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**Developments in Health Literacy Over Time: A  
Longitudinal Qualitative Research Study**

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**A thesis submitted for the degree of Doctor of Philosophy**

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Discipline of Health Promotion

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Submitted December, 2019

*Dedicated with love and gratitude to the memory of my parents John and Marie McKenna, and my brother Brian. Each of whom has inspired me and brought me to here.*

## AUTHOR'S DECLARATION

I declare/certify that, except where acknowledged, all parts of this thesis were undertaken by myself. The information contained in this thesis has not been used to obtain a degree in this, or another University.

*Verna McKenna*

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Verna McKenna

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# ABSTRACT

## **Introduction**

Conceptualising health literacy as a relational concept, which involves how individuals interact with complex health and social systems, requires a greater understanding of the context of people's health experiences.

## **Aims**

The overall aim of this study is to examine how health literacy develops over time in the management of health and illness among a group of individuals attending a structured cardiovascular risk reduction programme. The study also examines the facilitators and barriers in that process.

## **Methods**

A longitudinal qualitative study design was undertaken to address the study aims. A semi-structured interview guide, informed by Sørensen's conceptual model of health literacy, was used to explore the development of health literacy and to identify changes in knowledge, attitudes and experiences over time at three separate time points. The HLS-EU-Q47 was used to provide a guide on the health literacy level of participants at Phases 1 and 3 of the study. Twenty-six participants were purposefully selected from a cardiovascular risk reduction programme. Thematic analysis and longitudinal question interpretive and analytic frameworks were used in data analysis.

## **Results**

Results from the study showed developments in health literacy across the functional, interactive and critical levels of health literacy. The health care provider provided a crucial role for individuals in the development of all aspects of health literacy. While, in the main, individuals reported perceptions of increased feelings of empowerment and control related to managing health and illness, these developments could be adversely impacted by both psychological and structural barriers.

## **Conclusions**

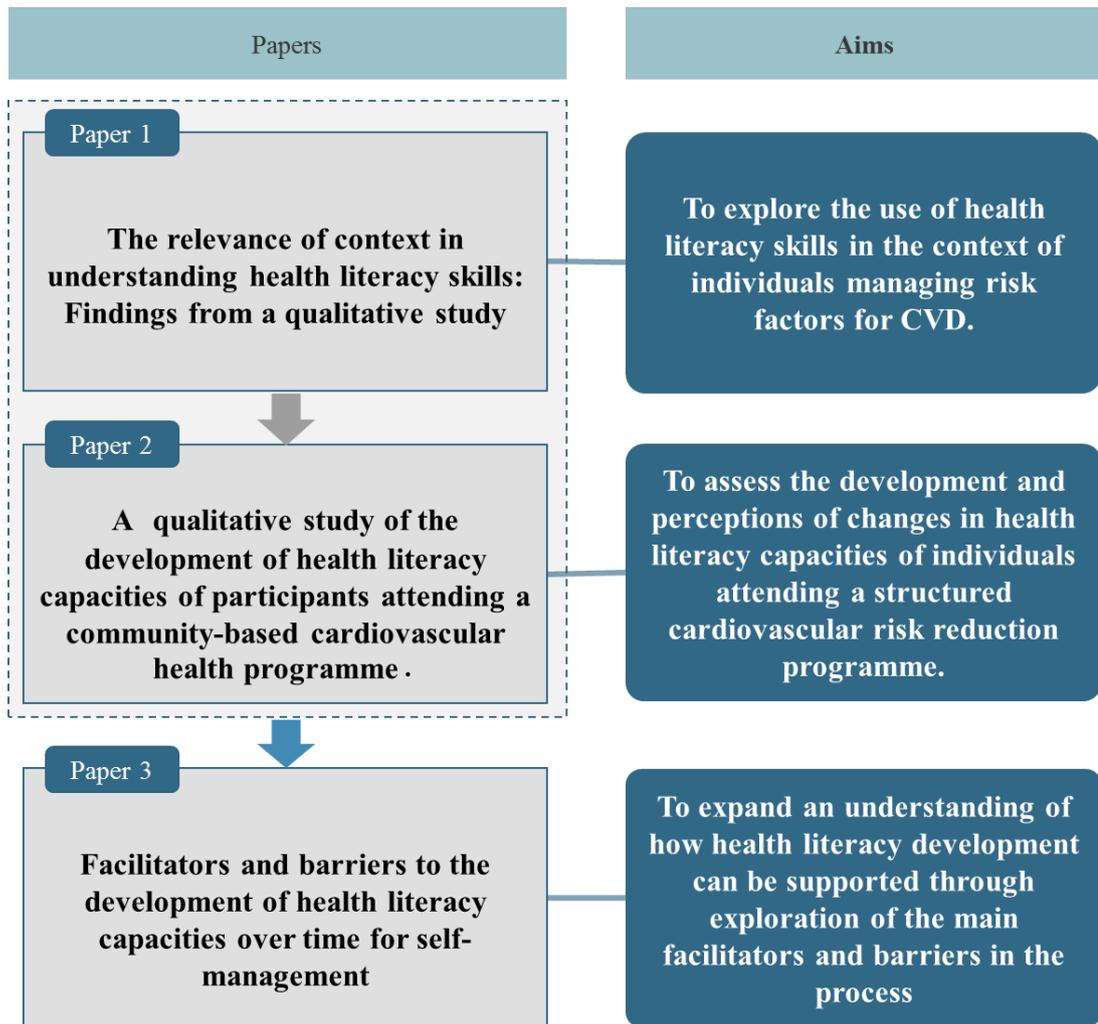
Positive developments in health literacy capacities are important for the self-management of health and illness. Longitudinal findings underscore the importance of healthcare providers in supporting the development of health literacy. These findings lend support to the need to integrate health literacy into health care interventions and to incorporate health literacy into medical training and other curricula for health professionals.

**Keywords:** Longitudinal qualitative research; self-management; health literacy; health care provider; determinants of health; health experiences; communication.

## OVERVIEW OF PAPERS

A flow chart of the papers and their aims is presented in Figure 1

Figure 1. An overview of the papers in this thesis



**Paper I: The relevance of context in understanding health literacy skills: Findings from a qualitative study**

McKenna, V. B., Sixsmith, J., & Barry, M. M. (2017). The relevance of context in understanding health literacy skills: Findings from a qualitative study. *Health Expectations*, 20(5), 1049-1060 <https://doi.org/10.1111/hex.12547>

**Contribution:** Devising the research methodology, developing semi-structured questionnaires, recruitment of study participants, data collection (interviews and HLS-EU surveys), transcribing of some interviews, thematic analysis of interview data, and statistical analysis of survey data and write-up of findings.

**Paper II: A qualitative study of the development of health literacy capacities of participants attending a community-based cardiovascular health programme.**

McKenna, V.B., Sixsmith, J., & Barry, M. M. (2018). A qualitative study of the development of health literacy capacities of participants attending a community-based cardiovascular health programme. *International Journal of Environmental Research and Public Health*, 15(6), 1157 <https://doi.org/10.3390/ijerph15061157>

**Contribution:** Devising the research methodology, developing semi-structured questionnaires, follow up with study participants, data collection (interviews), transcribing of some data from interviews, thematic analysis of data and application of aspects of longitudinal question framework and write-up of findings.

**Paper III: Facilitators and barriers to the development of health literacy capacities over time for self-management**

McKenna, V.B., Sixsmith, J., & Barry, M. M.. (2020) Facilitators and barriers to the development of health literacy capacities over time for self-management *Health Literacy Research and Practice*. 4(2):e104-e118 <https://doi.org/10.3928/24748307-20200221-01>

**Contribution:** Devising the research methodology, developing semi-structured questionnaires, data collection (interviews and HLS-EU surveys), thematic analysis of data and application of longitudinal question frameworks, design of matrices for summing and ordering data across the three time points, and write-up of findings.

