probably when your clothes don't start to fit you, or things start to get a bit tight, or you start to feel a bit bodily uncomfortable. And then you think 'Oh, I really need to do something about this'. [Participant 6, p. 3]

In other instances, bodily reactions that are perceived as being different or unusual are another form of information in this category. This point is reflected in the interview excerpt below. In this example the interviewee describes observed changes in her daughter's behaviour after consuming sweet types of food. Her comments reveal how her daughter's bodily reactions were perceived as distinctly different to her other two children, and that this difference in bodily response was seen as being information:

Like I can clearly remember the first Christmas we had where [daughter] was able to eat candy and she literally just transformed into another person and bounced off the wall. So that in itself was information, that within minutes of consuming something sweet she was into another world, she was out of control and would be bouncing off the walls. Whereas the other two were very docile children, they could eat candy and it never fazed them. [Participant 16, p. 3]

However although changes in a physical or psychological sense may often suggest a possible health issue or concern, changes may also represent an improvement in people's physicality or psychological wellbeing. For example, a pleasant or improved physical sensation such as a reduction or elimination of pain or discomfort may similarly be perceived as information.

This next quotation is provided to illustrated this point:

Like with the type of work that I do, even though I eat pretty healthy I was starting to get a frozen shoulder and tennis elbow.... and I have learnt that I need to do some particular types of physical exercises to help keep that under control or at bay... So I started doing some boxing, some cardiovascular type of exercise twice a week and I have found that I don't even need to have a regular massage anymore because I have loosened up all the muscles. And I find that type of exercise to be very invigorating, I really enjoy it. It feels good and I have been enjoying it and that becomes information because I realise that I am feeling different, but in a good way. [Participant 16, p. 7]

In a similar way the following interview excerpt also exemplifies this idea. In this example the interviewee had been discussing undergoing surgery for carpal tunnel syndrome. Their comparison between pain experienced prior to surgery and the elimination of discomfort post-surgery shows improved physical sensation as a way in which information may appear:

And the end result as far as I was concerned was very successful. The tingling fingers have gone and I have no issues with my hands. [Participant 8, p. 2]

## Experienced object of information

When people experience health information literacy as paying attention to bodily information, information is experienced in an observational or reflective manner. In other words, this category reveals how bodily information in the form of physical changes is experienced as a process of self-observation whereby people contemplate changes that have occurred to the physical self. Similarly, bodily information in the form of psychological changes is experienced reflectively, whereby people examine how they are feeling in an introspective or inward-looking manner.

The following quotation illustrates this point and provides evidence of how physical changes are experienced in an observational manner:

I went to see the doctor not that long ago actually. I found this small lump behind my ear, which turned out to be a tumour. So that was one of those times where I was quite happy that I am both curious and I do notice things. [Participant 15, p. 8]

Likewise in this next example the text shown in bold illustrates how information in the form of psychological changes is experienced in a reflective manner:

I was at the stage where I had become very, very anxious about nearly everything... I was frightened to go to work because a lot of my attention was to do with workloads and stress levels at work... I couldn't concentrate. I was having real difficulty reading more than a paragraph at a time... I can even remember a time where I knew there was something quite seriously wrong when I would stand on the footpath and think 'If that car blew a tyre and went straight over the top of me, I wouldn't have to worry about any of this anymore'... And eventually I was at work one day and I just broke down in tears. And even I thought that was really, really strange. [Participant 14, p. 3]

# Experienced act of using information

In this category the act of using information is experienced as interpreting bodily information. People recognise that changes in their physical or psychological wellbeing represent information about how their health or an aspect of their health may be faring. As such the experienced act of using information is perceived as a process of interpretation whereby people are endeavouring to deduce whether this can be regarded as a favourable or unfavourable change.

This idea is reflected in the brief interview excerpt below. In this example the interviewee had previously mentioned an instance where they discovered lumps on their back. The statement shown here illustrates the attempt to interpret what this bodily change could mean:

There were no actual symptoms per se, I just knew that that lump shouldn't be there, so what might it be? [Participant 17, p. 1]

Similarly in this next example, this interviewee's comments reveal how they have learnt through past experience to interpret changes in bodily information that may suggest the presence of kidney stones:

I've become acutely aware of the symptoms leading up to having kidney stones manifest themselves and what to look out for whereas before I wasn't... So after all that you become very acutely aware to stop if you are working too hard, like if you are sweating too much... [Participant 21, p. 2]

## Experienced outcome of using information

In this category, the experienced outcome of using information can be described in two ways: (i) prompting or encouraging people's engagement with other sources of health information; and (ii) providing guidance or reinforcement for people's actions or behaviours.

In some situations information in the form of physical or psychological changes serves to provoke or stimulate people's connection or reconnection to other sources of health information. This type of information works as a 'trigger', which instigates interaction with other kinds of health information.

The following section of an interview illustrates this idea. The text shown in bold demonstrates how changes in physique served as a prompt to engage with other kinds of information relating to health:

It's probably when your clothes don't start to fit you, or things start to get a bit tight, or you start to feel a bit bodily uncomfortable. And then you think 'Oh, I really need to do something about this'. And so you might get the information out and start to think 'Oh yeah, I can do 30 minutes a day of exercise, how am I going to fit that into my day?', or 'I could start taking a salad for lunch', those kinds of things. [Participant 6, p. 3]

Similarly in this next example the interviewee had earlier discussed being prescribed with a type of heart medication following diagnosis of a particular cardiac condition. The passage below illustrates how physical and psychological changes stimulated engagement with health information on the Internet as well as consulting their general health practitioner:

I'd been to the [heart] specialist and he had given me the prescription for the medication and I'd started taking them, it really knocked me out and I was like a zombie. I couldn't get out of bed – it was terrible. So I wanted to know what was going on. So I looked up on the Internet, did a bit of research and then I decided basically that I wasn't going to take these things any more. And then I went down to see the GP and confirmed it with him. [Participant 12, p. 3]

As a final example, this interviewee's statements in bold type likewise reflect how increasing pain or discomfort prompt people's engagement with other kinds of health information:

So if it [pain] starts changing your lifestyle for the worse so that you are not enjoying life or you are avoiding certain jobs or not going places because that's going to hurt. Or if you decide I'm not going to go for a walk today because this is really killing me, then it is time to look for more information or go back to a doctor. [Participant 2, p. 10]

Conversely, the experienced outcome of information use may also be described as providing guidance or reinforcement about people's actions or behaviours that impact on health. Here the outcome of using information from the body affirms present actions or behaviours, or directs changes in how people should consider acting or behaving in the future.

The two quotations shown here demonstrate this idea. In both instances, the interviewees' statements reveal how the experienced outcome of using information from the body prompts reconsideration of future behaviour:

I do find I go overboard with things because it's very easy to get involved [in the garden] and do a bit more and a bit more. But then you suffer for it for a few days in recovery unfortunately. So consequently in the long run it doesn't work. If you overdo it,

you end up having to rest for a few days to get the aches and pains under control. So your body is then telling you that you've done the wrong thing. [Participant 1, p. 2]

Like the other day I was up on the roof at home to fix some tiles and seal them off. Now I was using all the proper equipment like a harness and everything but when I came down off the roof my legs were actually shaking. And I was thinking that this didn't happen 5 or 10 years ago and I was also really exhausted after it as well. So even though I had all the right gear and all the right equipment the job was not as easy on my body as it used to be... it is telling me to wake up to myself and stop climbing on the roof. [Participant 21, p. 4]

## Experienced object of learning

In this category people are learning self-awareness of how the body is feeling in either a physical or psychological sense. In other words, when people experience health information literacy as paying attention to bodily information they are learning about tuning in to their own body to answers to questions such as 'What is happening with my body?', 'Why am I feeling this way?' or 'Are things with my body working in the way that they normally do?'.

This idea is reflected in the interview quotation below:

So mostly I'm listening to how I am feeling within myself. My own body. I listen to myself. Sometimes it takes a few knocks on the head before I think 'Wait a minute, that's what's it's all about'... That's my real guiding line, is how I feel myself against other information that I gather ... Truly it has to be how you feel internally. [Participant 9, p. 3]

#### Experienced act of learning

In this category the way of learning can be described as reflecting on physical or psychological changes and contemplating what these may indicate about the body's current health. In other words, people are ruminating over changes they are experiencing or noticing in their body and considering what these may imply.

This idea is demonstrated in the following quotation where the interviewee discusses discovering a lump behind their ear. The interviewee's concluding sentence in bold type shows their reflection on, and awareness of, how disregarding bodily changes may result in adverse health outcomes:

I went to see the doctor not that long ago actually. I found this small lump behind my ear which turned out to be a tumour. So that was one of those times where I was quite happy that I am both curious and I do notice things. Because I am now old enough to know people who have suffered badly unnecessarily... [Participant 14, p. 1]

Likewise this next example provides further illustration of how the act of learning is experienced when paying attention to bodily information. Here the interviewee's statement in bold again shows reflection on differences between their children's behaviour and considering what the cause of this may be:

I don't remember using a lot of information as in information from books or things like that. I really used to just observe [the children], especially the hyperactive one because I was very concerned. And I noticed this problem as soon as she started to eat solid food. So I became very aware of that difference between the children and thinking about what was causing it. [Participant 16, p. 4]

## Experienced outcome of learning

In this category the experienced outcome of learning can be described as identifying a particular course of action to respond to bodily changes. This identified course of action is a reactive measure and refers to different paths or approaches that people elect to follow.

For example, a particular course of action may involve deciding to seek help or advice from a health professional in relation to physical or psychological changes experienced. However a course of action could also be described as recognising how the body should or should not be used in the future. In other words, the experienced outcome of learning when paying attention to bodily information could also be expressed as 'Where to from here?' or 'What do I need to do now?'.

The following quotation illustrates the experienced outcome of learning in this category as identifying a particular course of action. In this example the interviewee's statement in bold shows this as electing to seek professional medical advice:

Well just that I had a sense of what it might be, you know like the worried well. There was no actual symptoms per se, I just knew that that lump shouldn't be there, so what might it be? ... You know I think that after reading a bit about it I decided that I needed to go the GP because it wasn't conclusive. I suppose if I think about it if I had read something that said there was a 99% probability that it was a pimple I wouldn't have worried about it, or waited until the next time I was at the doctor. So it was

probably the lack of clarity, that would be it. So I knew it was time to go to the doctor. [Participant 17, p. 1]

Similarly the text shown in bold below provides a further illustration of this point:

I'd been to the [heart] specialist and he had given me the prescription for the medication and I'd started taking them, it really knocked me out and I was like a zombie. I couldn't get out of bed – it was terrible. So I wanted to know what was going on. So I looked up on the Internet, did a bit of research and then I decided basically that I wasn't going to take these things any more. And then I went down to see the GP and confirmed it with him. Because if I was going to die because I wasn't going to take these things, then I would continue taking them, even if they made me feel bad. But if there were no adverse consequences then I was going to stop using them. [Participant 12, p. 3]

As a final example, these comments below from an interviewee reflect their awareness of several different approaches they could take in response to experiencing weight gain. Dialogue to emphasise this point is shown in bold:

It's probably when your clothes don't start to fit you, or things start to get a bit tight, or you start to feel a bit bodily uncomfortable. And then you think 'Oh, I really need to do something about this'. And so you might get the information out and start to think 'Oh yeah, I can do 30 minutes a day of exercise, how am I going to fit that into my day?' or 'I could start taking a salad for lunch', those kinds of things. [Participant 6, p. 4]

# Experienced role

In this category people's experienced role when engaging with information to learn about health is akin to an interpreter. When paying attention to bodily information people are translating bodily information in the form of physical and psychological changes to ascertain what this means in regards to their health. In this way, people perceive themselves as being an interpreter of 'oneself'.

The idea of being an interpreter is reflected in dialogue shown in bold type below:

I suppose as you get older you become a bit more attune with what you are capable of doing versus what your body is capable of giving you. So it's basically not trying to do things that you would have done when you were 25 or 30 and just tempering what you are doing with a degree of common sense and awareness about what can happen if you

don't. Whether that is kidney stones or you are becoming so tired that you are not capable of doing anything, like exhausting yourself to the point where you don't want to do things anymore and it becomes a task instead of something you enjoy. So it is about creating that awareness within yourself, recognising what your body is trying to tell you and just going with it. [Participant 21, p. 2]

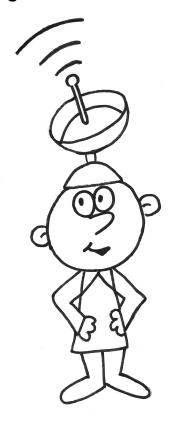
# **Summary**

Table 6 provides a summary of Category 4, where health information literacy is experienced as paying attention to bodily information.

Category 4: Paying attention to bodily information				
Key quote	when my daughter was small I managed to rip the calf muscle in the			
	back of my leg. I had had twinges two or three days before but had the			
	idea if I just did things gently this would go away. This worked for two or			
	three days until I decided to play a game of tennis, and I lasted about five			
	minutes and then spent the next few weeks on crutches. I know now that			
	over the years that if I stretch properly before I start, the right kind of			
	exercises, well if something starts to hurt, I need to stop and listen to my			
	body. [Participant 3, p. 8]			
Meaning	Using information to learn about health is about observing and listening to			
	the body to learn about its health.			
Structure of	Focus	information from the body		
Awareness	Background	prior knowledge of self; personal health		
		knowledge		
Dimensions of	Variation			
Information	Experienced nature of	physical or psychological changes		
	information			
	Experienced object of	observational or reflective manner		
	information			
	Experienced act of using	interpreting bodily information		
	information			
	Experienced outcome of	engagement with other health		
	using information	information; guiding future behaviour		
Learning	Experienced object of	self awareness of the body		
	learning			
	Experienced act of learning	reflecting on physical or psychological		
		changes		
	Experienced outcome of	identified course of action		
	learning			
Role	Experienced role	interpreter		

**Table 6: Category 4 Summary** 

# 4.7 Category 5: Staying informed about health



In this category people experience health information literacy as staying informed about health. People recognise that they need to be equipped with information about health that is relevant to their present or future stages of life. For this reason people perceive the importance of absorbing information that will assist them to continue growing and developing their knowledge about health. Staying informed about health therefore refers to using information over the course of life for the evolution of understandings about health.

The following quotation illustrates the meaning associated with this experience:

... well one of my friends has irritable bowel syndrome. And as you get older your bowel changes and I thought 'Oh, maybe I need to know a little bit more about this', like prostate cancer and bowel cancer. So I started to have a bit of a look on the Internet about it. Not that I have these things, but it's nice to have a little bit of forewarning. So I started to look on the Internet about it, to see if I had any of the symptoms. There's lots of symptoms, but if you look through and if you have 5 of the symptoms you might go and see your GP. Not that I have any of these symptoms so far, but I think it's nice to know that information and that it's there. [Participant 13, p. 3]

#### **Structure of Awareness**

When experiencing health information literacy as staying informed about health people's attention is directed towards absorbing information. In other words, people are focussed on 'taking in' information that relates to health. The focus of this experience towards absorbing information is illustrated by the following quotation:

I think you just pick up information a long the way that you don't realise you get, but you realise later that it is there [points to head]. So you pick it up whether you realise it or not. It's in there somewhere! There's probably some interesting stuff in there really, but you never know what might be useful! [Participant 20, p. 7]

The background of awareness for this category is comprised of two elements: (i) personal health knowledge; and (ii) personal presence.