## CHAPTER 1: INTRODUCTION

### 1.1 Background

Health literacy is a complex social construct (Pleasant, 2014) and a critical factor in empowering people to take charge of their health (Kickbusch, Pelikan, Apfel, & Tsouros, 2013). It is a key concept in health promotion policy that can be traced back to the Ottawa Charter (WHO 1986) and its conceptualisation of health promotion as a process of “empowering people to increase control over and improve their health” (WHO, 1986, p.1). This definition resonates with the WHO’s conceptualisation of health literacy, which firmly reflects a health promotion perspective (Nutbeam, 2008), whereby health literacy is viewed 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 good health” (Nutbeam, 1998, p. 10). Health literacy has received increased recognition in subsequent health promotion declarations, with the recent Shanghai Declaration on promotion of health in the 2030 Agenda for Sustainable Development (WHO, 2016a, 2017) identifying health literacy as a critical determinant of health. It also commits to developing, implementing and monitoring intersectoral national and local strategies for strengthening health literacy in all populations and in all educational settings. In addition, it is recognised that health literacy interventions and practices can contribute to reducing health disparities, which can promote health equity and social justice (International Union for Health Promotion and Education, 2018; Logan et al., 2015). Health literacy is understood to be

linked to literacy and encompasses people’s knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Sørensen et al., 2012, p.3).

The IUHPE’s 2018 position statement on health literacy define it as” the combination of personal competencies and situational resources needed for people to access, understand, appraise and use information and services to make decisions about health. It includes the capacity to communicate, assert and act upon these decisions “(p. 79).

The definition of health literacy used in this study, includes competencies and capacities. Capacity refers to the skills, abilities and potentialities of individuals to effectively access, understand, appraise and use information (Institute of Medicine, 2004; Mancuso, 2010; Centers for Disease Control and Prevention, 2016). Health literacy competencies refer to the skills and abilities people use to realize their potential in health situations and make sense of health information and services (CDC, 2019) Anyone who needs health information and services also needs health literacy competencies to access, understand, appraise and apply health information as set out in Sørensen et al, 2012)

The current study addresses health literacy ‘capacities’, which refer specifically to the skills, abilities and potentialities of individuals to effectively access, understand, appraise and use information (Institute of Medicine, 2004; Mancuso, 2010; Centers for Disease Control and Prevention, 2016).

The ability of a person to understand and process health information can become restricted by hindering factors, which have to do with the way health information is written and/or the way it is communicated by health professionals. Nutbeam (2000) has outlined three levels of health literacy, functional, interactive and critical. Functional literacy refers to the basic level of reading and writing skills required to obtain, understand and use factual information on, for, example health risks, medication prescriptions or how to use the health care system. Interactive literacy refers to advanced skills that allow a person to extract information, derive meaning from different sources of communication, and apply new information to changing circumstances. Critical health literacy refers to more advanced skills for critically analysing and reflecting on information or advice received and using information to exert greater control over life events and situations. However, it is recognised that even with advanced literacy skills, the ability to obtain, understand and apply health information in a specific health context can be poor (Nutbeam, 2015). Although different definitions of health literacy are used and health literacy is an evolving concept, there is agreement that health literacy means more than simply being able to read pamphlets, make appointments, understand food labels or comply with prescribed actions from a doctor (Nutbeam, 2000; WHO, 2016b).

Health literacy is understood to be more than a personal resource, with the growing recognition that higher levels of health literacy can also yield social benefits such as mobilising communities to play an active role in improving their own health and the engagement with community action for health to address the social, economic and environmental determinants of health. (Nutbeam, McGill, & Premkumar, 2017; Chinn, 2011) The WHO (2015) redefined health literacy as “the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health” (p. 12) This means that attention is shifting from a view of health literacy as the sole responsibility of individuals towards equal attention being given to ensure that health systems and governments present clear, accurate, appropriate and accessible information for diverse audiences (Rudd, 2015). The WHO (2017) also recognise the crucial role of health literacy in meeting the social, economic and environmental ambitions of the 2030 Agenda for Sustainable Development, which calls on UN member states to support the introduction of Universal Health Coverage by 2030. Health literacy is viewed as a crucial driver in ensuring the success of such an initiative. Promoting health literacy is seen as critical to transforming health systems to provide quality, people-centred and equitable care. This requires users to be able to access information about the health system, its services and other patients’ experiences to make informed health-care decisions, and to contribute to policy-making, decision-making, monitoring and accountability (WHO, 2016b; United Nations, 2015).

## 1.2 Health literacy: chronic illness and self-management

Health literacy plays a crucial role in chronic disease management (Poureslami, Nimmon, Rootman & Fitzgerald, 2017; van der Heide et al., 2018; Dunn & Conard, 2018). Effective chronic disease prevention and self-management both require an active and informed public with the health literacy competencies necessary to carry out self-care plans and make informed decisions related to health promotion behaviour and lifestyle changes (Pleasant, 2014). This is relevant across both primary and secondary health care.

For lifestyle-related diseases such as cardiovascular disease (CVD) and diabetes, extensive and on-going patient self-care is required (Ishikawa et al., 2009; van den Brouke et al., 2014). The European Diabetes Literacy Project (van den Brouke et al.,

2014) focussed on the development of an EU-wide strategy for diabetes self-management education. This was developed in recognition of barriers to effective self-management faced by patients with limited literacy. The project was also based on the premise that patient empowerment through self-management education is viewed as central to improving the quality of diabetes care and preventing Type 2 Diabetes.

Limited functional health literacy is known to have negative effects on patient knowledge and understanding regarding health, disease, medications and treatment (Gerber et al., 2005; Guerra, Dominguez & Shea, 2005; Kalichman et al., 2000; Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005) as well as on the desire to participate in health care decision making. (Manusco and Rincon, 2006; Bárragan et al., 2005). Health literacy has dynamic and important interfaces with CVD prevention, recognition, management and treatment (Magnani et al., 2018). A statement published by the American Heart Association (AHA) in 2018 (Magnani et al., 2018) summarizes contemporary studies, drawing on a synthesis of the existing literature, informed by systematic reviews, relevant to health literacy and CVD and positions health literacy as a crucial concept in CVD research and healthcare. The authors identified only a limited number of studies that examined health literacy as an independent variable in relation to cardiovascular risk, cardiovascular events, and strategies to improve or augment secondary prevention after cardiac events. Nevertheless, health literacy has been associated with poorer outcomes preceding and following coronary events. In a hospital-based registry of 1967 patients (1197 [60.9%] with acute coronary syndrome), limited health literacy and numeracy proficiency were associated with decreased adherence to medications preceding admission (Kripilani et al., 2015).

A study by Dunn, Margaritis, & Anderson, (2017) used semi-structured interviews with both patients and health care providers to understand the health literacy of patients with CVD and diabetes. An important finding was the critical role of social support systems in the development of health literacy for patients with CVD and diabetes, as well as in reducing anxiety. A review on the role of health literacy for self-management skills in chronic disease management (Mackey, Doody, Werner & Fullen, 2016) concluded that there is an association between health literacy and self-management skills; however, more robust intervention research is needed to fully

understand the magnitude and direction of that association. Interactive and critical health literacy are acknowledged to play an important role in the successful management of chronic illness. While recognising that functional, interactive and critical health literacy each impact in a unique way on (the abilities for) self-management, in general interactive and critical health literacy are stronger predictors for successful self-management than functional health literacy (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). The WHO's 2013-2020 action plan for the global strategy for the prevention and control of NCDs has highlighted the essential need for family and community-based interventions to adequately address the fact that causal risk factors are deeply entrenched in the social and cultural framework of society (WHO, 2013). The plan addresses health literacy as an important element in reducing risk factors and the creation of health promotion environments and aims to:

develop, strengthen and implement, as appropriate, multisectoral public policies and action plans to promote health education and health literacy... as important factors in furthering the prevention and control of non-communicable diseases, recognizing that a strong focus on health literacy is at an early stage in many countries. (p. 96)