Awareness of personal health knowledge refers to people's accumulated understandings about health that they have learnt and experienced over the course of life. Although people are focussed on absorbing information, they are aware that by 'taking in' other information it serves to enrich their existing understandings about health in some way.

Similarly personal presence is also situated in the background of awareness for this category. When staying informed about health, people are aware of their presence in this experience as they absorb information that is perceived as being relevant or potentially relevant to their health. In other words, people are aware that they are staying informed about health for their own personal wellbeing.

However although people are aware of these two elements their presence is integral to discerning the focus of this category on absorbing information. For this reason, both of these elements are situated in the background of awareness.

Figure 7 below depicts the structure of awareness for this category:

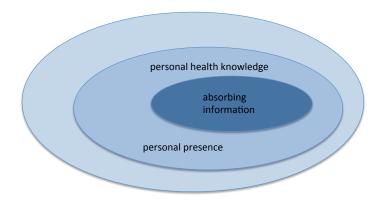


Figure 7: Structure of Awareness - Category 5

#### **Dimensions of Variation**

#### Experienced nature of information

In this category people describe information as details about health that are relevant or potentially relevant to their particular situation or stage of life. In other words people recognise that what they perceive as being information changes over the lifespan to reflect their needs or circumstances.

People appreciate that particular illnesses or conditions are often age related or more commonly experienced in a particular stage of life. For this reason information concerning health is perceived as details that relate to health matters which are pertinent or potentially relevant to people's present and future stages of life.

The idea of information as details that are relevant or of interest to a particular age or stage of life is illustrated in the interview quotation shown below. In this example, dialogue to demonstrate this point is highlighted in bold:

I guess if it is something that I think I could use myself. So I am thinking about whether it is relevant to me. Like somebody might tell you something about babies or children and because I don't have babies or young children anymore it isn't really relevant to me and it is not something that I am going to use. So I suppose that changes over time, what interests you. Nowadays it might be something like where somebody has gone to a particular dentist or a particular procedure they may have had, something new that is available that I think I might need to have in the future. [Participant 15, p. 4]

Similarly, the text highlighted in bold portrays awareness of how interests in health information change over time:

I suppose it is to do with your age and your interests at the time. Like when I was having kids I picked up information about pregnancy and children and toilet training. But then you get older and you are picking up pamphlets on arthritis and diabetes and heart disease. So it is probably more to do with your age, the age bracket you are in. Or if someone you know is going through something with their health and you are wanting to know a bit more about it, to either try and help them or to be sympathetic. But generally it is more to do with me the person rather than just accumulating general health knowledge. [Participant 2, p. 6]

As a final example, the interview dialogue in bold below also provides evidence where information about health is regarded as being health matters of perceived relevance:

... down at the local chemist they have a big box of information leaflets. I don't know whether they like you to pull them out and have a look but I do. You've got to do something while you are waiting. And so I'll pick out something at random and that's always interesting information. But I guess if you see something that is more relevant than idle interest then you'll have a better look at it. [Participant 12, p. 5]

#### Experienced object of information

When people experience health information literacy as staying informed the object of information is experienced in a fragmented manner. The idea of a fragmented manner reflects the extent of information involved as well as the intermittent way in which information is experienced. For this reason the experienced object of information can be described as taking 'ingredients' or 'excerpts' or 'snippets' of information relating to health that people encounter or come across as part of day-to-day life.

The following interview passage provides evidence of the way in which the object of information is experienced in this category. In this example comments to reflect the fragmented manner in which information is experienced are highlighted in bold:

... there's that television show, I think it's called 'You Are What You Eat' or something like. Different shows like this, well now I won't sit down and say 'I'm going to watch this', but I find little excerpts from these sort of shows and 'A Current Affair', I enjoy hearing what's on there, like I don't study 'The Biggest Loser' or any of these things with great interest... I take bits out of them. [Participant 3, p. 8]

Similarly, the text below in bold provides another example of how information is experienced sporadically in the course of daily life. Furthermore the interviewee's use of the term 'vignette' reveals that the extent of information involved is small or limited in quantity:

I like the radio, radio is good. There's a program I like to listen to, I can't think of the name, it's only short, **probably around 5 minutes**. It's done by some fellow with a funny accent and he has doctor at the front of his name, so I think he must be medical doctor, a general practitioner. And his program is just a **5 minute vignette** and he always talks about something that I can relate to, either for myself or for somebody else. So I'll listen in and think 'Oh yeah, that makes sense'. [Participant 8, p. 6]

## Experienced act of using information

In this category people experience the act of using information as collecting and storing information about health. People understand that information about health may not always be useful or needed in an immediate sense but may be potentially valuable for a future point in time. In this way, people recognise that collecting and storing information about health provides a means through which they can stay informed about different topics or issues.

When collecting and storing information people describe how this may be experienced in a tangible or intangible manner. Collecting and storing information in a tangible manner refers to physical collections of information people accumulate about health, while in contrast memorising or remembering health related information is described as how this may be experienced in an intangible way.

The idea of collecting and storing information in a tangible manner is illustrated in the following two quotations below. In each instance the interviewees' comment reveals how they collect and store health related information in a physical sense:

I get magazines out of the library – something like Health and Wellbeing or the Women's Weekly I'll look at those and get information out of them... sometimes those things from Coles or Woolworths, the free recipe booklets... And I have a box – a file in the pantry that I keep those sorts of things, nutrition and recipes and I can always go and look at them. Like the other week I got this flyer thing at IGA about salmon cakes. It was a recipe but it also had information in it about what's good for you. So there was nutrition tips like mixing coriander in to make the salmon cakes – because it is good for you. So I put that in my recipe box. [Participant 5, p. 6]

I've always been a bit of a collector of those kinds of information... I keep a filing cabinet at home and when I get stuff like that I put it in a file. So there's a file in my cabinet that's about health and fitness. And I refer to that, I go back to it, if there's something on my mind. [Participant 6, p. 2]

Conversely, these next two examples provide evidence of how people may experience collecting and storing health information in an intangible manner:

A lot of time too you'll talk to people about their health problems and you'll store it away for later reference, it may not necessarily relate to you at the time. But then you'll dig it up further down the track – and you'll think 'Oh I remember so and so saying this'. [Participant 4, p. 6]

I do like the programs on TV that I find. Like the 'Ready Steady Cook' program – at the end of that they sometime have a nutritionist come on and talk for a few minutes. And she might have a little snippet of information. I do tend to take that in from the TV. I find those sort of things stimulating. [Participant 5, p. 3]

## Experienced outcome of using information

In this category the experienced outcome of using information can be described as enhancements to people's knowledge about health. People understand that engaging with information about health will not always involve or translate into immediate application. For this reason, the experienced outcome of information use refers to developing and enriching people's knowledge about health for potential future needs.

Continuing this idea people are likewise aware that they have a 'store' of knowledge about health that comprises information they have accumulated throughout life. In this way, the experienced outcome of using information can be described as depositing fragments of information into this store to ensure their knowledge about health continues to grow, and that they have a foundation of general health knowledge to draw upon as needed in the future.

The following quotation provides evidence of how the outcome of information use can be described as enriching people's knowledge about health:

Quite often with the TV it's not information that you can particularly act on, you just kind of just store it away in amongst all the other stuff. It just adds to your store of knowledge in your head. [Participant 4, p. 5]

Finally, this next example is provided to illustrate people's awareness of having an accumulated store of information concerning health. From this comment it is conceivable to deduce how when staying informed about health people experience the outcome of information use as continuing to grow and develop a store of knowledge as they journey through life:

You go through life and if are an observant person, which I think I am, you kind of build up an underlying store of information and when you need it you can dip into it, you remember reading something in the chemist, or in the doctor's office or something like that and it's a start for further investigation. Is it something that I need to go and see the GP about, or is it something that I can do something about myself, go and buy something at the chemist to fix the problem rather than going to the GP? ... It's hard to identify any particular concrete examples I guess. I think you just build up a general pool of knowledge really and once you do have a problem then you can use that background knowledge to decide what to do next I suppose. [Participant 12, p. 5]

## Experienced object of learning

In this category people are learning about health matters they identify as personally relevant in an actual or potential sense. In other words the experienced object of learning refers to an array of topics that people perceive as pertinent and important within the context of health.

The idea of learning about health matters of personal relevance is demonstrated in the following quotation. Here the comment about a personal 'attachment' to a particular medical condition illustrates how certain health topics are regarded as being personally significant:

Like my mother has macular degeneration. So if something comes up about that you just automatically tune it to that. So that sort of stuff. I think if it has had a personal attachment somewhere then you are more likely to pick up on that stuff than other stuff. [Participant 20, p. 7]

#### Experienced act of learning

In this category the way of learning can be described as encountering or pursuing information about health. Encountering information refers to learning that happens when people serendipitously 'come across' information about health in the course of day-to-day life. In contrast, pursuing information refers to learning that happens as a resulting of people 'tracking down' or 'looking into' a particular health matter.

This idea is illustrated in the quotation shown below. Here the interviewee's comments provide an example of how learning is experienced through encountering information in a serendipitous manner:

Actually this is a true but embarrassing story. This is before I had kids so it would have been about 1991. I had just come out of the shower and I was watching TV, there used to be this program on Channel 9 called Sex. That is what the program was called so naturally it attracted your attention obviously. But the program wasn't just about sex it was about a whole plethora of things like sexual health, intimacy. And I came out of the shower and there was this giant set of testicles on the TV screen and they were showing you how to examine them. And I thought 'I'll have a crack at that, that looks like it could be a bit of fun'. [Participant 17, p. 4]

Conversely, this next excerpt is shown to illustrate how learning may happen through encountering information serendipitously, but that people may similarly experience the act of learning as a more purposeful and self-directed pursuit of further information. Evidence of this point is highlighted in bold:

... well it's sort of like someone sows a bit of a seed in your mind and you think 'I should just go and do a bit of research on that'. You know like my neighbour has just been diagnosed with diabetes and he came over the other night with this little pricker thing and we all had a go at testing the sugar in our blood. And I though that perhaps I should just look a little bit into diabetes, just to find out a bit more information about it, just for interest really. [Participant 13, p. 3]

## Experienced outcome of learning

In this category the experienced outcome of learning can be described as confirming or changing practices in people's regime for health. Confirming practices refers to checking or verifying that existing habits or routines are helping to promote and protect health. Conversely, changing practices can be described as altering or adjusting habits or routines that comprise a regime for health.

The notion of confirming practices in a regime for health is reflected in the interview passage below. In this example the interviewee's comments illustrates confirmation of practices they were following with respect to diet:

... well my employer runs workshops on things of general interest and sometimes they cover topics to do with healthy lifestyles, and I've been to a few of them. And I found

those very useful... So the information I got there was interesting because I sort of checked what they said against the sorts of food we ate. Things like cutting out fries, I remember that bit, because I really like them unfortunately. So I used it in the sense that it confirmed what I was doing. It didn't actually change my existing lifestyle. So it was more that what they were saying with regards to diet matched what we were doing and I thought 'That's good'. And they also said about not smoking so I also thought 'Well I don't smoke so that's good too'. [Participant 8, p. 5]

Similarly this next quotation provides a further illustration of this point. Here, the interviewee's statement shows how regular examinations for prostate cancer are verified as a necessary part of a medical regime:

I suppose now that I am getting older you start talking with other blokes about things like prostate cancer, things like how often you need to have that checked, and I'm more aware of having to have that done. So I'm more willing to accept that doing that is part of a medical regime now that I should be having done, rather than ignoring it because I'm not too keen about having someone shove their fist up my ass. [Participant 21, p. 5]

In contrast the outcome of learning may also be experienced as changing practices in a regime for health. This next extract demonstrates this point where the interviewee describes adjusting habits towards eating and food preparation:

I got some paperwork in the letterbox one day which was about the amount of fat that has increased in our diet and it showed a very good chart of the amount of fat in comparison to a packet of potato chips, which you often eat on a regular basis. I used that chart to put up on my refrigerator to remind myself about trimming meat, trimming excess fat off meat, and limiting some of the foods that I ate. I actually threw it out the other day because it's been sitting there for quite some time, and it's been making quite a bit of an impression. [Participant 6, p. 1]

As a final example, this quotation offers a further illustration of how the outcome of learning may be experienced as changing practices in a regime for health. In this example, dialogue to illustrate this point is shown in **bold**:

Actually this is a true but embarrassing story. This is before I had kids so it would have been about 1991. I had just come out of the shower and I was watching TV, there used to be this program on Channel 9 called Sex. That is what the program was called so naturally it attracted your attention obviously. But the program wasn't just about sex it was about a whole plethora of things like sexual health, intimacy. And I came out of the

shower and there was this giant set of testicles on the TV screen and they were showing you how to examine them. And I thought 'I'll have a crack at that, that looks like it could be a bit of fun'... So that was a funny incident but it was a true story of a segment on a TV show that I saw. But I didn't know about needing to examine your testicles, and I learnt that from a TV program! So that show was pitched as like an infotainment show. It was pretty good. They used to have this doctor on the show called 'Dr Feelgood'. [Participant 17, p. 4]

#### Experienced role

In this category people's experienced role when engaging with information to learn about health is akin to a life long learner. When staying informed about health people are aware of the need to keep engaging with information to ensure understandings about health remain relevant to their personal situation, stage of life and preparing ahead for potential future health information needs. For this reason people perceive themselves as life long learners that are continually endeavouring to evolve their understanding and enrich their knowledge about health.

This point is illustrated by the two interview quotations provided below:

I also go to water aerobics and the physio. So I get information, exercises from health professionals or your friends, the internet, pamphlets, books. There's a lot you know, once you start thinking about it. But often with something say like water aerobics you don't always specifically go there to get certain information, but you might learn how to do a particular exercise to help a certain muscle that you didn't know before. You don't set out to get that kind of information. It just kind of evolves because you are there. And that's what you do with life really isn't it, you evolve as you learn more [information]. [Participant 2, p. 6]

Because of my age, although I might not have the problem, someone else I know might and it's sort of nice to know a bit about it – keep it in the back of your mind just in case for the future. I'm a very inquisitive type person and even though it doesn't affect me now, it may affect me in the future. I know that treatments and things can change in that time. But it's nice to know these things. It's just for my own personal knowledge really. [Participant 13, p. 4]

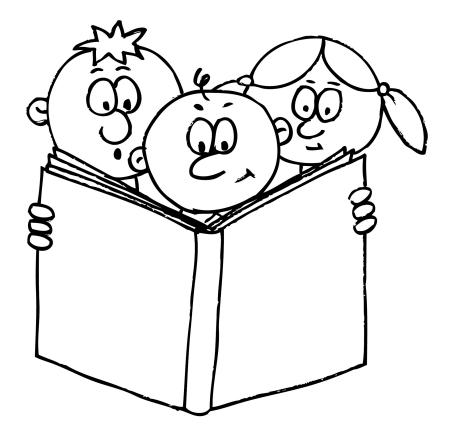
# Summary

Table 7 provides a summary of Category 5, where health information literacy is experienced as staying informed about health.