### 1.3 Health literacy: the policy context

Health literacy is relevant to all five areas of health promotion action defined in the WHO Ottawa Charter for Health Promotion (building healthy public policy, creating supportive environments, strengthen community action, developing personal skills and reorienting the health services) (WHO, 1986). Promoting an awareness of health literacy contributes to health promotion planning, advocacy, and programme and policy designs that can improve individual and community health and ultimately promote health equity (IUHPE, 2018). Health literacy has been consistently emphasised within WHO health promotion policy initiatives and strategies. In 2009 health literacy was named as one of the main themes of the 7<sup>th</sup> WHO Global Conference on health promotion held in Nairobi. This was followed by the publication in 2013 of 'Health Literacy: The Solid Facts' (Kickbusch et al., 2013). This marked an important development in focussing attention on health literacy as an important public health policy issue and highlighted action points for health literacy practice including a focus on the attributes of health literacy settings. Health literacy was again

emphasised as one of three action areas in the Shanghai Charter on Health Promotion, which was ratified at the 9<sup>th</sup> WHO Global Conference on Health Promotion in Shanghai in 2016 (WHO, 2016a; WHO, 2017). Health literacy has also been integrated into other policy directives including the Sustainable Development Goals (SDGs) and the UN Political Declaration on the prevention and control of non-communicable diseases (United Nations, 2018). This Declaration included strengthening health literacy through education in one of its action areas. The WHO has also supported the development of WHO Health Literacy demonstration projects across a number of WHO regions. These projects promote the use of a health literacy toolkit developed in collaboration with the Deakin University in Melbourne, Australia. Members of the United Nations Economic and Social Council have endorsed that health literacy is an important factor in the overall public health of a country. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to significantly increase the effectiveness of health care programmes and treatment. The Council provided a clear mandate for action in 2009 stressing that "health literacy is an important factor in ensuring significant health outcomes and in this regard, call for the development of appropriate action plans to promote health literacy" (United Nations, 2009).

A paper published by Quaglio et al., 2016, usefully outlines key development in the European context. The EU's European Commission has pointed out the necessity for policy efforts at the EU level as well as fundamental principles and values for actions on health. In recognition of the growing emphasis on patient-centred healthcare, citizens' empowerment is highlighted as a core value indicating that "community health policy must take citizens' and patients' rights as a key starting point based on participation in, and influence on, decision making as well as competences needed for well-being including health literacy" (European Commission, 2007, p. 4). A number of countries have developed national policies, strategies and guidelines on health literacy including the United States of America, Canada, New Zealand, Austria, Scotland and Ireland (Quaglio et al., 2016). A study by Trezona, Rowlands & Nutbeam (2018) examined a number of national health literacy policies to identify their potential for improving health literacy and health outcomes. Overall, the findings indicated that most policies present health literacy as a universal challenge; recognize the importance of professional education in improving the quality of communication; and, recognize

that the health literacy responsiveness of the health system needs to be improved. Health literacy has been recognised as the key to developing policies that are effective in improving health, improving the effectiveness of health systems and promoting equity (Rowlands et al., 2018). The WHO European Region published a health evidence synthesis in 2018 that highlighted the need to broaden the range of areas of activity required for holistic health literacy policies.—This included the need to strengthen the evidence base for health literacy at all societal levels, incorporating robust qualitative and quantitative evaluations into health literacy policies and interventions, and to incorporate facilitators of successful implementation into health literacy policy (Rowlands et al., 2018).

A key development at the European level is the *draft WHO European Roadmap for Implementation of Health Literacy Initiatives Through the Life Course* (WHO, 2019) which is aimed at supporting health literacy development over the life course, through five strategic directions: increasing capacity building on health literacy; advocating and facilitating cross-sectoral integration of health literacy; advancing development and implementation of health literacy initiatives; improving digital health literacy; and strengthening the measurement, monitoring and evaluation of health literacy (WHO, 2019).

#### 1.4 Ireland-Health literacy and policy

An early study on literacy in Irish adults (Central Statistics Office, 2012) found that 1 in 6 Irish adults are at or below level one on a five level literacy scale (International Adult Literacy Survey) (Kirsch, 2001), meaning that they may be unable to understand basic written information. Findings from the European Health Literacy Survey (Sørensen et al., 2015) found that 40% of Ireland's population had limited health literacy. This represents a significant proportion of the Irish population that have difficulty accessing, understanding, appraising and applying information related to health (Doyle, Cafferkey & Fullham, 2012). The Health Promotion Strategy 2000-2005 acknowledged poor literacy skills as a barrier to accessing health information and services (Department of Health, 2000). In 2002 the National Adult Literacy Agency (NALA) launched the Health Literacy Policy and Strategy Research Report (NALA, 2002) which marked the first time literacy was significantly discussed in

relation to health in Ireland. NALA, in partnership with the Health Service Executive (HSE), produced a Literacy Audit for Healthcare Settings resource in 2009 to address the issue of literacy demands in health care settings (Lynch, 2009). NALA, in partnership with the Department of Health (2013), have also produced a Health Literacy Action Plan that forms part of the Healthy Ireland framework (2013-2025). The Healthy Ireland framework contains the first ever government commitment to health literacy in its statement to “address and prioritise health literacy in developing future policy, educational and information interventions” (Department of Health, 2013, p. 25). The HSE’s Healthy Ireland Implementation Plan 2015-2017 contains a specific commitment to “promote and provide national tools for training, resource development, and health literacy audits in services to raise standards of health literacy among patients, service users, and carers” (HSE, 2014, p. 19).

### 1.5 Health literacy and health experiences and outcomes

The impact of low levels of health literacy on health outcomes has been well documented in Ireland, as well as at an international level and the WHO has highlighted health literacy as a social determinant of health (Commission on Social Determinants of Health, 2008). Research demonstrates strong associations between health literacy and the social determinants of health. Findings from the European Health Literacy Survey identified that certain sub groups of the population, such as those with low income, lower education (including those with lower access to education and lower educational attainment); and, lower social status had higher levels of limited health literacy (HLS-EU Consortium, 2012). Similarly, a study examining population health literacy and the complexity of health information, showed strong associations with the social determinants of health (SDH), with those already at risk of lower health through SDH also being at higher risk of low health literacy (Rowlands et al., 2015).

Low literacy in a population is associated both directly and indirectly with a range of poor health outcomes (Parker, 2000). Many different aspects of healthcare are impacted, from responsiveness to health education messages, to engagement with disease prevention services and also the poor self-management of disease (DeWalt, Berkman, Sheridan, Lohr & Pignone, 2004; Berkman, Sheridan, Donahue, Halpern,

& Crotty 2011; Sheridan, et al., 2011). A longitudinal cohort study in the UK concluded that a third of older adults in England have difficulties reading and understanding basic health related written information and that this limited understanding is associated with higher mortality (Bostock & Steptoe, 2012). The literature on health literacy has predominately emphasised the area of functional health literacy and how this effects both *health behaviours* associated with and the *treatment* of communicable and non-communicable diseases. This is a significantly important body of work that can impact on the health outcomes of individuals with low levels of functional health literacy. However, there is a need for further research that links the critical level of health literacy (i.e. information appraisal, understanding the social determinants of health and collective action) with interventions in the disease prevention and health promotion fields. From a health promotion context, critical health literacy is an important component in the uptake and maintenance of health behaviours that can prevent the onset of chronic illness. Where chronic illness already exists, it is an important part of the self-management of illness that the individual must engage with. Interactive and critical health literacy, aligned to the concept of health promotion, present health literacy as both a personal and population asset that can bring increased autonomy and control over health decision-making (Nutbeam, 2008; Pleasant & Kuruvilla, 2008; Mårtensson & Hensing, 2012).

Any examination of how individuals engage with self-management must address the health literacy of both the individuals and health practitioners, as both are working together to address health issues (Zarcadoolas, Pleasant, & Greer, 2005), (Zarcadoolas, Pleasant, & Greer, 2009). Linking research across the two areas of health literacy and health communication is needed to ascertain the “efficacy of innovations in health communication and to explore how the unique characteristics of health and health care settings may inhibit or enhance communication objectives” (Rudd, Rosenfeld and Simonds, 2012, p.26).