	Category 5: Stay	ying informed about health						
Key quote	well one of my friends has irritable bowel syndrome. And as you get older your							
J 1	bowel changes and I thought 'Oh, maybe I need to know a little bit more about this',							
	like prostate cancer and bowel cancer. So I started to have a bit of a look on the							
	Internet about it. Not that I have these things, but it's nice to have a little bit of							
	forewarning. So I started to look on the internet about it, to see if I had any of the							
	symptoms. There's lots of symptoms, but if you look through and if you have 5 of							
	the symptoms you might go and see your GP. Not that I have any of these symptoms							
	so far, but I think it's nice to know that information and that it's there. [Participant							
	13, p. 3]							
Meaning	Using information to learn about health is about using information over the course to							
8	life for the evolution of understandings about health.							
Structure of	Focus	absorbing information						
Awareness	Background	personal health knowledge; personal presence						
	Margin							
Dimensions of V	Variation							
Information	Experienced nature of	something that is relevant or potentially relevant to a						
	information	particular situation or stage of life						
	Experienced object of	fragmented manner						
	information							
	Experienced act of using	collecting and storing information about health						
	information							
	Experienced outcome of	enhancements to people's knowledge about health						
	using information							
Learning	Experienced object of	personally relevant health matters (actual or potential)						
	learning							
	Experienced act of	encountering and pursuing information						
	learning							
	Experienced outcome of	confirming or changing practices in a health regime						
	learning							
Role	Experienced role	lifelong learner						

**Table 7: Category 5 Summary** 

# 4.8 Category 6: Participating in learning communities



In this category people experience health information literacy as participating in learning communities. People are aware that they know and have information they can share to assist others in learning about health. Equally people also understand how others can in turn be a resource that they can draw upon for learning about health. In this experience health information literacy extends beyond using information as an individual for personal benefit, and also encapsulates using information by way of communicating it for the purpose of helping others to learn. When participating in learning communities using information is about embracing and recognising relationships with others as valuable networks for learning about health.

The following quotation illustrates the meaning associated with this experience:

We had a chap who came last month who said that he was getting all the information he could, because his doctor doesn't really know anything about it. So he came to us to get the information. A lot of time people come to our [diabetes] support group before they get to see the specialist, the diabetes educator, because there's such a long waiting list to get in. So our support group can help them in that way. [Participant 7, p. 2]

#### **Structure of Awareness**

When experiencing health information literacy as participating in learning communities, people's attention is directed towards conveying and obtaining information. In other words people are focussed on imparting as well as attaining health information in a 'give and take' type manner through their interactions with others. The focus of this experience towards conveying and obtaining information is illustrated by the following quotation:

I suppose when I walk in the morning with my group of friends, we walk to keep fit and not get hugely fat. And I suppose we talk lots about people with medical problems and what the doctor has told them. So we relay stories that we've heard from other people, or 'I've found this particular recipe and this is supposed to help cleanse you,' all that kind of thing. I suppose it is just more to do with daily living, asking people what they do. And then we'll say 'let's walk a bit faster to get our heart rate up, or let's run up this hill'. And sometimes we say 'let's not run up this hill let's do this tomorrow, it's a bit hard!'. [Participant 2, p. 4]

The background of awareness for this category is comprised of two elements: (i) relationships; and (ii) personal presence.

People are aware of how their relationships with others are integral to participating in learning communities and provide a means for conveying and obtaining information about health. In a similar way people also understand how participation and reciprocity are pivotal components for realising the notion of a learning community. For this reason people are aware of their personal presence, their involvement in terms of the role and contribution they make when participating in communities where learning about health may occur.

However although people are aware of these two elements, their role is to facilitate the category focus on conveying and obtaining information. For this reason both of these elements are situated in the background of awareness.

Figure 8 below depicts the structure of awareness for this category:

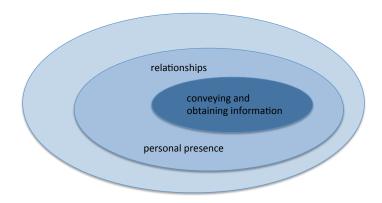


Figure 8: Structure of Awareness - Category 6

#### **Dimensions of Variation**

## Experienced nature of information

In this category information is described as relationships with other people that can be drawn upon to learn about health. In other words, information is constituted through the connections people have with others in the various communities to which they belong.

Furthermore, the idea of community in this category comprises people's relationships with family, friends and colleagues, as well as their connections to organisations such as leisure or seniors clubs, or groups that provide health related support. Therefore the notion of community in this category implies both formal and informal connotations.

The following section of an interview illustrates the idea of family as being a kind of community through which information about health may emerge. In this example the interviewee had earlier described his wife as source of information through which he could learn about health. When asked to further explain this point, his statement below in bold reveals how familial relations are perceived as an avenue through which information about health may appear:

Well she is interested in keeping the family healthy, and she's a conscientious person. She looks into things like diet, what's a good diet and what's a bad diet and what you should be eating and we talk about it. She's also got her own health problems so we talk about those as well. So there's a cross-fertilisations of ideas I guess of what happens in the family. And she's much closer to my daughter than I am, because she's doing the mothering job, so they talk about female issues. And sometimes I hear about it and

sometimes I don't, it depends I guess on the sensitivity of the subject! [Participant 12, p. 4]

Furthermore, information from relationships with other people can be characterised in two distinct ways: tangible and intangible.

Tangible forms are described as tactile health information such as books, brochures, magazines and newspapers and are primarily textual in nature. The following section of an interview illustrates the idea of tangible forms of health information:

I recently had a friend who has been very ill. Her family were reading lots of information about her illness and I had a book that was about cancer and diet and I passed that book onto them. And I told them about some of the information that was in the book and then said, 'This is for you, read it, if you choose to, if you don't, then that's your choice too, or read it and take out the information that is valuable to you'. [Participant 6, p. 8]

In contrast, intangible forms are described as health information that is oral or verbal in nature. This form is particularly prevalent in this category and while it comprises factual details about health, it primarily refers to people's experiences or stories regarding various health issues or topics.

The long quotation shown below reflects the idea of intangible forms of health information. In this example, the interviewee illustrates how conversation concerning another person's experience helped resolve an ongoing health issue:

But you know interestingly I did resolve the feeling bloated thing too – even though I didn't go to the doctor. I accidentally found through somebody else who had exactly the same problem. She told me what I could do to end this problem and I have been fine ever since. So that was a case where I didn't know what it was, I couldn't remember how long I had had the problem but it wasn't urgent. And when I talked to her she said it was the same as her daughter and they had found out that their daughter was lactose intolerant. So they modified her diet and she didn't have anymore problems. So I thought I would try and do what they had done so I went on a strict dairy free diet and the problem went away completely. And I've since learnt about dairy alternatives that I can have so I can still have things like dairy but where I don't have bloating or tummy problems from eating them. So that was a case of getting information sort of by accident, where you come across somebody that has a problem a bit the same as yours and you swap stories. [Participant 14, p. 9]

## Experienced object of information

When people experience health information literacy as participating in learning communities, information is experienced in an individual or collective manner. In other words this category reveals how when participating in community people experience information in a personal as well as a mutual fashion. In particular the collective or mutual aspect of how information is experienced in this category is reflected in interviewees' descriptions through the use of the term 'we'.

The following quotation illustrates this point and provides evidence of the individual and collective manner in which information is experienced when participating in learning communities:

Sometimes I read the healthy lifestyle section in the Courier Mail or Sunday Mail. Especially if they have great exercises you can do with those fitness balls, exercises to make your tummy flat. And we'll often talk about that, the group of ladies that I walk with and say 'hey did you see that thing in the paper the other day?', 'if you do this then you get this'. [Participant 2, p. 5]

### Experienced act of using information

In this category the act of using information is experienced as obtaining information through the different communities that people belong to as well as imparting or giving it to others who may find it valuable or useful. The act of using information is therefore dual faceted in the sense that people experience using information for their own benefit as well as when they pass it on or share it with others. Therefore in this category, the experienced act of using information is equally concerned with receiving information as it with communicating information to others.

The following interviewee's quotation provides evidence of how the act of using information is experienced:

...well we use our information to pass onto others through our support groups... So finding out that information that I can pass onto others. It's not just been for me, but it's also been about sharing information too. [Participant 7, p. 7]

Similarly, another interviewee's comment reveals how the act of using information is experienced as providing information to others. Referring to a support group he attended for men diagnosed with prostate cancer he mentions:

Well I guess the other thing I do is that I tell other people about it too. So like I use it if somebody else, like other men that have prostate cancer find out that I've got it and want to know how I deal with it. Sometimes other men my age when I mention that I've had it they might ask what I've done. And then I'll pass on information about the support group because maybe it might help them. So I have cards for the group in my wallet and I'll pass those on. And I often tell other blokes about these meetings and what I've done and I what I get out of them. [Participant 11, p. 4]

As a final example, the following quotation also highlights the dual faceted nature of how the act of using information is experienced in this category. This excerpt shows how conversation provides an avenue through which people may impart or receive information about health:

You know we often have conversations with friends, with colleagues. You know you have general conversations where you say 'I read this article the other day that said this is causing this', or 'We really need to eat more of this stuff', or 'The vegetables we get now have quite changed in comparison to what they used to be', all of those kinds of things. [Participant 6, p. 5]

#### Experienced outcome of using information

In this category, the experienced outcome of using information can be described as changes or contributions to people's health knowledge. In other words people's engagement with information either generates the acquisition of information or the communication of information which becomes part of people's knowledge about health.

However the specific point in time in which information is 'used' can be described as contextually dependent. For example, in some instances people may use information in an immediate or imminent manner in order to deal with or respond to an existing health issue. In contrast, information may also be 'used' in the sense it is something that can or may be drawn upon at a future point in time.

The interview excerpt below provides an example of where the experienced outcome of information use is presumably drawn upon in an immediate manner. In this example the interviewee describes a conversation with member of a diabetes support group where they sought advice about managing hypoglycaemic episodes:

Everybody's diabetes is different. We understand that. But the basic things are still the same. So there's always people you can talk to if you are worried about something. Like

a few years ago I was having a lot of hypos. I wasn't sure if I was doing that correctly, what I was doing and what to do for hypos. So I asked one of the members and they explained it... So we do talk amongst ourselves. [Participant 7, p. 5]

### Experienced object of learning

In this category people are learning a myriad of information relating to health. This diversity in the content of learning is reflective of the nature of this experience as well as the way in which learning occurs.

The variety of information that can be learnt about health when participating in learning communities is demonstrated in the interview passage below. In this example, the interviewee's comment demonstrates the diversity in what is learnt from attending meetings of a support group for men diagnosed with prostate cancer:

So if a man has prostate cancer, I'll tell him to go to those meetings. Because when you go to those meetings, every man that is in that room can honestly say they know what you are going through. And I've learnt heaps about different things that I can do to deal with it. [Participant 11, p. 4]

## Experienced act of learning

In this category people are learning through socially interacting with others, that is by participating in and engaging with different communities of people. Social interactions may occur through people's involvement in formalised communities such as health related support groups but also include engagement with informal communities such as colleagues and friends. In addition, the act of learning in this category could also be described as incidental in the sense that this typically happens in a spontaneous manner.

The following quotation provides an illustration of how the act of learning is experienced when participating in learning communities:

And people share information about what's happened to them, or you share information with them about your health, their health. So you learn from what other people do. So that's information to me that I get from listening to other people's experience.

[Participant 6, p. 8]

## Experienced outcome of learning

In this category, the experienced outcome of learning can be described as changes to personal and community knowledge about health. In other words, when health information literacy is experienced as participating in learning communities the outcome of learning embraces changes in collective or community knowledge about health as well as changes to people's own knowledge about health.

This idea is reflected in the following interview excerpt. In this example, the interviewee had mentioned using a health magazine called *Diabetic Living*. This comments reveals how the outcome of learning is experienced as changes to individual and community knowledge about health:

Well aside from reading it myself I also do the newsletter for our diabetes support group so if I find anything interesting I put it into the newsletter so I use it that way and I can share it around. Spreading the word! [Participant 7, p. 3]

Continuing this idea, this long quotation provides another example to illustrate the experienced outcome of learning when participating in learning communities. Here interview dialogue to demonstrate the idea of changes in knowledge at personal and collective levels is highlighted in bold:

Oh yeah, I just thought about something. The club that I belong to. We have guest speakers that come ... I was talking to my optometrist and I asked if they ever spoke at seniors' gatherings. And I asked if they would like to come to the club and talk about things like eye health and macular degeneration. So he came along and spoke and there's information there and he also left some brochures too. So hopefully the group would have picked up something, because I did... Diet is another thing, what's good for you to eat. You know like when you go into the supermarket and there's all those different types of milk. And you have no idea about what sort of milk you should buy. So I'm getting a dietician to come out to the club early next year to talk about what we should be eating. So hopefully from that me and some of the others might gather some information, get some pamphlets and then look at our diet, the fatty foods we might be eating. It's another way we can get information. [Participant 13, p. 6]

#### Experienced role

In this category people's experienced role when engaging with information is akin to a donor and a beneficiary. When participating in learning communities people are aware of how their relationships with others provide a source and way through which they can learn and obtain information about health. Similarly people are equally aware of the role they play in providing information to others that they know about health. For this reason people's experienced role is dual faceted in the sense that it is equally perceived as playing the role of donor as well as a beneficiary.

This idea is reflected by the two interviewee's statements provided below:

We often send each other things across the internet, pamphlets and share recipes. My daughter also is an occupational therapist. So sometimes I'll ring her up and ask her what she thinks about something relating to health. What would an OT say about this? I don't dwell on things like this, but sometimes things come up in your general day. And with my friends it's really about sharing ideas or a pamphlet, or something that someone else has gotten off the Internet." [Participant 2, p. 4]

Well sometimes you get information from other people who might be a bit more knowledgeable, might have done their own research into something and share that in a social context. So like the other night when we were out, my friend was talking about going off sugar. So him sharing that information that he was cutting back or down on sugar, well that made me think about how that change had benefited somebody else. And I have always shared information I know about sinus when people tell me they are having sinus problems. So I will tell them what I tried at one stage and that I haven't tried anything else since because it worked so well. So yes, sharing information in that way. It's really incidental information isn't it, things that come up in a social context. [Participant 22, p. 4]

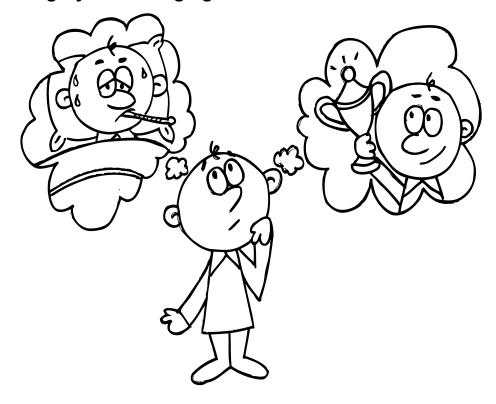
# Summary

Table 8 provides a summary of Category 6, where health information literacy is experienced as participating in learning communities.

	Category 6: Participati	ng in learning communities						
Key quote	We had a chap who came last month who said that he was getting all the							
	information he could, because his doctor doesn't really know anything about it. So							
	he came to us to get the information. A lot of time people come to our [diabetes]							
	support group before they get to see the specialist, the diabetes educator, because							
	there's such a long waiting list to get in. So our support group can help them in that							
	way. [Participant 7, p. 2]							
Meaning	Using information to learn about health is about embracing and recognising							
	relationships as valuable networks for learning about health.							
Structure of	Focus	conveying and obtaining information						
Awareness	Background	relationships; personal presence						
Dimensions of Variation								
Information	Experienced nature of	relationships with other people; tangible and						
	information	intangible in character						
	Experienced object of	individual or collective manner						
	information							
	Experienced act of using	obtaining and imparting information						
	information							
	Experienced outcome of	changes or contributions to people's health						
	using information	knowledge; contextually dependent						
Learning	Experienced object of	myriad of information relating to health						
	learning							
	Experienced act of learning	socially interacting with others						
	Experienced outcome of	changes to personal and community knowledge						
	learning	about health						
Role	Experienced role	donor and beneficiary						

**Table 8: Category 6 Summary** 

# 4.9 Category 7: Envisaging health



In this category, people experience health information literacy as envisaging health. People understand the temporal nature of human existence and recognise that how they experience health in the present will not necessarily be permanent or lasting. In other words, people realise that their health is susceptible to change at some point in the future. As such people are using information to contemplate different possibilities in how the human condition may be experienced, and reflecting on different practices that are perceived to promote or adversely impact on health. When envisaging health using information is about 'thinking forward' to project an image of how people want their health to be, and being mindful of maintaining good health as an enduring goal.

The following quotation illustrates the meaning associated with this experience:

... with regard to general health you see other people. So I'll look back to my childhood and see or think about the lifestyles that my elders, people who were older than me had. So their lives were generally shorter. Their diet was terrible, but exercise was good, but diet was bad and general stress levels were very high. They ate a lot of fried foods, a lot of drinking. So recognising that from my memories is useful for me because I think that I really don't want to go down that way. [Participant 8, p. 4]

#### **Structure of Awareness**

When experiencing health information literacy as envisaging health people's attention is simultaneously directed towards the health of their present and future self. Collectively, people are focussed on these two entities to consider (i) how the health of their present self is faring in relation to how they wish their future health to be; and (ii) whether they are taking appropriate action to ensure their desired future self is realised.

The focus of this experience towards the present and future self is illustrated in the interview excerpt shown below:

So when you are younger and having kids, you don't have a lot of time, but that's why you have a body then that is young and fit and it can do lots of stuff. But I believe now in this time of my life, say from 45 onwards, this is the time when we need to start looking at from now to the end, because this is the body that I'm going to be left with for the rest of my life. So to me it is important that I am looking after it and making sure that it is getting nurtured in the way that it needs to. [Participant 23, p. 3]

The background of awareness for this category is comprised of two elements: (i) the concept of health, and (ii) personal health knowledge.

People's awareness of the concept of health refers to their overarching understanding of what health fundamentally means. People are aware that health, or more specifically the condition of being human can be experienced on a continuum that spans across good and poor health. In a similar way, people are also aware of their own personal health knowledge, that is, what they have learnt and experienced about health through the course of life.

Although people are aware of these two elements, their presence in the structure of awareness is important in terms of facilitating the focus of this category on the health of their present and future self. Furthermore, collectively they also provide a background of understanding against which the focus of this category is considered. For this reason these two elements make up the background of awareness for this category.

Figure 9 below depicts the structure of awareness for this category:

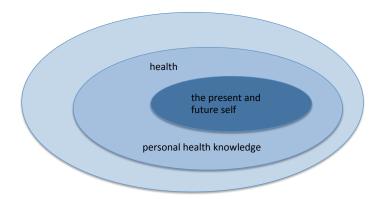


Figure 9: Structure of Awareness - Category 7

#### **Dimensions of Variation**

## Experienced nature of information

In this category information is described as role models, or more specifically visual images of other people that can be used to learn about health.

While information appears in the form of role models, inherent within these are the particular diets, lifestyles or habits they may embody, along with whether people perceive or regard different role models as being either 'good' or 'bad' examples of health.

The following section of an interview illustrates the idea of information constituted in the form of 'good' role models of health. In this example, the interviewee comments on friends who had started to follow a particular diet. Their remarks shown in bold reveal their awareness of evident physical changes and more specifically how these changes were perceived to represent a 'healthier' self and therefore a 'good' role model of health:

Other friends who had used it [the CSIRO diet] and I could see the physical changes, the weight change. And I also saw how much healthier they were looking. Granted some of them were doing other things too. And one of our friends who is younger than us, she had a stroke. So that was a bit of a shock, that someone younger than us could have a stroke – and she had been very overweight. It was also the fact that things didn't change like magic, it was a steady change so I thought that was better than some rapid weight loss diet, there was a steady trueness. It was a visual example of what can happen with following good nutrition and other things like exercise. And my friend who had the stroke well I could see her coming back to health by following that diet. [Participant 9, p. 4]

In contrast, this next long quotation provides evidence of information constituted in the form of 'bad' role models of health. This point is illustrated by the text shown in bold type:

Well I used to always have a laugh when I was grocery shopping - this was when I had three kids at home and my basket was always full of fruit and vegetables and things. And I will pull up to a basket, you know like get in line with someone or behind someone and I would look around and see what other people had in their baskets. And then I would just look at that person and it would just pretty much spell it out. You didn't have to go any further than that. When you look in that basket and all you can see is white bread, coke, candy, coco pops you just see fat, unhealthy and that that is just wrong. So what was in that basket was that person. That to me was information in the sense that 'You want to know what's wrong with your health?', well to me that basket is wrong. And even the checkout people would often comment on how healthy my basket was. But to me our health starts and ends with what you put in that grocery basket. And I still do it today with my husband when we are at the grocery store. I tell him to look around and see what other people have in their baskets compared to what we have in ours, and you see people with litres and litres of coke, all the white bread and the junk cereal and the candy and heaps and heaps of packaged or processed food. [Participant 16, p. 5]

Furthermore a distinguishing aspect about the nature of information in this experience is how it may appear in two distinctly different ways. While visual images of role models may emanate from people's encounters with others in the present, visual images may also be constituted through reflecting or drawing upon memories of people from the past.

The following interview excerpt demonstrates the idea of visual images of role models people may encounter as part of day-to-life. In this example, the interviewee refers to a particular friend who had suffered a stroke and subsequently started on a particular diet for weight loss. Their comments in bold provide evidence of visual images of role models encountered in the present day:

Other friends who had used it and I could see the physical changes, the weight change. And I also saw how much healthier they were looking. Granted some of them were doing other things too. And one of our friends who is younger than us, she had a stroke. So that was a bit of a shock, that someone younger than us could have a stroke – and she had been very overweight. It was also the fact that things didn't change like magic, it was a steady change so I thought that was better than some rapid weight loss diet, there was a steady trueness. It was a visual example of what can

happen with following good nutrition and other things like exercise. And my friend who had the stroke well I could see her coming back to health by following that diet.

[Participant 9, p. 4]

Similarly, the text highlighted in bold below provides evidence of drawing upon memories of people from the past as information:

... with regard to general health you see other people. So I'll look back to my childhood and see or think about the lifestyles that my elders, people who were older than me had. So their lives were generally shorter. Their diet was terrible, but exercise was good, but diet was bad and general stress levels were very high. They ate a lot of fried foods, a lot of drinking. So recognising that from my memories is useful for me because I think that I really don't want to go down that way. [Participant 8, p. 4]

## Experienced object of information

When people experience health information literacy as envisaging health, information is experienced in a superimposed manner. In other words, people experience information as overlaying images of role models over images of themselves to imagine potentially different ways in how their future self may be 'seen'.

The superimposed nature of how information is experienced in this category is illustrated in the interview passage below:

Because I know a few people with diabetes and I think I don't want to end up like that... It plays on my mind and I don't want to get huge. [Participant 2, p. 4]

## Experienced act of using information

In this category people experience the act of using information as imagining different possibilities of how their future self may be with regards to health. People are aware that their future health can be considered as an amalgam of anticipated as well as unanticipated possibilities, and visualise this as a spectrum of possibility. In this way, the act of using information is experienced as contemplating and envisaging the various scenarios that might occur with respect to their future health.

The idea of using information as imagining the different possibilities of peoples' future health is reflected in the interview quotation below. In this example, the interviewee had discussed using information to learn about weight loss and then commented on conversations

with a colleague who had underwent gastric banding surgery for weight loss. Remarking at how the surgery's side effects have left a lasting impression, their subsequent statements in bold illustrate them imagining a future where their own weight may necessitate the same type of surgical procedure:

And there was this other person I worked with once you had the same thing done, the lap band surgery. I remember that she said she thought that once it was done she would never have a problem. So she said that she thought if she wanted to have a little bit of pizza she could have a little bit of pizza. But she said that it wasn't like that, that she still had to watch everything. And if they eat the wrong things, it makes you vomit. Even fluids, they can only drink a certain amount of fluids. So that has all had a quite an impact on me. And I have thought that I don't want to end up at a point where I needed to do something like that. I would rather die! Because I love food and the social part that comes with it. I would rather have the choice, make the choice to not eat something rather than have a procedure done where I could never ever eat that sort of food again. [Participant 15, p. 5]

Similarly in this next example, the interviewee mentions purchasing a particular cookbook after her husband had experienced significant weight gain and describes witnessing the results others had achieved by using it to prepare food. Her comments shown in bold indicate contemplation of heart failure as a possible consequence of weight gain together with visualising the differences in what this might mean regarding his potential lifespan:

Although awhile ago my husband became quite overweight. So I bought the CSIRO cookbook and we've trimmed a lot of weight off him and consequently off me too....

Well I had a look at the book. They looked like nice recipes, they were easy to do, to cook. It makes sense, it was good food. And I've seen others that it's worked on. I thought that we'd give it a go because I really didn't want my husband to die from heart failure in the next few years, I'd like him to be around for a few more years, for a long time yet. [Participant 9, p. 4]

#### Experienced outcome of using information

In this category, the experienced outcome of using information is conceptions of how the future self may be in regards to health. In other words people's engagement with information generates ideas about the different ways in which they may experience their future health.

Likewise raising people's awareness of what is perceived as 'good' and 'bad' practices with regards to health is an experienced outcome of using information when envisaging health.

More specifically this could be described as awareness of diet, habits and lifestyles that may either promote or adversely impact on health.

## Experienced object of learning

In this category, people are learning about differences in how the human condition may be experienced. This could also be described as developing greater awareness and understanding of the lived concept of health. In other words, people are learning that health is experienced on a continuum and that as human beings people may experience differing 'states' of health. Therefore the content of learning in this experience represents a panoramic view of health and the possible variation that exists within.

### Experienced act of learning

In this category, the way in which people are learning can be described as comparing and contrasting possible situations that might occur in the future with respect to health. Possible situations may be characterised as particular diseases or illnesses that could happen, but also include broader contemplation of differences in the ways that health may be experienced (i.e. health status). In addition, the act of learning is also experienced in this category as a process of reflection whereby people are considering and imagining how they wish or want to experience their health in the future.

The act of learning when experienced as comparing and contrasting possible future situations, as well as a process of reflection is reflected in the quotation shown below. In this example the interviewee's comments illustrate contemplation of potential differences in how her future health may be experienced in terms of the capacity or capability to accomplish various activities, and reveals consideration of how she would like her future health to be:

And I think that I'm probably much healthier than what I used to be. I mean I used to be a smoker as well. But now I've given up smoking, I haven't smoked for a number of years, and I stopped smoking long before we got the advertisements on cigarette packets and those kinds of things. Simply because there came to be a time in my life where I thought I want to be able to run around with my grandchildren still. I want to be to do things, I want to be able to walk up stairs without puffing. [Participant 6, p. 3]

Similarly, this next example provides further evidence of how the act of learning is experienced when envisaging health. In this instance the statement provides evidence of reflecting on various medical conditions that might develop, as well as an expressed desire about how the interviewee hoped not to be:

But from day to day it's also about looking after yourself enough to avoid the stuff that you've read about, to avoid diabetes and heart disease and osteoporosis and all those kinds of things... I don't want to be sitting around in a wheelchair in a nursing home. [Participant 2, p. 8]

## Experienced outcome of learning

In this category, the experienced outcome of learning can be described as a vision of the ideal future self, that is a conception of how people wish or want their future health to be. Furthermore, inherent within this vision are people's intentions or desires to be as healthy as they can possibly be, and being mindful of maintaining good health as an enduring goal. For this reason, raising people's awareness by way of reminding and validating the importance of continually striving for good health is also a critical part of the experienced outcome of learning in this category.

The following quotation illustrates the experienced outcome of learning in this category. In this example interview dialogue to emphasise this dimension is highlighted in bold:

I like how I am now but I just want to make sure that I stay fit and healthy. I still want to be 80 or 90 and be able to walk and dance and do the things that I want to do. Actually I've got a little story for you here. I was at the [hotel] yesterday and the band was playing was playing and there was this old guy dancing with this young girl and it was just gorgeous to see.... And there was also this old lady there who someone told me was 92 and they said 'You watch she'll be up there soon dancing. And if you don't dance fast enough she'll tell you to buzz off and then go off and find someone to dance with that is faster than you'. Now that's the sort of life that I want to be living when I'm 92. Do you know what I am saying? That's where I want to be. I want to be that old lady on the dance floor, dancing faster than some young guy. [Participant 23, p. 3]

# Experienced role

In this category, people's experienced role when engaging with information to learn about health is akin to a navigator. When envisaging health people are simultaneously considering their present state of health alongside how they would like it to be in the future. As such people perceive themselves as navigators that are engaging with information to bring about a vision of the ideal future self that will serve to guide and steer their health into the future.

This idea is illustrated in the interviewee's statement shown below:

For me it is all about staying healthy. If I can go into old age with a healthy body then I won't have to do all the drugs. So I don't want to be on lots of drugs so basically trying to stay healthy is a focus for me. I want to stay as healthy as I can for as long as I can. I want to be able to enjoy life as much as I can for as long as I can. Age is just a number. I want to be around to see my grandkids grow up, not that I have any right now, but when they come along I want to be there for that. So that is generally is my focus, what I can see in the foreseeable future for me, is staying informed and staying health. I am looking ahead and doing whatever I can to take a healthy body with me into the future. [Participant 20, p. 9]

# Summary

Table 9 provides a summary of Category 7, where health information literacy is experienced as envisaging health.