## 1.6 Study context

This study examines how health literacy may develop over time among a group of individuals attending a structured cardiovascular risk reduction programme. It sets out to examine health literacy in the context of managing health and illness and includes

all aspects of health literacy (functional, interactive and critical). The rationale for the study is that health literacy is a generative concept that can change over time in the context of changing circumstances in an individual's daily life as regards his or her health needs (Zarcadoolas, Pleasant, & Greer, 2003; Kwan, Frankish, & Rootman, 2006). It sets out to examine how these changes might occur over time as well as the facilitators and barriers in that process. The current study addresses health literacy 'capacities', which refer specifically to the skills, abilities and potentialities of individuals to effectively access, understand, appraise and use information (Institute of Medicine, 2004; Mancuso, 2010; Centers for Disease Control and Prevention, 2016). This definition aims to capture and embrace the depth of health literacy as an asset (Nutbeam, 2008). It also incorporates the view of health literacy as being part of social practices rather than as solely skills based (Papen, 2008). As such, the starting point is that health literacy is viewed as more than an abstract skill that may be measured through individual performance tests (Papen, 2008). Health literacy is understood to be context-dependent and must, therefore, be understood within the social relations which shape the various aspects of health care provision and the management of health and wellbeing. This study adopts a qualitative approach and is concerned with moving away from a focus on functional health literacy, health literacy level measurement or the patient in the clinical setting to exploring developments in health literacy over time as individuals manage their health and illness in the context of their daily lives.

This study was underpinned by the Health Literacy Survey model empirically validated by Sørensen et al., (2012) whereby health literacy is recognized as a process involving the consecutive competencies of accessing, understanding, appraising and applying health information, which also links health literacy to its antecedents and consequences (Sørensen et al., 2012). According to the model, application of the competencies provides individuals with the abilities to take control over their health by overcoming personal, social, structural and environmental barriers to health. Health literacy is viewed as a dynamic construct and the skills and competencies of health literacy develop over the life course as contextual demands change over time (Levin-Zamir, Leung, Dodson, & Rowlands, 2017; Sørensen et al., 2012). This research study is concerned with the development of health literacy over time. Edwards, Wood, Davies, and Edwards, 2012 have pointed out that little is currently known or

understood about how health literacy might develop over time or the process by which people might become more health literate. Their Health Literacy Pathway model describes developments in health literacy for individuals but is overly focused on responding to ill-health rather than acknowledging the social determinants of health and the role of health promotion (Guzys, Kenny, Dickson-Swift, & Threlkeld, 2015). This study is focused on the practice of health literacy in the management of health and illness, including interactions with health professionals, and how broader social factors might impact on this development.

The current study is framed within the ‘asset model of health literacy’ which emphasises that health literacy is an asset to be developed and is seen as an outcome of health education and communication (Nutbeam, 2008). Health literacy is seen “as a means to enabling individuals to exert greater control over their health and the range of personal, social and environmental determinants of health” (p. 2074) and therefore, is clearly placed within a health promotion framework. Health literacy is viewed as a generative concept that develops over a lifetime (Zarcadoolas et al., 2003). This conceptualisation of health literacy lends itself to a longitudinal study design, which can explore developments and changes over time and is based on the Sørensen et al., (2012) definition of health literacy outlined earlier.

The research questions for the study are:

Does health literacy develop over time in the context of prevention and health promotion practices in the management of health and illness?

What are the barriers and facilitators to health literacy capacity development?

### 1.7 Study aim

The aim of this study is to investigate and describe how individuals participating in a structured cardiovascular risk reduction programme develop and practice health literacy in the management of their health and illness

Study objectives:

- To describe the experiences of individuals attending a structured cardiovascular disease (CVD) risk reduction programme in accessing, understanding, appraising and applying health information.
- To examine the barriers and facilitators to the development of health literacy for individuals in managing their health and illness over a 12 month period.
- To identify any changes in accessing, understanding, appraising and applying health information over a 12 month period.
- To explore the kinds of health literacy developments that occur.
- To examine the application of health knowledge to wider social contexts following participation in the programme.

A longitudinal study took place over a 12 month time period, following a group of participants attending a cardiovascular risk reduction programme, in order to address the aim and objectives of the study. The community based programme provides integrated care for people with a range of risk factors for cardiovascular disease (primary care) as well as those with established heart disease and those at high multi-factorial risk of developing the disease (secondary care) (Gibson et al., 2014). Participants are referred through various pathways including general practice and hospital departments (cardiology, stroke and endocrinology). These participants were

purposefully selected in order to capture the health care, disease prevention and health promotion domains of health literacy. Each phase of the overall study was linked to a particular time point in the programme. At Phase 1 (time point 1) participants were about to embark on a community-based cardiovascular risk reduction programme. The study focussed on exploring and describing how these individuals practice health literacy in their everyday management of health and illness. It also examined the barriers and facilitators identified in the process (Paper I). The second phase of the study (time point 2) collected data after 12 weeks of attending the programme. This allowed the study to examine any developments in health literacy capacities over the time period as well as a focus on the different levels of health literacy (Paper II). The final phase of the study (T3) examined overall changes in the 12 month time period (Paper III). Across all three study phases, it was apparent that the role of the health care provider was central in terms of initial descriptions of interactions (T1) and in terms of perceived changes in interactions and relationships (T2, T3). The longitudinal nature of the study provided a unique perspective on the experiences of participants in managing their health and illness.

## 1.8 Outline of thesis structure

The remaining chapters of the thesis consist of a review of the literature that informed the thesis, a summary of the methods used in each phase of the study, and the findings and their implications as reported in each paper. The papers are included at the end of the thesis (Appendices 1-3), followed by additional appendices.

Chapter 2 reviews the relevant literature including conceptualisations and measurement of health literacy. In addition, critical health literacy and the areas of social practices are also addressed.

Chapter 3 sets out the methodological basis of the study and the rationale for the chosen study design. The chapter explains how the pilot was conducted and the development of data collection tools. It also provides details on the procedures and methods employed by the study. Detailed accounts of thematic and longitudinal qualitative analysis are provided and linked to each of the published papers.

Chapter 4 summarises the findings from Papers I-III. Additional findings, not reported in the papers, are also presented here.

Chapter 5 discusses the findings of the study in the context of the existing literature and methodological issues are considered. The implications for research, practice and policy are also outlined.

Chapter 6 sets out the final conclusions and recommendations arising from the study.

## CHAPTER 2: LITERATURE REVIEW

### 2.1 Introduction

This chapter will provide an assessment of the research related to topics of relevance to the study question and begins with an exploration of the history and development of health literacy, as well as literature on advancements in conceptualisations of health literacy. The chapter will then discuss literature on the measurement of health literacy, both health literacy in general, as well as developments to measure critical health literacy specifically. This is followed by an exploration of the concept of critical health literacy, health literacy in relation to empowerment and self-efficacy and literature on developments in health literacy research. Health literacy as a social practice and critical realism, as a philosophical approach to the study is set out. The final element of this chapter will conclude with an overall summary.

### 2.2 History and development of the concept of health literacy

Health literacy has been a debated concept in the literature since the 1990s. Originally tied to the notion of compliance within the health care system, research activities were focused primarily on measurement and the functional aspects of reading and writing in healthcare contexts, an emphasis that can be attributed to a predominantly paternalistic focus in the medical field. A changing medical culture towards a more patient-centred approach dovetails with the development of broader understandings of health literacy in the 21<sup>st</sup> century.

Health literacy is linked to literacy (Sørensen et al., 2012). Literacy is the ability to read, write, speak and listen to a level that enables a person to communicate effectively, understand written information and participate fully in society (Public Health England, 2015). Historically it has generally been understood to be a collection of cultural and communicative practices shared among members of particular groups (Hobbs, 2016). As society has evolved so too has the complexity of the concept of literacy. The National Assessment of Adult Literacy (NAAL) (2003) acknowledges two distinctive elements of literacy, those that are task-based, and those that are skill-based (Kutner, Greenburg, Jin & Paulsen, 2006). Task-based literacy focuses on the

extent to which a person can perform key literacy tasks such as reading a basic text and writing a simple sentence. Skill-based literacy focuses on the knowledge and skills an adult must possess in order to perform these tasks. These skills range from basic, word-level skills (such as recognising words) to higher level skills (such as drawing appropriate inferences from continuous text) (Nutbeam, 2009; UNESCO, 2004; Kickbusch & Maag, 2008). The multi-dimensionality of literacy is also emphasised in the work of The United Nations Educational, Scientific and Cultural Organisation (UNESCO) which define it as the:

ability to identify, understand, interpret, create, communicate, compute and use printed and written materials associated with varying contexts. Literacy involves a continuum of learning in enabling individuals to achieve their goals, to develop their knowledge and potential, and to participate fully in their community and wider society (UNESCO, 2004: p. 13).

Low literacy in a population is associated both directly and indirectly with a range of poor health outcomes (Parker, 2000). Typically low literacy is often associated with poor socio-economic circumstances and in turn with adverse health effects that are independent of other risk factors (Jahan, 2008). The impact of low levels of literacy on health outcomes has been well documented across many countries. Different aspects of healthcare are impacted, from responsiveness to health education messages, to engagement with disease prevention services and also the poor self-management of disease (Dewalt et al., 2004).

Work in the USA is recognised as the starting point of the interest in investigating literacy skills relevant to health care. This followed on from a number of nationwide surveys of functional health literacy, which uncovered widespread difficulties with basic reading and writing (Kirsch, Jungeblut, Jenkins & Kolstad, 1993). These survey findings have identified the association of health literacy with the reading, writing and numeracy skills of individuals accessing health care service and health information (Mancuso, 2009). This focus led to the proliferation of the development of direct measures of reading and word recognition such as the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999; Davis, Michielutte, Askov, Williams, & Weiss, 1998). Screening questions about reading

ability have also been developed to assess these skills, again, in medical settings (Chew, Bradley, & Boyko, 2004; Morris, MacLean, Chew, & Littenberg, 2006). Developed on the basis of robust psychometric qualities, these measures have been utilised in many studies to examine and even predict patient outcomes. Patients with low scores on such tests have been found to have poorer overall health knowledge (Gazmararian, Williams, Peel, & Baker, 2003; Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005), worse health outcomes related to their health condition (DeWalt et al., 2004; Schillinger et al., 2002; Wolf, Gazmararian, & Baker, 2005) and higher rates of mortality (Baker et al., 2007, Bostock & Steptoe, 2012; McNaughton et al., 2015)

### 2.3 Conceptualisations of health literacy

Health literacy is not simply the use of literacy in a health context. Health literacy is now being defined as a unique social construct that, although sharing attributes with literacy is much more than the possession or use of literacy skills in a health context (Pleasant et al., 2016). Having a high level of literacy skills does not necessarily mean people will use those skills in relation to their health. Conversely, studies have also demonstrated that people with lower literacy and education levels can demonstrate both interactive and critical health literacy (Smith, Nutbeam & McCaffery, 2013). Therefore, health literacy can be viewed as what people do with the skills they do possess. This conceptualisation is also supported by the Calgary Charter on Health Literacy (Coleman et al., 2009) where health literacy is viewed as the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills. This approach goes beyond a focus on the level of skills that an individual possesses to an emphasis on what one actually does with those behavioural skills. It sees both health literacy and literacy as behaviours and, therefore, behaviour change is a valid outcome of improved health literacy (Pleasant, 2014; Coleman et al., 2009).

Over recent years health literacy has moved beyond just focusing on personal skills into a multidimensional and relational concept (Pleasant, 2014; Pelikan, Röthlin, & Ganahl, 2014). Multiple definitions have evolved over time (Sorenson et al., 2012;

Pleasant, 2014; Batterham et al., 2014) and are well documented in a number of reviews (Sørensen et al, 2012; Malloy-Weir, Charles, Gafni, & Entwistle, 2016). Core elements of current health literacy definitions include the following abilities: to access/obtain health information; understand health information; process/appraise health information and; apply/use health information (Pleasant, 2014). More recently there has been a commitment that future definitions should include system demands and complexities as well as individual skills and abilities; include measurable components, processes and outcomes; recognise potential for analysis of change and demonstrate linkages between informed decisions and actions (Pleasant et al., 2016).

Health literacy builds on the idea that both health and literacy are critical resources for everyday living and it is still termed as an emerging concept or developing field with definitions evolving since the early 1990s. As such there is no single universal definition of health literacy. Early definitions can be broadly classified into those that focus on the application of cognitive skills, such as reading and numeracy skills to understand and use information to function in the health-care setting (Kirsch et al., 1993; Nutbeam 1998; Seldon, Zorn, Ratzan, & Parker, 2000). Later definitions have expanded the concept to include social skills and applying these skills to include one's ability to access information and to promote and maintain health (Kickbusch, Wait & Maag, 2005; Rootman & Gordan-El-Bihbery (2008); Sørensen et al., 2012).

Developments in these definitions reflect a growing understanding that health literacy encompasses more than the ability to read and to comprehend health information (Kickbusch and Maag, 2008). The varying foci of different definitions can also be understood in terms of two distinct fields: medical/clinical and the public health/health promotion field. Within the medical/clinical fields health literacy is seen to refer to knowledge and actions within the health care setting *only* (Peerson & Saunders, 2009). Its most reductionist view places it firmly within a biomedical framework and emphasises the relationship between physician and patient, communication around prescriptions and better patient compliance with treatment regimens (Pleasant & Kuruvilla, 2008). Health literacy is viewed as a negative, a problem that patients have or as a risk factor (Pleasant & Kuruvilla, 2008; Nutbeam, 2008).

The second perspective on health literacy, the public health/health promotion context, places health literacy within a socio-ecological framework and views it as an asset.

Health literacy is viewed as a means of enabling individuals to exert greater control over their health and the range of social and environmental determinants of health (Nutbeam, 2008). This broader notion of health literacy moves beyond accessing information within health care settings towards developing the capacity to understand and act on information sources that are integral to making essential judgements and decisions outside of health related settings and about health *per se* (Peerson & Saunders, 2009). This is reflected in Kickbusch, Wait and Maag's (2006) context-based definition of health literacy as:

the capacity to make sound health decisions in the context of everyday life, at home, in the community, at the workplace, in the health care system, in the market place, and in the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information, and their ability to take responsibility. (p. 8)

Similarly, the Institute of Medicine (IOM), in the USA, defines health literacy as resulting from the interaction of individuals with the social and informational demands of the health contexts in their environment, which could include health care contexts, public health contexts, health promotion contexts or chronic disease management contexts. Health literacy is seen as a synergy between individuals and contexts and this is reflected in the IOM (2004) Health Literacy Framework, which underscores the essential contribution of literacy to health literacy and the fact that health literacy and general literacy can affect both health outcomes and costs to individuals and societies. Freedman et al., (2009) explicitly extend the concept of health literacy to 'public health literacy which comprises an understanding that health literacy is based on critical skills and civic orientation.

Building on this preliminary framework, Kwan, Frankish and Rootman (2006) identify both internal or personal and external factors that influence the health information context. These in turn influence the acquisition of health knowledge and subsequent health decisions and actions. In the WHO Glossary of Health Promotion, published in 1998, Nutbeam defined health literacy as 'cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health' (Nutbeam, 1998). This definition allows the potential for health literacy to be a useful composite health

promotion outcome measure as well as providing a more concrete meaning to the term ‘empowerment for health’, a key value within health promotion (Kickbusch & Maag, 2008). Health literacy is viewed as being critical to empowerment through improved access to health information and the capacity to use this information effectively (Nutbeam, 1998). The public health approach to health literacy sees the acquisition of health knowledge as an integral part of health literacy rather than a separate outcome (Nutbeam, 2000; Kickbusch, 2001; St. Leger, 2001).

Zarcadoolas et al., (2005) have defined health literacy in the context of society’s requirement for a plurality of literacies in order to function. Health literacy is defined as “the wide range of skills and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks and increase quality of life” (p.196). This definition refers specifically to the use of health information and concepts in making informed choices, reducing health risk and increasing quality of life (Gillis & Gray, 2012). These researchers have developed a multi-dimensional model of health literacy which integrates four interactive domains of literacy: science literacy, civic literacy and cultural literacy which build on the fourth dimension of fundamental literacy as the foundation of health literacy. This is similar to Nutbeam’s definition (2000), in its inclusion of the key processes of accessing, understanding and using health information as well as emphasising evaluating information as a key element (similar to the critical level where health information is analysed and applied).