	Category 7:	Envisaging health						
Key quote	with regard to general health you see other people. So I'll look back to my							
	childhood and see or think about the lifestyles that my elders, people who were older							
	than me had. So their lives were generally shorter. Their diet was terrible, but							
	exercise was good, but diet was bad and general stress levels were very high. They							
	ate a lot of fried foods, a lot of drinking. So recognising that from my memories is							
	useful for me because I think that I really don't want to go down that way. [Participant							
	8, p.4]							
Meaning	Using information to learn about health is about 'thinking forward' to project an							
	image of how people want the health of their future self to be, and being mindful of							
	maintaining good health as an enduring goal.							
Structure of	Focus	the present and future self						
Awareness	Background	health; personal health knowledge						
Dimensions of	Variation							
Information	Experienced nature of	role models; visual images of past and present						
	information							
	Experienced object of	superimposed manner						
	information							
	Experienced act of using	imagining different possibilities;						
	information	contemplating/envisaging different scenarios						
	Experienced outcome of	possible visions of the future self; raising awareness						
	using information	of health practices						
Learning	Experienced object of	differences in how the human condition may be						
	learning	experienced						
	Experienced act of learning	reflecting on possible situations; considering and						
		imagining personal desire for future health						
	Experienced outcome of	the ideal future self; reminding/validating good						
	learning	health						
Role	Experienced role	navigator						

**Table 9: Category 7 Summary** 

# 4.10 Outcome space

This section presents the outcome space for the phenomenon of health information literacy. It portrays the relationships between the categories of description by providing details about how different categories relate to one other. The outcome space is in part an interpretivist entity, as although it is derived from the data and therefore empirical in nature, its ultimate arrangement is based upon the interpretation of the researcher (Åkerlind, 2003). In some phenomenographic studies, the outcome space developed will be hierarchical, whereby 'lower' categories are subsumed by 'upper' categories. However for the phenomenon of health information literacy, the relationship between the categories of description was not interpreted as hierarchical. Instead, a number of critical differences were identified across the phenomenon of health information literacy. These differences revealed key variations across the categories with respect to meaning, structure of awareness and the dimensions of variation.

Critical differences concerning variation in meaning were revealed between Categories 1-3, Category 4 and Categories 5-7. The meanings of Categories 1-3 share a pragmatic nature, and are primarily concerned with the practical consequences of using information to learn about health. However Category 4 represents a threshold in the variation of meaning across the categories, and is directed to the practice of developing self-awareness. Finally, the meanings of Categories Five, Six and Seven are related in the sense that they portray a broader 'journey' and realisation of the phenomenon as an eternal practice of engaging with information.

In addition, critical differences regarding variation in the structure of awareness were discovered between Categories 1-3 and Categories 4-7. Across Categories 1-3, the focus is directed to objects 'external' to the experiencing person. However, across Categories 4-7, there is a shift in focus to aspects more 'internal' to the experiencing person. Continuing this idea, critical differences were also identified in the placement of elements relating to knowledge within the structure of awareness. Across Categories 1-3, elements relating to knowledge resided within the margin of awareness and were not considered relevant. However the placement of this element shifted to the background across Categories 4-7, where awareness of personal knowledge provided contextual understanding to the experience.

Furthermore, a number of patterns were identified across the dimensions of variation for the phenomenon. These patterns reflected critical differences in (i) the experienced nature of information; (ii) the experienced object of information; (iii) the experienced act of using

information together with the experienced act of learning; and (iv) the experienced outcome of using information together with the experienced outcome of learning.

Across Categories 1-2, the experienced nature of information comprised a synergy of facts and experiences, while in Categories 4-7 the experienced nature of information was perceived as something that was person centred. Finally Categories 3 and 5 both emphasised the experienced nature of information as something that was personally relevant.

Critical differences concerning the experienced object of information were also discerned, whereby in Categories, 2, 4 and 7 information was experienced in a reflective manner. In contrast, the object of information across Categories 1, 3, 5 and 6 was experienced as pieces that formed part of a larger puzzle.

Moving to the experienced act of using information together with the experienced act of learning, differences were apparent between Categories 1, 3, 5 and 6 and Categories 2, 4 and 7. In Categories 1, 3, 5 and 6 the experienced act of using information and the experienced act of learning all involved 'working with' information in some way. While in Categories 2, 4 and 7 the experienced act of using information and the experienced act of learning all involved 'thinking on' information through reflection.

Finally, variation was also identified across the categories with respect to the experienced outcome of using information and the experienced outcome of learning. This variation reflected a shift in awareness of either information use or learning as the dominant experienced outcome across the categories, with Categories 1-3 suggesting greater awareness of information use, and Categories 4-7 suggesting greater awareness of learning.

The remainder of this section is devoted to further explicating the critical differences discerned across the phenomenon of health information literacy.

#### Variation in meaning

The relationships among the categories of description with regards to variation in meaning are shown in Table 10 below. Starting with Categories 1, 2 and 3, these meanings can be regarded as having a pragmatic nature, or in other words, the essential meanings are primarily concerned with the practical consequences of using information to learn about health.

In Category 1, this involves gathering information to develop comprehensive understanding about a particular health matter. In Category 2 it concerns choosing a particular path or approach to follow, while in Category 3 it refers to sifting and filtering information. For each

of these categories the essential meaning of the phenomenon (i.e. using information to learn about health) refers to what can be considered as the concrete, applied or everyday practicalities and consequences of engaging with information.

The placement of Category 4 however may be regarded as akin to a threshold in the variation of meaning across the categories. Here, Category 4 represents the point at which the essential meaning of using information to learn about health becomes directed to the idea of developing self-awareness. The meanings of Categories 5, 6 and 7 are related in the sense that they portray a broader 'journey' and realisation of the phenomenon as an eternal practice of engaging with information. In Category 5, this is refers to engaging in lifelong learning to 'stay informed', while in Category 6 this concerns relationships and networks as 'learning communities' that will support learning about health throughout life. Finally in Category 7, the essential meaning of the category involves realising a desired 'future self' that serves as a perpetual goal.

Categ	gory	Building a new	Weighing up	Discerning valid	Paying attention	Staying informed	Participating in	Envisaging
		knowledge base	information	information	to bodily	about health	learning	health
					information		communities	
Mean	ing	Using information	Using information to	Using information	Using information	Using information	Using information	Using information
		to learn about	learn about health is	to learn about	to learn about	to learn about	to learn about	to learn about
		health is about	about considering	health is about	health is about	health is about	health is about	health is about
		gathering	what options are	sifting or filtering	observing and	using information	embracing and	ʻthinking
		information for a	available for health	information,	listening to the	over the course to	recognising	forward' to
		new knowledge	care and choosing a	understanding	body to learn	life for the	relationships as	project an image
		foundation and	particular path or	what is 'real' or	about its health.	evolution of	valuable networks	of how people
		developing a	approach to follow.	'authoritative'		understandings	for learning about	want the health of
		comprehensive		information and		about health.	health.	their future self to
		understanding of a		differentiating this				be, and being
		particular health		from information				mindful of
		matter.		that is 'rubbish'.				maintaining good
								health as an
								enduring goal.
	Focus	specific health	health care options	quality of	information from	absorbing	conveying and	health of the
SS		topic		information;	the body	information	obtaining	present and future
Structure of Awareness				quality of			information	self
				information				
				source				
	Background	particular health	quality of	information	personal health	personal health	relationships;	personal health
		context; personal	information/source;	overload;	knowledge; prior	knowledge;	personal presence	knowledge; health
		presence	personal presence	information bias	knowledge of self	personal presence		
	Margin	prior knowledge	existing knowledge	personal health				
		of health topic	of health matter	knowledge				

Table 10: Variation in the meaning and structure of awareness

# Variation in the structure of awareness

Referring again to Table 10, three observations can also be made with respect to variation across the categories in the structure of awareness.

First, there is a change in focus across the categories from aspects that are 'external' to aspects that are 'internal' to the experiencing person. In Categories 1, 2 and 3 the category focus is directed to 'objects' that can be considered as 'external' to the experiencing person. This includes a specific health topic (Category 1), health care options (Category 2) and the quality of information and information source (Category 3). However there is a change in the focus of the experiencing person across Categories 4, 5, 6 and 7. Collectively this reflects a change in focus to aspects that are more 'internal' to the experiencing person. To express this in a different way, the overall focus of these categories shifts towards having a more 'inward' flavour, whereby the experiencing person's awareness is more directed to 'the self'. In Category 4 the focus is directed towards looking 'inside' to information from the body. Then in both Categories 5 and 6 there is a focus on 'absorbing' or 'bringing' in information to 'the self'. Finally in Category 7 there is an inward looking focus to the health of the present and future self.

Second, there is a pattern in the structure of awareness across the categories with respect to elements concerning knowledge. Looking across Categories 1, 2 and 3, elements relating to knowledge (i.e. prior knowledge of a health topic, existing knowledge of a health matter and personal health knowledge) all reside within the margin of awareness. In these categories while knowledge is co-present in the awareness structure, it is not considered of relevance to the experiencing person. However in contrast, across Categories 4, 5 and 7 the element of personal health knowledge appears in the background of each category. In these categories the experiencing person's awareness of their own personal health knowledge provides contextual understanding to the experience, and is important in terms of enabling the focus of each category to be discerned.

Third, a pattern can similarly be found in the structure of awareness across Categories 1, 2, 5 and 6 in regards to the element of 'personal presence'. In each of these categories the experiencing person's awareness of 'self' is perceived as being relevant to the element in focus, and is critical in providing contextual understanding. In Category 1, people are somewhat aware of themselves as they engage with information because the focus is connected to personal health in some way. Likewise in Category 2, engagement with information concerns options for health-care and hence there is an awareness that this will somehow impact upon the experiencing person's wellbeing. In Category 5, personal

presence is important in providing contextual relevance to what information is taken on board (i.e. absorbed), and finally in Category 6 this element is essential for people's involvement and contribution to community learning. Moving to Category 3 however, the element of personal presence does not appear, as people's awareness is primarily concerned with information as an object, rather than how it may relate to the personal self. Furthermore, although the element of personal presence similarly does not appear in Categories 4 and 7, it could be said that as these categories exhibit a deep 'inward' focus the notion of this element in the experience is perhaps implicit.

#### Variation in the experienced nature of information

Looking across the categories (refer Table 11) the way in which information appears as an object can be grouped into three distinct strands: (i) facts and experiences; (ii) something that is person centred; or (iii) something that is personally relevant.

Starting with Categories 1 and 2, the experienced nature of information comprises a synergy of facts (i.e. medical or clinical details) as well as experiences (other people's stories, narratives or vignettes) about different health matters. In contrast, in Categories 4, 6 and 7 the experienced nature of information can be viewed as something that is person centred. In Category 4, this refers to physical or psychological changes within a person, in Category 6 information 'appears' through relationships with other people, and finally in Category 7 where information is constituted as visual images of others. Similarly the experienced nature of information in Categories 3 and 5 both emphasise information as something that is personally relevant. In other words, for information to be perceived as informing it must be pertinent to a person's needs, situation and stage of life.

Category	Experienced nature of information
Building a new knowledge base (Category 1)	information sources; facts and experiences
Weighing up information (Category 2)	facts and experiences
Discerning valid information (Category 3)	something that exhibits or comprises particular qualities; suitable for needs and situation; obtained from a trustworthy source
Paying attention to bodily information (Category 4)	physical or psychological changes
Staying informed about health (Category 5)	something that is relevant or potentially relevant to a particular situation or stage of life
Participating in learning communities (Category 6)	relationships with other people; tangible and intangible in character
Envisaging health (Category 7)	role models; visual images of past and present

Table 11: Variation across the experienced nature of information

#### Variation in the experienced object of information

Two distinct strands can be discerned in regards to 'how' people experienced the 'object' of information in each category. First, where the object of information is experienced in a reflective manner, and second, where the object of information is experienced as 'pieces' that form part of a larger 'puzzle' (refer Table 12).

In Categories 2, 4 and 7 the object of information is experienced in a reflective manner. In Category 2, information is seen as facts and experiences (i.e. other people's stories) that people reflect upon to examine and contemplate what it may mean for their own personal situation. In Category 4, people observe information in the form of changes that have physically occurred within their body, or reflect upon changes in how they are feeling in a psychological sense. Finally, in Category 7, the notion of reflection is implicit as information takes the form of visual images of role models that people superimpose over themselves to image different ways in how the potential future self may be 'seen'.

Category	Experienced object of information
Building a new knowledge base (Category 1)	layered or staged manner; kaleidoscopic
Weighing up information (Category 2)	reflective or introspective manner
Discerning valid information (Category 3)	filtered or sifted manner
Paying attention to bodily information (Category 4)	observational or reflective manner
Staying informed about health (Category 5)	fragmented manner
Participating in learning communities (Category 6)	individual or collective manner
Envisaging health (Category 7)	superimposed manner

Table 12: Variation across the experienced object of information

In contrast, in Categories 1, 3, 5 and 6, the object of information is experienced in a way that can be seen as pieces that form part of a larger puzzle. Starting with Category 1, the different sources of information people draw upon can be viewed as pieces that layer upon one another, and eventually connect to form a new knowledge base. In Category 3, the filtered or sifted manner in which information is experienced suggests it can be viewed as pieces that are either dismissed or adopted to form part of people's personal health knowledge. Moving to Category 5, the object of information is experienced in a fragmented manner whereby 'ingredients', 'excerpts' or 'snippets' of information are regarded as pieces that build upon each other to ultimately enhance people's knowledge about health. Finally, the idea of the object of information as pieces is apparent in Category 6 when viewed in connection with the experienced nature of information in this category (i.e. other people). In this instance it can be considered that when information is seen as being 'other people' (refer Table 11), the array of relationships people have with others comprise separate pieces that when taken together comprise an overarching learning community.

#### Variation in the experienced act of using information and the experienced act of learning

Looking at the two dimensions that refer to the act of using information and the act of learning, there is variation across the categories resembling either 'working with' or 'thinking on' information (refer Table 13).

In Categories 1, 3, 5 and 6 the experienced act of using information and the experienced act of learning involve 'working with' information in some way. Starting with Category 1 this refers to researching sources of information to develop comprehensive understanding about a health matter. Category 3 involves comparing and contrasting different pieces of information so as to be mindful of the background or biases that may be present. In Category 5 people experience working with information through encountering or pursuing it, and collecting and storing it for immediate or potential future use. Finally, in Category 6, people are working with information when it is communicated through social interactions that involve obtaining or imparting information.

In Categories 2, 4 and 7 the experienced act of using information and the experienced act of learning all involve 'thinking on' information through reflection. Starting with Category 2 this involves reflecting and contemplating different health care options available for treating or resolving a health matter, and the potential impact of these options on personal wellbeing. In Category 4, thinking on information involves reflecting on physical or psychological changes to interpret whether bodily information can be regarded as a favourable or unfavourable change. Finally in Category 7 this concerns reflecting on possible situations so as to imagine different possibilities for a person's future health.

Category	Experienced act of using	Experienced act of learning		
	information			
Building a new knowledge base (Category 1)	developing comprehensive understanding	the practice of researching		
Weighing up information (Category 2)	weighing up information to contemplate various options	contemplating various details; reflecting on significance for personal wellbeing		
Discerning valid information (Category 3)	being aware of the background or biases in health information	comparing and contrasting information		
Paying attention to bodily information (Category 4)	interpreting bodily information	reflecting on physical or psychological changes		
Staying informed about health (Category 5)	collecting and storing information about health	encountering and pursuing information		
Participating in learning communities (Category 6)	obtaining and imparting information	socially interacting with others		
Envisaging health (Category 7)	imagining different possibilities; contemplating/envisaging different scenarios	reflecting on possible situations; considering and imagining personal desire for future health		

Table 13: Variation across the experienced act of using information and act of learning

#### Variation across the experienced outcome of using information and outcome of learning

Looking across the two dimensions that concern the experienced outcome of using information and the experienced outcome of learning (refer Table 14), there is variation that reflects a shift in awareness of either information use or learning across the categories.