Health literacy allows the public and personnel working in all health related contexts to find, understand, evaluate, communicate, and use information according to the Calgary Charter on Health Literacy (Coleman et al., 2009). Further, health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live healthier lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills. The level of skills and abilities an individual needs to successfully make informed decisions and to take and sustain actions that promote their health, prevent ill health and manage chronic illness, are dependent on the way information is made available and presented. It is also dependent on the environment in which individuals’ health actions are supported. A starting point in the exploration of a broader and more

complex understanding of the concept of health literacy must begin with the work of Nutbeam (2000) in which different ‘types’ or levels of health literacy are outlined. These serve to set out the practical application of literacy skills and range from those needed to be able to function effectively in everyday situations (functional/basic), to more advanced cognitive and literacy skills which can be used to actively participate in everyday activities and to apply new information to changing circumstances (interactive), through to the most advanced cognitive skills which can be applied to critically analyse information, and to use this information to exert greater control over life events and situations (critical literacy) (Nutbeam, 2000). The exact means by which these levels are operationalised continues to be debated. In terms of decision-making processes, the interaction between these three levels appears to be iterative rather than linear in nature (Smith et al., 2013). Studies have demonstrated that persons with lower education and literacy levels can exhibit interactive and critical level skills. In addition, high functional health literacy does not guarantee that an individual will demonstrate interactive and critical level skills. (Smith et al., 2013; Ishikawa & Yano, 2011; Chinn, 2011). Other authors have argued that the different levels are hierarchical and mutually exclusive (Higgins, Begoray, & MacDonald, 2009; Chinn, 2011).

Abel (2008) directly links definitions of health literacy to having an understanding of the social determinants of health and highlights that health literacy, understood in the context of health promotion, is about emphasising subjective well-being and social functioning over and above the confines of medically defined outcomes. He recognises that health literacy may have both different meaning and functions in different contexts. Within health promotion practice, health literacy is equated with understanding the conditions that determine health and knowing how to change them. Abel (2008) proposes that health literacy is linked to the idea of cultural capital which comprises people’s social abilities and competence for action

## 2.4 Measuring health literacy

As documented in a review on the assessment and measurement of health literacy by Mancuso (2009), the predominant early focus of health literacy on the ability to read medical advice led to the development of a wide range of measurement tools that focus on a narrow interpretation of health literacy, as set out earlier. These early screening tools and measures of health literacy attempted to objectively measure literacy skills in a health context. In response to the limitations of those approaches in terms of advancing knowledge, developments moved towards more systematic, yet subjective, tools to measure health literacy through self-reports (Pleasant, 2014). In objective measurement, people are challenged by standardized test stimuli to measure an underlying trait; in subjective measurement, people self-report their responses to questions about their experience, typically on Likert scales (Nguyen, Paasche-Orlow, & McCormack, 2017). A key challenge with the subjective approach is that it is not possible to know how a person's responses relate to their actual skill level. For example, people who have not had much exposure to the health system may not appreciate the high degree of complexity they may encounter, so they may have inflated responses (Nguyen et al., 2017). A recent meta-analysis found that health literacy had a positive impact on the self-care activities of people living with diabetes. but only for studies which assessed health literacy using self-report measures and not for those which used skills-based instruments (Marciano, Camerini & Schulz, 2019). Therefore, it is important to considering the type of health literacy measure used when examining the health literacy outcomes of various chronic illness self-management programmes.

Measures of health literacy can also be classified as measures of 'general or 'disease-specific' health literacy. A review by Braden, Neill, Ignacio & Ziebland (2014) which focussed on 35 self-administered health literacy instruments, classified measures into two groups: general (stated as measuring "health literacy", or literacy and its implications for general use of health information); and condition- or specialty-specific (stated as measuring "literacy" with a health-related prefix, such as "oral health literacy or "colon cancer literacy").

Narrow definitions of health literacy, and the associated measurement tools, are less suited to the field of health promotion, which addresses a much broader understanding of the determinants of health. This view was supported by a call for a greater emphasis on a public health perspective and for taking health literacy research outside the realm of clinical settings (Peerson & Saunders, 2009). These earlier instruments have also been challenged for being too clinician-centred, psychometrically questionable and as representing only a partial measure of the factors that influence patients' ability to stay healthy or manage their illness. (Barber et al., 2009; Jordan, Osborne, & Buchbinder, 2011). It is also recognised that both the theoretical understandings and methods of measuring the complex social construct of health literacy are still undergoing evolution (Pleasant, 2014; McCormack, Haun, Sørensen, & Valerio, 2013).

A number of reviews have charted the proliferation in the development of various measures (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014; Altin, Finke, Kautz-Freimuth, & Stock, 2014; Guzys et al., 2015, Liu et al., 2018), together with various definitions and frameworks (Sørensen et al., 2012; Guzys et al., 2015; Pleasant, 2014; Haun et al., 2014). Haun, Luther, Dodd, & Donaldson (2012) examined measurement variation for health literacy assessments for the Short Form of the Test of Functional Health Literacy in Adults; the Rapid Estimate of Adult Literacy in Medicine; and a 4-Item Brief Health Literacy Screening Tool (known as the BRIEF). Findings indicated that the instruments measure health literacy differently and, therefore, are likely to be conceptually different. Similar findings on the lack of consistency between measurement tools, leading to difficulties in interpretations and comparison, were highlighted by Jordan, Osborne and Buchbinder, (2011). Overall, these reviews highlight the absence of a consensus on measurement, or the availability of a single rigorously validated health literacy measure that addresses the full range of dimensions represented in the complexity of the health literacy construct. In addition they note a continued dependence on assessment formats, rooted in functional health literacy and the clinical setting (Haun et al., 2013; Altin et al., 2014; Liu et al., 2018). Guzys et al., (2015) also highlight the need for a greater emphasis on critical health literacy as espoused in the public health literature, including exploring health literacy within the context of families, communities and population groups. The authors argue that such an approach would, in turn, capture the dynamic relationships within

communities as well as the societal influences on health knowledge, beliefs and behaviours.

Sørensen et al., (2012) acknowledge that the ability to interpret and evaluate health information cannot be restricted to medical issues but must extend to health promotion and prevention. The development of the Health Literacy Survey European Questionnaire (HLS-EU-Q) followed a concept validation approach in line with the principles outlined by Pleasant, McKinney, & Rikard, (2011). The process began with a systematic review of existing definitions and models of health literacy to create an integrated definition and conceptual model of the health literacy concept (Sørensen et al., 2012). The HLS EU consortium developed a 47 item health literacy scale, which explicitly addresses the areas of cure and care (managing symptoms, complaints, illness and treatments), disease prevention (managing risk factors for health) and health promotion (managing resources for health and well-being) (HLS-EU Consortium, 2012). The European HLS-EU-Q is one of a smaller number of health literacy measurement instruments, which focusses on self-report as a method of health literacy evaluation (Pleasant, 2014). Although potential criticisms of self-report measures include questions regarding accuracy, their potential for validating the broader theoretical constructs of how health literacy actually functions in the lives of individuals, communities and populations is considered valuable (Pleasant, 2014).

An interesting study by Gerich and Moosbrugger (2018) focussed on generating an in-depth understanding of factors and experiences associated with high or low subjective HLS-EU scores. The study focussed in particular on exploring the extent to which high HLS-EU scores reflect the health-related empowerment of individuals as a prerequisite to make informed decisions about their health and treatment. This was achieved, firstly, through the use of cognitive interviews with twenty individuals which found that the rating of subjective health literacy depended on various factors including health-related knowledge, personal and social resources, locus of control, patient-doctor interaction, prior experience and task awareness, trust and health-related activation. Based on these results a quantitative study then used measures of the factors identified to more systematically investigate the results. Findings showed that high scores on the subjective HLS-EU may actually reflect high empowerment (high personal and social resources) as well as motivation and competence to access

health information. It may also reflect low personal health-related competence and involvement but high external locus of control and having a high level of trust that the health system and health experts will maintain health and resolve health problems. The authors conclude that while the HLS-EU-Q can be considered a subjective measure of the manageability of health related tasks, findings using the measure alone cannot provide information about specific background and expected consequences of high and low scores. This also ties in with the view that health literacy relates to what people do with the skills they possess (Pleasant 2016) as outlined earlier.