In Categories 1, 2 and 3 there is greater awareness of information use compared to awareness of learning. Collectively these categories represent experiences of engaging with information that is external to the personal 'self' and in consequence there is greater awareness of the experienced outcome of information use compared to the experienced outcome of learning.

However in Categories 4, 5, 6 and 7, there is greater awareness of learning as the experienced outcome compared to information use. Collectively these categories encapsulate the process of life-long learning, which involves continually developing and enriching the personal 'self'. Here in contrast to Categories 1, 2 and 3, although information use is experienced within each of these categories, there is greater awareness of learning as the experienced outcome.

Experienced outcome of using	Experienced outcome of	
information	learning	
answering questions; contextually	construction of new knowledge	
dependent	base; awareness of information	
	sources	
informing a decision-making process	making a decision	
distinguishing information that is	adoption or dismissal of	
valid and useable	information	
engagement with other health	identified course of action	
information; guiding future behaviour		
enhancements to people's knowledge	confirming or changing	
about health	practices in a health regime	
changes or contributions to people's	changes to personal and	
health knowledge; contextually	community knowledge about	
dependent	health	
possible visions of the future self;	the ideal future self; reminding/	
raising awareness of health practices	validating good health	
	information answering questions; contextually dependent informing a decision-making process distinguishing information that is valid and useable engagement with other health information; guiding future behaviour enhancements to people's knowledge about health changes or contributions to people's health knowledge; contextually dependent possible visions of the future self;	

Table 14: Variation across the experienced outcome of using information and learning

#### 4.11 Conclusion

This chapter has presented the findings emanating from this study. It has described the qualitatively different ways in which people experienced health information literacy and discussed the critical differences and relationships that were uncovered among the categories of description. In next chapter, I discuss these results in terms of the different contributions they offer to information literacy research, to understandings of 'information', to education regarding people's use of health information, and to the broader body of knowledge concerning consumer health information.

# Chapter 5: Discussion: Contributions, implications and conclusions

#### 5.1 Introduction

In this final chapter, I discuss the contributions this study provides to both theory and practice. The chapter is divided into seven parts. In the first part I discuss the contribution this study provides to information literacy research. Then, in the second and third parts I examine the study's contribution to understandings of information in the context of health, and what the findings reveal about current approaches to consumer education concerning health information. In the fourth part I also consider what the outcomes of this study contribute to the broader domain of consumer health information. The final three parts of this chapter then outline the study's limitations, propose directions and suggestions for future research, and offer some concluding remarks.

#### 5.2 Research overview

The aim of this study was to investigate the experience of health information literacy. The main research question was 'What are the qualitatively different ways in which people experience health information literacy?'.

Emanating from this question, the study's objectives were identified as follows:

- To identify the qualitatively different ways in which people experience using information to learn about health.
- To provide descriptions of the various ways in which people experience using information to learn about health.
- To develop greater understanding about the phenomenon of health information literacy among the study's participants.
- To develop greater understanding about what people constitute as information that is used to learn about health.
- To contribute knowledge about the various ways in which people experience health information literacy, and examine what this provides to health information literacy education and to consumer health information research.

Using interpretive phenomenography, this study has identified the qualitatively different ways in which participants experienced health information literacy. It has provided

descriptions in the form of seven (7) categories of description that represent the various ways in which people experienced using information to learn about health, and thereby provided greater understanding about how this phenomenon was experienced among a participant group. In addition, the study's findings have provided knowledge that enhances our understandings about what people may experience as 'informing' or constitute as information that is used to learn about health. In this final chapter, I address the study's final objective outlined above, that is, what knowledge from the outcomes of this research may provide to health information literacy education and consumer health information research.

## 5.3 How does this study contribute to information literacy research?

This study contributes to a nascent area of research that has explored the phenomenon of information literacy in everyday life or community settings. Within the field of information literacy research and scholarship, investigations into everyday life or community settings have for some time been identified as a significant gap for enquiry. Little more than a decade ago, Bruce reported that research into information literacy was "still in its infancy" (2000, p. 91), and acknowledged that investigations within community or everyday life settings had "barely begun" (p. 96). Partridge, Bruce and Tilley (2008) along with Lloyd and Williamson (2008) similarly echoed this same sentiment several years later. They too both recognised the paucity of information literacy research undertaken within the context of everyday life, and affirmed the importance of investigating this area as central to bringing about greater understanding of the phenomenon.

However the last few years have seen increased research attention to information literacy in everyday life settings. Examples include Gunton's study (2011) that investigated how people experience information literacy in church communities, Smith and Hepworth's study (2012) that investigated the ways young people experienced information in academic as well as everyday life and Walker (2012) who studied the use and understanding of information by parents of young children. These recent studies can be regarded as evidence that this line of research enquiry has finally begun to prosper. As such, the findings of this study can be considered to strengthen and enrich conversations about information literacy beyond library, educational or workplace contexts. Furthermore, these findings can also be seen as providing evidence to enhance the picture that we have of information literacy, and more specifically how it may appear in settings beyond where research has conventionally taken place.

The findings of this study also further reveal the deep contextual nature of information literacy, and provide additional evidence of the need to recognise context in discourse about the phenomenon. Although the importance of context is increasingly recognised in information literacy scholarship, Lloyd and Williamson noted that researcher's acknowledgment and attention to this remains a largely emergent feature (2008). However this is perhaps not surprising given the historical trajectory of information literacy research, where its early phases were limited to investigations in library or academic environments. Consequently, knowledge concerning the contextual differences in how information literacy may manifest itself has emerged as research enquiry began to expand beyond formal educational settings.

As research into information literacy continues to progress, the reported outcomes are frequently serving to challenge and emphasise differences in how information literacy is understood and discussed, compared with earlier scholarship emanating from library and educational environments. This situation then perhaps raises the question about the degree to which we can meaningfully discuss information literacy if discourse is devoid of context. Based upon the findings of this study I put forward that discussions undertaken in context are indeed essential to uncovering the essence of information literacy, and to revealing its complexity as a phenomenon. In fact, it is perhaps even conceivable to suggest that attempts to meaningfully discuss information literacy in isolation from context reduce the concept to a virtually meaningless entity.

In addition, I also suggest that the outcomes of this research affirm a need to reconsider or reconceptualise the construct of information literacy in everyday life contexts, and by extension how we provide information literacy education in community settings. At present, discourse concerning information literacy with respect to the broader population typically portrays citizens through a 'deficiency' lens, by focusing on people's 'lack' of information skills, and in consequence the objective of information literacy education is directed towards 'improving' these various deficiencies (e.g. Aspinall, Beschnett & Ellwood, 2012; Strong, Guillot & Badeau, 2012; Janik & Chateau, 2005).

However based upon the findings of this study, I propose that the current 'deficit' approach requires reconsideration, and that this needs to be reconceptualised to an approach that both recognises and attends to 'diversity'. Adopting a 'diversity' approach to information literacy would more appropriately recognise that different approaches to engaging with information exist, and therefore focus on raising people's awareness about the different ways they might experience information literacy. In consequence, the objective of information literacy

education would be redirected to offering opportunities to provide and encourage variety in people's approach to information use for learning in different contexts.

Finally, the results of this study also provide an opportunity to reflect upon what information literacy may conceivably exemplify within everyday life. This idea has similarly been discussed in the literature by other researchers who have investigated information literacy in educational and workplace settings, and who have described this phenomenon as 'a way of engaging with, and learning about subject matter' (Bruce & Candy, 2000, p. 7), as a 'learning approach' (Lupton, 2004), and as a 'way of knowing' an information landscape (Lloyd, 2005b, p. 84).

In contrast, I propose that the outcomes from this study have revealed that people's experience of information literacy in everyday life exemplifies a 'way of being'. Within the course of our everyday lives we learn through using information in a variety of ways. It may help us learn to better understand matters of personal relevance, assist us with making decisions that impact upon our life, or to contend with its abundance in contemporary society. However we also may also engage with information as a way of learning about ourselves, to help equip us with information for the future ahead, for playing our part to bring about learning in others, and to create an identity of who we do or do not want to be.

The idea of exemplifying information literacy as a 'way of being' is further evidenced by the findings of this study, which have shown that as information users in everyday life we take on different roles when we use information to learn. For this study, people's experienced roles when using information to learn about health saw them acting the part of researcher, as an empowered and informed consumer, an analyst, an interpreter, a lifelong learner, a donor and beneficiary, and finally, a navigator. Collectively these roles portray people's lived experience of being an information user within the context of learning about health.

Ultimately they have revealed information literacy to be a phenomenon that enables us to act within and to connect with our information worlds, and that facilitates and empowers us to both be and to become.

## 5.4 How does this study contribute to our understanding of 'information'?

The outcomes of this study have revealed significant variation across the phenomenon of health information literacy in the experienced nature of information (refer Table 15 below). As such, by revealing critical differences in 'what' people experience as being informing

(Bruce, 2008) when using information to learn about health, this study contributes to understandings of the nature of 'information' in the context of health.

Category	Experienced nature of information
Building a new knowledge base (Category 1)	information sources; facts and experiences
Weighing up information (Category 2)	facts and experiences
Discerning valid information (Category 3)	something that exhibits or comprises particular qualities; suitable for needs and situations; obtained from a trustworthy source
Paying attention to bodily information (Category 4)	physical or psychological changes
Staying informed about health (Category 5)	something that is relevant or potentially relevant to a particular situation or stage of life
Participating in learning communities (Category 6)	relationships with other people; tangible and intangible in character
Envisaging health (Category 7)	role models; visual images of past and present

Table 15: Variation across the experienced nature of information

Starting with Category 1, the portrayal of information as being particular sources of information similarly reflects how the notion of 'what' is information is commonly described in the literature. However some notable differences are apparent when comparing how information sources were described in this research, compared to how they are portrayed in consumer health information literature.

Consumer health information discourse typically treats information sources as being of a formal or informal nature. Formal information sources are considered to encompass health professionals, medical associations, established medical institutions and consumer health associations, while informal sources include personal contacts (e.g. family, friends, colleagues), the media (e.g. television, radio, social media), lay publications and online sources (Cutilli, 2010; Genuis, 2012). Continuing this idea, discussion concerning information sources in consumer health information literature frequently attends to the 'source' from which information emanates, emphasising 'expert' as opposed to 'layperson' sources.

However in Category 1, people did not appear to distinguish between 'formal' and 'informal' or 'expert' and 'layperson in their experience of engaging with different sources of health information. Instead it was engaging with a wide array of sources that people perceived as being of greatest importance, rather than the combination of formal or informal

and expert or layperson sources that they accessed. Continuing this idea, people similarly appeared to regard engaging with sources of information in diverse forms as important when learning about health. In this way, drawing upon 'objects' of information in textual, digital, audio-visual or human (i.e. other people) forms was perceived as being essential for building a knowledge base. However distinctions in consumer health information literature about the nature of an 'object' of information seldom appear, or alternatively appear to assume this to be something in a textual form.

The description of information as a synergy of facts and experiences (Categories 1 & 2) also reveals an interesting nuance concerning the experienced nature of information. This finding illustrates how people's experience of becoming informed requires not just clinical, technical or factual details, but learning about other people's experiences in a narrative form. This idea was similarly reflected in research by Genuis (2012), who investigated women's use of health information to manage the menopause transition, and Rubenstein (2012), who examined women's health information interactions in an online breast cancer community. The findings from both of these studies confirmed the importance of stories that described other people's 'lived experience' as a form of health information. However both Genuis (2012) and Souden (2011) comment about how health information is defined and portrayed in the literature as something that imparts clinical or factual details, while 'information' in the form of narratives that discuss people's lived experience are often ignored.

In both Categories 3 and 5, the findings of this study portrayed the object of information as something that is seen as suitable for people's needs and situation, or something that is seen as being personally relevant. This observation was likewise reported in a study by Marshall, Henwood and Guy (2012) which investigated people's use of information to self-manage their weight. Their findings showed how people expressed a desire for more 'tailored' information that was specific to their personal goals and circumstances, rather than generic information concerning healthy living. Marshall, Henwood and Guy noted that while over recent decades health information policy has heavily emphasised the need for information to be 'right' (i.e. medically correct), people's need for 'personalisation' added further complexity to health information provision. They concluded that people's desire and need for information 'personalisation' was one the most significant challenges presently facing contemporary health information providers.

The identification of information experienced in the form of physical or psychological changes (Category 4) provides a noteworthy discovery in revealing a type of information in which there appears to be limited conversation or reference to in the literature. In fact discourse regarding consumer health information customarily typecasts information as a

purely objective entity, and thereby overlooks types of information that may emanate from people's subjective experience of health (e.g. Cutilli, 2010; Rees, 2003).

However evidence of people drawing upon bodily information within a health context can be found in the literature. For example the 2011 study by Souden to examine the information experience of people with chronic health conditions confirms people's reliance on their own bodies as a source of information. Souden's findings revealed that sensations from people's own bodies such as experiencing pain, reduced functioning or uncomfortable physical symptoms were all regarded as being important types of information. In addition people reported drawing upon information from their subjective experiences to monitor and track their health condition, and to help determine any adjustments that might be necessary in their health regimens or lifestyle. As such the results of this present study can be regarded as contributing to an evidence base that affirms the importance of this type of information in health contexts, and the need for this to be recognised and considered as a component of people's informational world.

The idea of relationships with other people being experienced as the object of information (Category 6) is consistent with recognition in information research literature that family, friends, colleagues and different social networks frequently play an important role in people's informational world (Warner & Procaccino, 2004; Marshall et al., 2009; Rubenstein, 2012). However, while there is ample evidence to affirm this fact, Genuis (2012) points out that both health and information professionals continue to be largely mistrustful of people drawing upon 'informal' types of health information such as knowledge that is constructed in social contexts. Instead practice across both of these professions continues to focus on facilitating consumer and patient use of empirically derived authoritative health information on an almost exclusive basis (Genuis, 2012). Continuing this idea, Rubenstein (2012) similarly affirms that irrespective of how health care providers regard health information that people obtain from their peers, this practice is unlikely to end. For this reason Rubenstein instead proposes that health professionals need to acknowledge this reality, and to draw upon a framework that both anticipates and responds to this situation during interactions with consumers or patients in a productive and collaborative manner. The findings of this present research offer an evidence base that could inform the development of a framework in this area.

Finally, the description of role models, or more specifically visual images of others that provide 'good' or 'bad' examples of health (Category 7) reveals a further interesting nuance of what may be experienced as information that is used to learn about health. Although the idea of role models as 'information' is not evident within consumer health information

discourse, use of the role model concept is widely reported within health education literature for programs or interventions directed at behaviour change, risk communication or treatment adherence.

For example findings from a study by Lockwood, Chasteen and Wong (2005) reported that both positive and negative role models served an important function in healthy ageing for older adults because they provided examples of what people hope to become as well as what they hope to avoid. Their findings revealed that positive and negative role models enabled people to make 'upward' and 'downward' social comparisons across a number of different areas of health behaviour such as diet, exercise, psychological outlook, smoking, alcohol, sleep and substance abuse. They concluded that people's use of both positive and negative role models encouraged and helped them to consider making health behaviour changes, contemplate the benefits of healthy lifestyles or the potential costs of unhealthy habits. Consequently, although the notion of role models may not be widely articulated within consumer health information literature, the present research suggests that the use of health-related exemplars in health education may be regarded as a form of information that people can use to learn about health.

The discovery of broader understandings of 'what' may be experienced as information is consistent with previous research into information literacy that has taken a qualitative and experientially focussed approach. For example the findings from studies by Lloyd (2005a, 2006) into firefighters' experiences of information literacy; Lupton's study of the relationship between information literacy and learning among music and tax law students (2008); and Gunton who explored people's experience of information literacy within church communities (2011) each revealed more diverse 'forms' of information than is commonly reported in information literacy research.

Although the concept of information is a topic that has received ongoing analysis and debate in the broader field of information science (e.g. Bates 2005, 2006; Buckland 1991), Lupton (2008) noted that the term has been seldom scrutinised within the information literacy field. She reported that 'information' in audio, visual, environmental, kinaesthetic, embodied and affective forms were generally ignored, but instead commonly limit the idea of information to something that is objective and print or text based. Therefore considering the importance of information as a critical concept to our understanding of information literacy, there is argument for this to be afforded greater attention in information literacy research.

In summary these findings have highlighted that there is considerable disconnect between how 'information' is portrayed in consumer health information literature and to what people experience as 'informing' or draw upon as 'information' to learn about health. By and large it can be said that consumer health information literature conceptualises 'information' from a biomedical perspective and consequently treats the concept of health information as an entity that imparts facts such as clinical evidence or medical instructions. As such it can be said that consumer health information currently does not view or attend to the concept of health information in a holistic manner, and therefore provides a limited perspective of what may be meaningful to people as information in the context of health and health care (Souden, 2011; Genuis, 2012). Therefore the findings of this study provide further evidence that broadens understandings of what may be constituted as information about health, and emphasises the importance of attending to people's lived experience in the overall context of consumer health information provision.

It is therefore suggested that descriptions of the different ways in which information may be experienced provide the following contributions to understandings about health information:

- Assist in broadening our understandings of what may be experienced as 'information'
  that can be used to learn about health. The findings of this research have reinforced a
  need to expand current thinking around what constitutes health information 'content' to
  more adequately reflect the kinds of information that people may experience as
  informing.
- Provide an evidence base that can inform the expansion and diversification of approaches
  to health information provision for consumers. In identifying variation across the
  phenomenon of health information literacy these findings may support new opportunities
  regarding the design or dissemination of consumer health information.

## 5.5 How might these outcomes contribute to education about using health information?

The findings of this study have revealed knowledge that is of relevance to health information literacy education. They present a more nuanced, holistic understanding that recognises that people experience using information to learn about health in a variety of ways. Specifically the findings of this present study have provided descriptions that exposed significant variation across the phenomenon of health information literacy in (i) what people experience as being the content of learning (i.e. the experienced object of learning); and (ii) how people experience learning, that is, the way in which learning happens (i.e. experienced act of learning) (refer Table 16 below).

Category	Experienced object of	Experienced act of learning		
	learning			
Building a new knowledge base (Category 1)	comprehensive content about a particular health topic	the practice of researching		
Weighing up information (Category 2)	costs, risks, benefits and potential outcomes of available options	contemplating various details; reflecting on significance for personal wellbeing		
Discerning valid information (Category 3)	evaluating information	comparing and contrasting information		
Paying attention to bodily information (Category 4)	self awareness of the body	reflecting on physical or psychological changes		
Staying informed about health (Category 5)	personally relevant health matters (actual or potential)	encountering and pursuing information		
Participating in learning communities (Category 6)	myriad of information relating to health	socially interacting with others		
Envisaging health (Category 7)	differences in how the human condition may be experienced	reflecting on possible situations; considering and imagining personal desire for future health		

Table 16: Variation in the experienced object of learning and the act of learning

This holistic representation of health information literacy constrasts with previous research that focuses on specific aspects of consumer health education for example as:

- learning to use technology (particularly computer training) to obtain health information (e.g. Xie & Bugg, 2009; Strong, Guillot & Badeau, 2012);
- learning to search for health information, especially searching for heath information on the Internet (e.g. Aspinall, Beschnett & Ellwood, 2012; Alfasso, 2011);
- learning about different sources where health information can be accessed (e.g. books, websites) (Janik & Chateau, 2005; Gross, Famiglio & Babish, 2007);
- learning to evaluate health information, particularly health information that is available online (e.g. Werner & Chimato, 2005; Aspinall, Beschnett & Ellwood, 2012; Strong, Guillot & Badeau, 2012); and
- learning to use specific sources of health information, particularly using electronic databases of health information such as MedlinePlus (e.g. Werner & Chimato, 2005; Strong, Guillot & Badeau, 2012; Broering, Chauncey & Gomes, 2006).

In comparing the research outlined above and the findings of the present research, some important similarities and differences emerge. There is an apparent affiliation between health information literacy education programs described in the literature and the content of learning and way that learning happens in Category 1 (Building a new knowledge base) and

Category 3 (Discerning valid information). For example with Category 1, it is conceivable that education aimed at teaching people to find information, and develop awareness of sources where health information can be obtained would support this way of experiencing health information literacy, where the way of learning is experienced as the practice of researching, and the object of learning concerns content about a particular health matter.

Continuing this idea with Category 3, it would also appear that education aimed at assisting people to evaluate information would similarly support this way of experiencing health information literacy where the experienced object of learning concerns evaluating information. However educational programs described in the literature to assist people with ascertaining the reliability of health information typically utilise a 'checklist' or criteria type approach as the way of learning about this. It could be argued that this type of didactic approach may not fully support this way of experiencing health information litearcy, where the way of learning is experienced as comparing and contrasting different pieces of information. Similarly, current education regarding evaluating health information heavily focuses on information that is accessed online. In contrast the outcomes of this study demonstrate significant diversity in what may be experienced as information. As such, it is plausible to suggest that a 'checklist' for evaluating information accessed online may not necessarily be transferable or accommodate the diverse ways in which information about health may appear.

However the study has also revealed that existing health information literacy education programs neglect to capture a number of ways through which people may experience learning about health, as well as what they learn when they engage with information. For example, reflecting on physical or pyschological changes to learn about self-awareness of the body, or encountering and pursuing information to learn about actual or potential health matters of personal relevance. In fact when reviewing existing approaches to health information literacy education it is plausible to suggest that the overarching goal is exclusively directed to teaching specific information skills, rather than raising awareness about different ways in which information use may be experienced, or encouraging diversity in people's approaches to this.

Therefore this research contributes to consumer health information education through enhanced approaches to health information litearcy learning. In particular they will:

 Help broaden the awareness of health or information professionals involved in providing health information education to consumers, by depicting a spectrum of possible different ways in which the content and way of learning may be experienced across the phenomenon of health information literacy.

- Provide an evidence base that can be used to inform and expand existing approaches, activities and curricula for community based educational endeavours concerning people's engagement with health information.
- Affirm a need to shift the current focus of health information literacy education from training in information skills to raising awareness of the different ways in which people can experience using information to learn about health.

## 5.6 How does this study contribute to consumer health information research?

This study makes a significant contribution to consumer health information research by presenting health information literacy as an alternative theoretical construct that is relevant to this domain. In particular this study has advocated the value of working from a relational perspective, which understands the phenomenon of information literacy as the complex of ways in which people experience using information when learning in different contexts. As such the outcomes of this study provide evidence of knowledge that is possible from adopting a relational information literacy lens to investigate a phenomenon that is of significance to consumer health information research and scholarship.

Second, this study makes a significant contribution to consumer health information research by providing an evidence base in the form of a set of categories, to support theory and practice of health information literacy. These categories provide descriptions of the critically and qualitatively different ways in which people experience health information literacy, or in other words, they characterise and express the ways in which people relate to various aspects of the world in their lived experience of health information literacy. Such descriptions provide access to certain kinds of knowledge about people's ways of experiencing health information literacy as outlined below.

These descriptions portray the overall meanings that were assigned to the experience of health information literacy. These essential meanings are depicted through the respective labels that denote each category and described the experience of health information literacy as:

- Building a new knowledge base (Category 1)
- Weighing up information (Category 2)

- Discerning valid information (Category 3)
- Paying attention to bodily information (Category 4)
- Staying informed about health (Category 5)
- Participating in learning communities (Category 6)
- Envisaging health (Category 7)

In addition, these descriptions also provide us with understandings about the structural elements that are present in each way of experiencing health information literacy. The descriptions provide us with knowledge of the structural differentiation in awareness that exists when people experience health information literacy in certain ways. As such the outcomes of this study reveal knowledge of aspects that present as focal, contextual, and marginal elements in peoples' various experiences of health information literacy.

These descriptions also reveal common themes that run across the different ways in which this group of people experienced health information literacy. These common themes take the form of dimensions of variation, that provide descriptions which detail how the character of each dimension changes across each category, that is, how each theme is experienced in a qualitatively different way from one category to another. The outcomes of this study have provided knowledge of eight dimensions of variation that were present across people's experience of health information literacy. The dimensions of variation identified were as follows:

- Experienced nature of information
- Experienced object of information
- Experienced act of using information
- Experienced outcome of using information
- Experienced object of learning
- Experienced act of learning
- Experienced outcome of learning
- Experienced role

Finally, these descriptions depict the subject-object relations that comprise the experience of health information literacy in everyday life. They portray the different ways in which people, as information users, relate to information when learning about health. Continuing this idea,

these descriptions also provide us with a picture that represents peoples' collective understanding of health information literacy. In this way, the resulting categories cannot be seen as representing particular individuals, but instead when taken together, they reveal how health information literacy was experienced among a group.

Third, this study makes a significant contribution to consumer health information research by providing an evidence base that enables people, as users of health information to extend their understandings about the varied ways in which they may experience using information to learn about health. By outlining the variation in people's experiences of health information literacy, the outcomes of this study make it possible to broaden people's awareness of the different kinds of experiences that are possible. Continuing this idea it can be said that the availability of content oriented descriptions representing the ways in which people may respond to certain phenomena could constitute a learning framework. By becoming aware of the various ways in which health information literacy may be experienced, people can draw upon these different ways as appropriate, in order to more deeply and richly harness the benefit and power that may be derived from using health information. In addition, it is also important to emphasise that none of these descriptions can be seen as superior or better ways in which health information literacy may be experienced, and none of them are wrong. Instead each of these descriptions represent different ways of experiencing health information literacy and can be drawn upon as appropriate in particular settings.

Fourth, this study makes a significant contribution to consumer health information research by providing an evidence base that enables health and information professionals to extend and enhance their understandings about the varied ways in which their clients might use health information. Through providing an evidence base that presents descriptions of the ways in which health information literacy is experienced, the outcomes of this study can assist health and information professionals to better respond to people's health information needs, by raising their awareness of the different ways they might engage with health information, and encouraging them to vary their approaches to information use.

Pursuing this further, the findings of this study can also contribute to ongoing debate and discussion concerning the discourse and practice of 'co-production', which advocates the need to develop more active forms of patient and consumer engagement and participation within healthcare systems (Dunston, Lee, Boud, Brodie & Chiarella, 2009). In endeavouring to implement the ideals that underpin co-production, Dunston, Lee, Boud, Brodie and Chiarella (2009) report that a pervasive theme within the literature is "the need for getting close, eliciting and attending to the intimate experiences of health consumers" (p. 48). This

study provides an illustration of research that can be regarded as one response to such a need, and has examined the various ways in which people experience using health information in everyday life. It therefore offers an example of the kinds of knowledge that can be obtained by attending to people's experiences of different phenomena that are of interest to the healthcare sector, and can help to inform the approaches it takes towards information provision to patients and consumers alike.

In conclusion, it is worth questioning the significance and value of descriptions that portray variation in human experience and awareness. By way of offering an explanation, the writings of Martin and Booth (1997) provide one response that affirms the value of this activity for research. They contend that making sense of how people may handle certain problems, situations or aspects of the world, can only be faithfully investigated through gaining comprehensive understanding of the ways in which people experience those same problems, or situations or aspects of the world that they are dealing with or responding to. Continuing this idea, Barnard, McCosker and Gerber (1999) similarly offer another response that elucidates the necessity and value in revealing the "intellectual map that is our experience" (p. 219). They maintain that the way in which we experience various phenomena governs our decisions, guides our inquiry and provides explanations for our everyday lives and practice. As such, by obtaining greater knowledge of the ways in which we experience particular aspects of the world, we become aware and gain awareness of both "our social reality and ourselves" (1999, p. 219). Thus it can be suggested that the outcomes of this study have enabled people's lived experience of health information literacy to be exposed, and provided knowledge that that casts light upon how these different worlds appear, as well as the complexities and possibilities that are inherent within.

#### 5.7 Limitations

This study is subject to the following limitations:

First, this study has applied a phenomenographic approach to investigate how people experience health information literacy. This research approach has a particular manner in which it theorises experience and as such treats the investigation of experience in a certain way. Consequently it is acknowledged that different research approaches may have afforded alternative insights concerning the experience of health information literacy.

Second, the participants of this study were drawn exclusively from the greater Brisbane area of Queensland, Australia and hence it is possible that citizens from other locations in Australia may have other experiences of health information literacy. Therefore the outcomes

of this study cannot be seen as a complete presentation of all the possible ways in which health information literacy may be experienced.

Third, the results of this study also portray the experience of health information literacy at a particular point in time and within a particular culture. In an earlier section of this thesis I discussed how a number of elements are understood to influence the way in which a phenomenon is experienced. Accepting this premise it is therefore possible that a different picture of the phenomenon may emerge if the study were conducted in a different era or cultural context.

#### 5.8 Future directions for research

The findings of this study suggest a number of directions for future research. These recommendations for investigation would serve to broaden or extend the findings of this current study, or examine areas of related relevance. The following four sections explicate future directions for research that have emerged from this study.

#### 5.8.1 Building on the current findings

This research has explored the experience of health information literacy among persons aged 45-64 years. Future research could build upon these findings by extending this study to investigate how the phenomenon is experienced among other population age groups. This would enable exploration with respect to the generalisability of the study's findings, and to examine any differences that arise between various age cohorts. In addition, the significance and implications of possible differences between other population age groups for areas such as health information literacy education, health information provision and health education could be explored.

Future research could also investigate health information literacy from alternative theoretical perspectives. At present research into health information literacy has been largely conducted by drawing upon a behavioural perspective of information literacy, while the current study provides an example of research into health information literacy from a relational perspective. Opportunity therefore exists to examine health information literacy from a socio-cultural perspective, which understands information literacy as about "learning to communicate appropriately within a specific practice" (Limberg, Sundin & Talja, 2012, p. 116). This understanding of information literacy focuses on tool-based information practices within particular contexts and communities, and considers learning as a social activity that involves action, interaction and collective meaning-making (Limberg, Sundin & Talja, 2012).