Another assessment tool, the Health Literacy Questionnaire (HLQ) was developed using a validity-driven approach and is based on nine scales derived from views of general population, patients, healthcare professionals and policymakers. This tool is intended to be used within specific demographic groups, and in health promotion, public health, clinical interventions and in population health surveys (Osborne, Batterham, Elsworth, Hawkins & Buchbinder, 2013). A strength of the measure is its inclusion of an emphasis on capability of an organisation to provide services that enable a person to understand, engage with and use their health information/services in addition to assessing individual capabilities. The measure has been used with communities and organisation to assess the potential for targeted, locally-developed health literacy interventions to improve access, equity and outcomes (Batterham et al., 2014). A review of population health literacy assessment conducted by Guzys et al., (2015) highlighted the need for assessment and potential interventions to shift to promoting the knowledge and skills essential for critical health literacy at a societal level. Chinn and McCarthy (2013) developed the All Aspects of Health Literacy Scale (AAHLS) to measure functional, interactive and critical health literacy in primary care settings. The AAHLS consists of a fourteen-item self-report scale, developed in consultation with providers and users of primary health care to provide information on the health literacy needs and capabilities of service users. Findings from a study of shared decision-making in a low literacy population demonstrated evidence for the operation of all three levels of health literacy in the decision-making process. Based on these findings the authors highlighted the need to operationalise the measurement of all three health literacy levels (Smith et al., 2013).

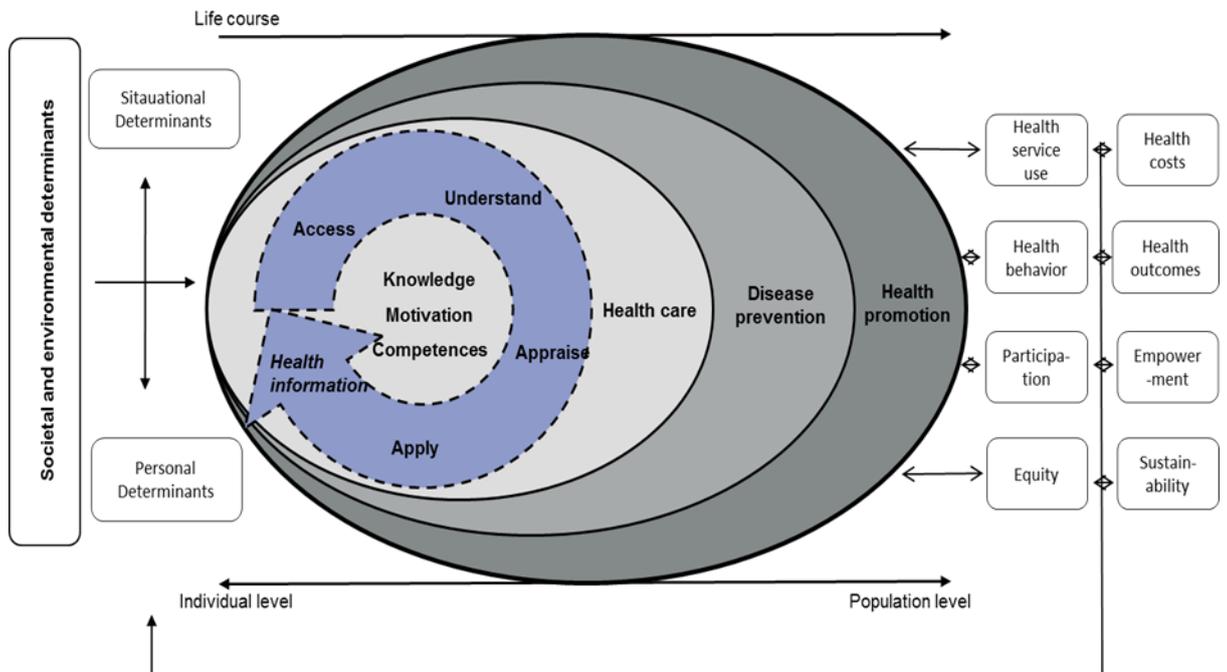
Another instrument, the Functional, Communicative and Critical Health Literacy (FCCHL) scale, has been used to identify the relationships between health literacy, particularly communicative and critical health literacy, and self-efficacy for diabetes management (Ishikawa, Takeuchi & Yano, 2008; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013; Inoue, Takahashi, & Kai, 2013). These studies build on earlier work by Ishikawa, Takeuchi and Yano (2008), which indicated that both communicative health literacy and critical health literacy, but not functional health literacy, were related to self-efficacy for diabetes management. In conclusion, instrument development to measure health literacy is ongoing and to date, there is no consensus on a definitive measure. The majority of measures are focussed on the clinical setting and a greater emphasis on community-based settings is warranted, particularly if measures are to adequately capture the critical level of health literacy. In addition, it is evident that the use of qualitative methods can make important contributions to the further development of measures that capture these broader constructs.

## 2.5 Theoretical framework

This qualitative study was underpinned by the Sørensen et al., (2012) HLS empirically validated conceptual model. Health literacy is recognised as a process involving the consecutive competencies of accessing, understanding, appraising and applying health information. The model also links health literacy to its antecedents and consequences (Sørensen et al., 2012). According to the model, application of the competencies provides individuals with the abilities to take control over their health by overcoming personal, social, structural and environmental barriers to health (see Figure 2 below).

Figure 2 Conceptual model of health literacy

(Adapted from Sørensen et al., 2012)



The model combines the qualities of a conceptual model outlining the main dimensions of health literacy (represented in the concentric oval shape), and of a logical model showing the proximal and distal factors which impact on health literacy, as well as the pathways linking health literacy to health outcomes. The core of the model shows the main competencies necessary to be considered health literate, namely the abilities to:

- (1) Access (refers to the ability to seek, find and obtain health information).
- (2) Understand (refers to the ability to comprehend health information).
- (3) Appraise (describes the ability to interpret, filter, judge and evaluate health information).
- (4) Apply (refers to the ability to communicate and use the information to maintain and improve health).

Effectively employing these four competencies enables a person to navigate three domains of the health continuum: as a patient in the health care setting, as a person at risk of disease in the disease prevention system, and as a citizen in relation to health promotion efforts in the community, work place, and educational system. The capacity to navigate this health continuum depends on cognitive and psychosocial development as well as on previous and current experiences, meaning that a person's health literacy is constantly evolving with life experience. The model incorporates a progression from an individual towards a population perspective. As such, the model integrates the "medical" conceptualisation of health literacy with the broader "public health" perspective. The competencies can also be linked to the levels of functional, interactive and critical health literacy whereby individuals become equipped to take control over their health using health literacy to acquire, understand, appraise and act on health information. This process can allow people to engage in actions to overcome personal, structural, social and economic barriers to health (Sørensen et al., 2012). The current study explores health literacy in the context of people managing their health and illness as they participate in a 12 week structured CVD risk reduction programme and up to nine months after.

## 2.6 Developments in health literacy research

Kickbusch et al. (2013) provide a typology of health literacy interventions which focus on one of three main areas: supporting people with lower health literacy, improving health literacy capacity and improving the organizational, government, policy and system practice. Although there is increasing recognition of the importance of health literacy for population health improvement, there are substantial gaps in the literature about the most effective intervention methods for enhancing health literacy and, specifically, how best to address the needs of population groups with low health literacy (Barry, D'eath, & Sixsmith, 2013). A number of reviews on the effectiveness of health literacy interventions have been published (Sheridan et al., 2011; Barry et al., 2013; Manafo & Wong, 2012; Taggart et al., 2012) and these show that the majority of reported interventions have been in clinical settings and generally focus on task-directed, functional health literacy (Nutbeam et al., 2017). A review of interventions to improve health literacy with community populations by Nutbeam et

al., (2017) focussed on those where interactive and critical health literacy were targeted outcomes. Only seven studies met the inclusion criteria with five of these having elements that were compatible with the development of interactive or critical health literacy (Austvoll-Dahlgren, Bjorndal, Odgaard, Jensen & Helseth 2012; Chervin, Clift, Woods, Krause & Lee, 2012; Carroll, Smith, & Thomson, 2015; Fleary, Heffer, Mckyer & Taylor, 2013; Xie, 2011). In general the majority of studies have focussed on the functional level of health literacy as outlined by Nutbeam with far less work exploring the communicative and critical levels of health literacy (Ishikawa and Yano, 2008).