#### 5.8.2 Health information literacy as a social practice

The results of this research have provided further evidence of the phenomenon of information literacy as being an individual as well as a social practice. As such further research is recommended to investigate people's experience of health information literacy in collective or social settings. Health related support or interest groups are suggested as potentially suitable community environments in which this might be explored.

#### 5.8.3 Curriculum for health information literacy education

The findings from this study have revealed that there is a significant disconnect between existing approaches to health information literacy education compared to how using information to learn about health is experienced by people in everyday life. As such future research could explore alternative designs and approaches to health information literacy education for the general population.

#### 5.8.4 Information literacy in everyday life

Findings from the current study have also affirmed the different character of information literacy outside of academic or educational settings. In this way, similar to other studies of information literacy in workplace or everyday life settings (e.g. Lloyd 2006, 2009; Bonner & Lloyd, 2011; Gunton, 2011; Kennan, Lloyd, Qayyum & Thompson, 2011) this research has highlighted the importance of context for gaining meaningful understandings about information literacy. Consequently it is recommended that further research be undertaken to explore the phenomenon of information literacy across a range of everyday life situations. Illustrative examples could include people's experience of information literacy with respect to financial or legal situations, or in particular stages of life such as entering parenthood or retirement.

#### 5.9 Conclusion

This thesis provides an account of research that has investigated a phenomenon of critical relevance to consumer health information: health information literacy. In response to the research question, it has explored and described the qualitatively different ways in which people experience health information literacy. In doing so, it has illuminated our understanding of people's experienced relationship with information in the context of health and health care

According to Sjöström and Dahlgren, one of the most challenging issues in health and health care is the irrefutable certainty that people experience and think about different aspects of the surrounding world in various ways (2002). As such, within the framework of health care it is fundamental that approaches to health related phenomena are founded on an awareness and understanding of the vast differences that may exist between people. It then follows that research to investigate the varying ways in which people experience particular phenomena in health can help us to gain deeper and richer understandings of how people respond to and make sense of their world.

This study has provided evidence of the relevance of health information literacy to the field of consumer health information, and demonstrated how the relational perspective provides a distinctive approach that facilitates and reveals a particular kind of knowledge. It has shown how through attending to and emphasising difference, it is possible to discover new meanings of a phenomenon that is largely elusive and yet pervasive in our everyday lives.

In conclusion, I hope that this account has provided an opportunity for you the reader to examine and reflect upon your own experiences of health information literacy. By extension I hope it has drawn your awareness and attention to alternative ways for engaging with information to learn about health, and engendered inspiration for how you may approach information use for this purpose in the future.

#### Appendix A: Recruitment flyer



#### PARTICIPATE IN RESEARCH

**Information for Prospective Participants** 

The following research activity has been reviewed via QUT arrangements for the conduct of research involving human participation.

If you choose to participate, you will be provided with more detailed participant information, including who you can contact if you have any concerns.

#### Informed for Health: Understanding health information literacy in Australia's ageing population

#### Research Team Contacts

Principal Christine Yates, PhD Research Student, Faculty of Science & Technology, QUT

Ph: 0430 356 829 Email: cl.yates@qut.edu.au Researcher:

Associate Professor Helen Partridge, Principal Supervisor, Faculty of Science & Technology, QUT

Researcher(s): Ph: (07) 3138 9047 Email: h.partridge@qut.edu.au

Please contact the researcher team members to have any questions answered or if you require further information about the project.

#### What is the purpose of the research?

This research project is being undertaken as part of a PhD program of research by Christine Yates at Queensland University of Technology, Brisbane.

The purpose of this research is to develop greater understanding about the ways people experience using information to learn about their health. The research team requests your assistance in order to gather information on the way people aged between 45-64 are using information to learn about their health.

#### Are you looking for people like me?

The research team is looking for males and females aged between 45-64 years who are currently residing in the Greater

#### What will you ask me to do?

Your participation will involve an interview conducted at a time and location that is convenient to you. The interview should last

#### Are there any risks for me in taking part?

The research team does not believe there are any risks beyond normal day-to-day living associated with your participation in this research.

It should be noted that if you do agree to participate, you can withdraw from participation at any time during the project without comment or penalty.

#### Are there any benefits for me in taking part?

It is expected that this project will not benefit you directly. However, it may benefit future provision of health services and research into how people use information to learn about their health.

#### Will I be compensated for my time?

We would very much appreciate your participation in this research.

Although it is unlikely this project will benefit you directly, it may benefit future work and research into how people use information to learn about their health.

#### Who is funding this research?

The project is funded by the Australian Research Council (ARC LP100100292). The funding body will not have access to personally identifying information about you that may be obtained during the project.

#### I am interested – what should I do next?

If you would like to participate in this study, please contact Christine Yates for details of the next step.

You will be provided with further information to ensure that your decision and consent to participate is fully informed.

Thank You!

QUT Ethics Approval Number: 0800000684

#### **Appendix B: Participant information sheet**



## PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT Interview

## Informed for Health: Understanding health information literacy in Australia's ageing population

QUT Ethics Approval Number 0800000684

#### **RESEARCH TEAM**

Principal
Researcher: Christine Yates, PhD Research Student, Faculty of Science & Technology

Associate
Researcher(s):

Professor Helen Partridge, Principal Supervisor, Faculty of Science & Technology

#### DESCRIPTION

This project is being undertaken as part of a PhD program of research by Christine Yates at Queensland University of Technology, Brisbane.

The project is funded by the Australian Research Council (ARC LP100100292). The funding body will not have access to project data personally identifies you.

The purpose of this research is to develop greater understanding about the ways people experience using information to learn about their health. The research team requests your assistance in order to gather information on the way people aged between 45-64 are using information to learn about their health.

#### **VOLUNTARY PARTICIPATION**

Your participation in this project is entirely voluntary. If you do agree to participate, you can withdraw from the project at any time without comment or penalty. Any identifiable information already obtained from you will be destroyed. Your decision to participate, or not participate, will in no way impact upon your current or future relationship with QUT.

Your participation will involve an audio recorded interview at a time and location convenient to you, that will take approximately 1 hour of your time. Questions will include asking you to describe a time when you used information to learn about your health, and the kinds of information you have used to learn about your health.

#### **EXPECTED BENEFITS**

It is expected that this project will not benefit you directly. However, it may benefit future work and research into how people use information to learn about their health.

#### RISKS

There are no risks beyond normal day-to-day living associated with your participation in this project.

#### PRIVACY AND CONFIDENTIALITY

All comments and responses will be treated confidentially and will be made anonymous when transcribed. The names of individual persons are not required in any of the responses. Any data collected as part of this project will be stored securely as per QUT's Management of research data policy.

All interviews will be audio-recorded and later transcribed. Only the PhD Research Student will have access to audio recordings from interviews conducted. Audio recordings will be destroyed once written transcripts have been completed. Due to the qualitative nature of data collection in the interview process it is not possible to participate in the project without being audio-recorded.

The comments provided as part of the interview process will not require verification at the conclusion of the interview or prior to final inclusion. Other members of the Research Team will have access to written transcripts from the interviews. This information will only be provided in a form that does not identify you.

It is intended the results of this research will be publically presented and published. Data may also be published in research reports as well as relevant journals and conference papers. In all instances this information will only be provided in a form that does not identify you. Please note that non-identifiable data collected in this project may be used as comparative data in future projects.

#### **CONSENT TO PARTICIPATE**

Once you understand what the project is about, and if you agree to participate, we ask that you sign the Consent Form (enclosed) to confirm your agreement to participate.

#### QUESTIONS / FURTHER INFORMATION ABOUT THE PROJECT

If have any questions or require any further information about the project please contact one of the research team members below.

Christine Yates - PhD Research Student Professor Helen Partridge - Principal Supervisor Information Sciences Discipline Information Sciences Discipline Faculty of Science and Technology Faculty of Science and Technology

Phone: 0430 356 829 Phone: (07) 3138 9047

Email: cl.yates@qut.edu.au Email: h.partridge@qut.edu.au

#### CONCERNS / COMPLAINTS REGARDING THE CONDUCT OF THE PROJECT

QUT is committed to research integrity and the ethical conduct of research projects. However, if you do have any concerns or complaints about the ethical conduct of the project (approval number: 0800000684) you may contact the QUT Research Ethics Unit on 3138 5123 or email <a href="mailto:ethicscontact@qut.edu.au">ethicscontact@qut.edu.au</a>. The QUT Research Ethics Unit is not connected with the research project and can facilitate a resolution to your concern in an impartial manner.

Thank you for helping with this research project. Please keep this sheet for your information.

#### **CONSENT FORM FOR QUT RESEARCH PROJECT**

#### Informed for Health: Understanding health information literacy in Australia's ageing population

#### RESEARCH TEAM CONTACTS

Email: cl.yates@qut.edu.au

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Information Sciences Discipline Faculty of Science and Technology Phone: (07) 3138 9047

Professor Helen Partridge - Principal Supervisor

Email: h.partridge@qut.edu.au

#### STATEMENT OF CONSENT

By signing below, you are indicating that you:

- have read and understood the information document regarding this project
- have had any questions answered to your satisfaction
- understand that if you have any additional questions you can contact the research team
- understand that you are free to withdraw at any time, without comment or penalty
- understand that you can contact the Research Ethics Unit on 3138 5123 or email <a href="mailto:ethicscontact@qut.edu.au">ethicscontact@qut.edu.au</a> if you have concerns about the ethical conduct of the project
- understand that the project will include audio recording
- agree to participate in the project
- understand that non-identifiable data collected in this project may be used as comparative data in future projects

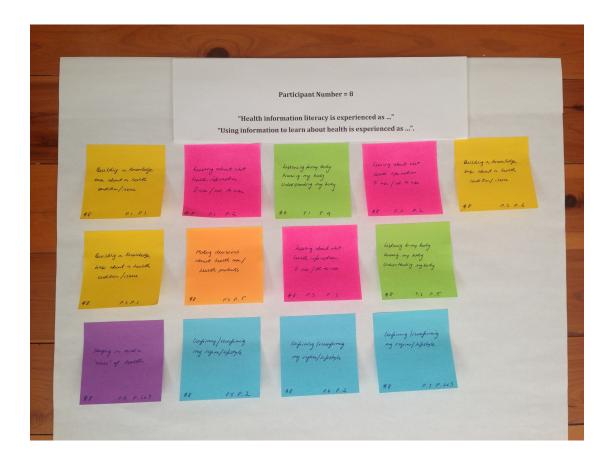
Name	
Signature	
Date	

Please return this sheet to the investigator.

#### **Appendix C: Interview introduction**

Thank you again for agreeing to take part in an interview for my research project, which is investigating how people experience using information to learn about their health. During the interview I'm going to ask you to talk about different times when you have used information to learn about your health, and to talk about kinds of information that you use to learn about your health. It is really important that you understand there are no right or wrong answers to the questions I am asking you today. I am interested in listening to your experiences, and to give you the opportunity to describe these in your own words. After you have answered each question I will most likely ask you for some more details about what you have discussed. This is so I can be sure that I have clearly understood what you have told me. During the interview I may write some notes occasionally and when I do, it is to remind me of different points that I want to ask you to explain further later on. I will be audio recording your interview and I will transcribe this into a text transcript. Once I've produced a text transcript of your interview, the audio recording will be destroyed. All the answers and things we discuss today are strictly anonymous and confidential. When I write up my research report I will be using extracts from your interview transcript. You will not be personally identified however, as I will give you a pseudonym that is a participant number. Finally, I also want to remind you that taking part in this interview is completely voluntary, and that you are free to withdraw from the process at any time. Do you have any questions about the interview before we begin?

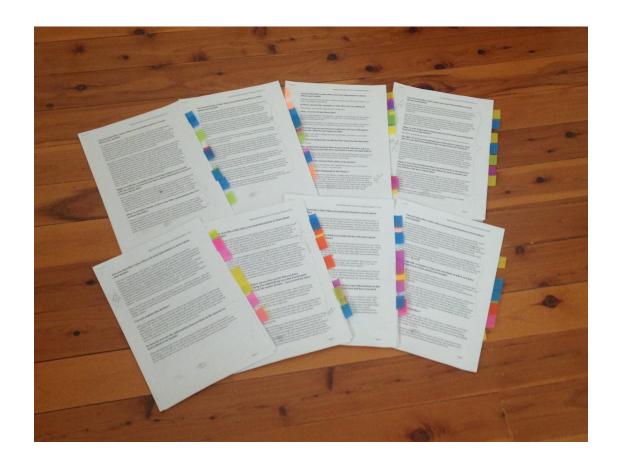
### **Appendix D: Participant meaning statements**



## **Appendix E: Groupings of meaning statements**



### **Appendix F: Interview transcripts**



### Appendix G: Dimensions of variation in the phenomenon of health information literacy

Category	Building a new	Weighing up	Discerning valid	Paying attention	Staying informed	Participating in	<b>Envisaging health</b>
	knowledge base	information	information	to bodily information	about health	learning communities	
Experienced nature of information	information sources; facts and experiences	facts and experiences	something that exhibits or comprises particular qualities; suitable for needs and situation; obtained from a trustworthy source	physical or psychological changes	something that is relevant or potentially relevant to a particular situation or stage of life	relationships with other people; tangible and intangible in character	role models; visual images of past and present
Experienced object of information	layered or staged manner; kaleidoscopic	reflective or introspective manner	filtered or sifted manner	observational or reflective manner	fragmented manner	individual or collective manner	superimposed manner
Experienced act of using information	developing comprehensive understanding	weighing up information to contemplate various options	being aware of the background or biases in health information	interpreting bodily information	collecting and storing information about health	obtaining and imparting information	imagining different possibilities; contemplating/ envisaging different scenarios
Experienced outcome of using information	answering questions; contextually dependent	informing a decision-making process	distinguishing information that is valid and useable	engagement with other health information; guiding future behaviour	enhancements to people's knowledge about health	changes or contributions to people's health knowledge; contextually dependent	possible visions of the future self; raising awareness of health practices

Category	Building a new knowledge base	Weighing up information	Discerning valid information	Paying attention to bodily information	Staying informed about health	Participating in learning communities	Envisaging health
Experienced object of learning	comprehensive content about a particular health topic	costs, risks, benefits and potential outcomes of available options	evaluating information	self awareness of the body	personally relevant health matters (actual or potential)	myriad of information relating to health	differences in how the human condition may be experienced
Experienced act of learning	the practice of researching	contemplating various details; reflecting on significance for personal wellbeing	comparing and contrasting information	reflecting on physical or psychological changes	encountering and pursuing information	socially interacting with others	reflecting on possible situations; considering and imagining personal desire for future health
Experienced outcome of learning	construction of new knowledge base; awareness of information sources	making a decision	adoption or dismissal of information	identified course of action	confirming or changing practices in a health regime	changes to personal and community knowledge about health	the ideal future self; reminding/ validating good health
Experienced role	researcher	empowered and informed consumer	analyst	interpreter	lifelong learner	donor and beneficiary	navigator

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