The role of health literacy in the management of chronic illness is another important focus of health literacy research. Although health literacy has been recognized as an important foundation for successful and sustained self-management, Muscat et al. (2019) have highlighted that few studies have explored the direct impact of chronic disease self-management programmes on health literacy. Their study assessed the impact of the Chronic Disease Self-Management Program (CDSMP) (Lorig et al., 2001) on different domains of health literacy using the Health Literacy Questionnaire (HLQ) (Osborne et al., 2013). Findings from the study indicated statistically significant improvements across all nine domains of the HLQ. This study builds on the findings of a systematic review of self-management skills in chronic disease management conducted to examine the role of health literacy (Mackey et al., 2016). A consistent association was found between low health literacy and poorer disease-related knowledge in respiratory diseases, diabetes, and multiple disease categories. A significant association between low health literacy and poorer self-efficacy was reported in cardiovascular diseases, diabetes, human immunodeficiency virus, and multiple disease categories. Health literacy was significantly associated with poorer beliefs in respiratory, musculoskeletal, and cardiovascular diseases. The findings from this review suggest that low health literacy may affect behaviours necessary for the development of self-management skills. Given that self-management strategies are core components for effective treatment of a range of chronic diseases, low health literacy poses a considerable health concern. The authors highlighted the need for further research to understand the mediating influence of health literacy on disease-related knowledge, self-efficacy, and beliefs (Mackey et al. 2016).

Magnani et al (2018) in their synthesis of the literature note that health literacy can be evaluated as part of programmes aiming to reduce CVD risk and to improve secondary prevention. They highlight that limited health literacy may be one factor that influences dropout rates in cardiac rehabilitation. Individuals with limited health literacy may experience barriers to referral to, engagement with, and participation in cardiac rehabilitation services and thus miss the physiological and non-physiological benefits after coronary events.

Diabetes self-management education (DSME) is generally considered to be a key determinant of the treatment outcomes of diabetes mellitus.-The European Diabetes study (van den Brouke et al., 2016) investigated the influence of health literacy on the self-reported effects of DSME programmes while taking the type of programme into consideration. Findings were in line with previous studies showing that DSME programmes have positive effects and that low HL is associated with lower diabetes outcomes. However, the study findings did not support the assumption that the effects of DSME programmes are influenced by the patient's health literacy. The authors acknowledged limitations of the study, and highlighted that further investigation is necessary to support their findings and to improve understanding about the impact of health literacy on DSME programmes' effectiveness (Vandenbosch et al., 2018).

Chinn (2011) advocates the use of qualitative methodologies to explore "how people actually interact critically with health information in real-life situations" (p64). Lai et al., (2015) also argue that health literacy studies need to shift from a predominantly patient focus to one that encompasses health interactions and health contexts. Qualitative research on people's lived experience of learning about lifestyles and health, and of making decisions on action is needed (Rowlands et al., 2019). This would enable the development of peoples' health literacy capacities to act on lifestyle and wider self-management skills. Increased insight is needed into how the development of health literacy capacity can be facilitated. The current study sets out to do this and a longitudinal qualitative study was designed to examine developments in the health literacy of individuals over time. To date the amount of qualitative research has been limited in comparison to measurement studies. An important study by Jordan, Buchbinder and Osborne (2010) used in-depth qualitative interviews to identify and understand what health literacy represents from the patient perspective.

The study identified seven key abilities that patients identified as critical to seek, understand and utilise information in the healthcare setting. These were, knowing when to seek health information; knowing where to seek health information; verbal communication skills; assertiveness; literacy skills; capacity to process and retain information; and application skills. The study also identified broader factors at the community level which could influence these abilities. While these findings provided some insight for health care providers into barriers that could impact on application of abilities, it did not address the dynamic nature of health literacy. A study by Edwards et al., (2012), used a longitudinal qualitative design over a 20 week period, to explore how patients become health literate for their condition, their experiences of healthcare communication and the impact of health. They developed the Health Literacy Pathway Model to explain the process. While useful, this model does not extend beyond responding to illness and does not address the broader determinants of health nor the health promotion domain of health literacy (Guzyz et al., 2015). The current study expands on the longitudinal qualitative approach to examine broader aspects of health literacy capacity development over a longer time period of 12 months. The use of a qualitative approach allows for an in-depth exploration of the development of health literacy over time for a group of individuals managing their health and illness in the context of their everyday lives. In contrast to a quantitative approach, a longitudinal qualitative approach allows for the identification and exploration of individuals' insights on how they use health literacy competencies and how these develop over time. This level of exploration is not possible using a quantitative approach.

## 2.7 Critical health literacy

The critical level of health literacy and its potential for expanding an understanding of the complexity of the concept of health literacy is now beginning to receive a greater level of attention in the literature (Nutbeam, 2000; Chinn, 2011; Sykes, Wills, Rowlands, & Popple, 2013; Sykes & Wills, 2018). Sykes et al., (2013) argue that there is a need to “locate responsibility for health beyond the individual level” (p.159) in order to develop critical health literacy. The concept considers “the interaction of the individual patient’s health literacy with the health and social contexts in which the patient lives” (Ishikawa and Yano, 2008, p.113). This definition resonates with Rubinelli, Schulz, & Nakamoto’s (2009) description that critical health literacy

“reflects the individuals’ capacity to contextualise health information for his or her own good health, to decide on a certain action after a full appraisal of what that specific action means for them in their own world” (p. 309).

Two main areas of critical health literacy were identified in a concept analysis by Sykes et al., (2013). The first involves higher-level cognitive and social skills that allow critical thinking and informed decision-making. Such skills enable individuals to contextualize health information and apply it to their personal situation and context to make informed decisions that can benefit their health and wellbeing. The second area recognises the importance of existing structural factors that indirectly impact on an individual’s health and wellbeing. These determinants of health include social and community networks, living and working conditions as well as socioeconomic, cultural and environmental conditions. Critical health literacy incorporates the empowerment of people to contest and take actions regarding these determinants. These authors noted that the original key components of critical health literacy (relating to empowerment, social action and as existing at both the individual and population level) have been largely overlooked in more recent discussions of the concept, which have tended to equate it with higher order cognitive individual skills. Focussing on critical health literacy as a driver for political and social change has direct relevance to public health and health promotion (Sykes et al., 2013). Similarly, Chinn (2011), in a review of critical health literacy, identifies and describes the constituent domains of the concept of critical health literacy as information appraisal, understanding the social determinants of health and collective action. The critical appraisal of information domain pertains to how individuals evaluate or judge information and contextualise it to their own circumstances.

Although the critical level of health literacy has received the least attention in the research literature, it is the area that is of most relevance within the field of health promotion practice as it resonates most closely with the overall aim of health promotion as the process of enabling people to gain control over their lives’ (WHO, 1986). Critical health literacy is about moving from being able to understand basic information to being able to contextualise it and to use it to gain control and /or change the determinants of a particular outcome. In order to be able to achieve that there are certain competencies which an individual must possess.

## 2.8 Health literacy: empowerment and self-efficacy

While there is consensus in the literature of an association between health literacy and empowerment (Nutbeam, 2000; WHO, 2016) the exact nature of that relationship continues to be contested. However, there is a growing consensus that while health literacy does not automatically lead to empowerment, it may well be understood as an instrument in the process (Cron Dahl & Eklund Karlsson, 2016). Both concepts are regarded as distinct but closely connected through knowledge, skills, and power dimensions (Cron Dahl & Eklund Karlsson, 2016; Sykes et al., 2013; Porr, Drummond & Richter, 2006). Porr et al., (2006) further consider that individuals' competencies, self-efficacy, critical thinking and reflection are important factors in the process. Sykes et al., (2013) used a concept analysis approach to identify critical health literacy as being similar to empowerment, the key attributes of which were health knowledge, confidence, self-efficacy and empowerment. The WHO's 2016 Shanghai Declaration states that the empowerment of individuals, brought about by health literacy, 'enables engagement in collective health promotion action', which resonates with definitions of critical health literacy.

Health literacy is firmly connected to concepts such as self-efficacy and action planning in the context of health and health behaviours (Gutnick et al., 2014; Pears et al., 2016). Further, these concepts can correlate with health literacy and are also seen as facets of health literacy. Previous research has indicated that health literacy interventions can improve health outcomes such as self-efficacy (Rudd & Keller, 2009; Schillinger, Handley, Wang, & Hammer, 2009). Improving self-efficacy levels in patients can result in increased confidence in making lifestyle change, which is inherent to self-management (Bodenheimer Lorig, Holman, & Grumbach, 2002). Such findings are congruent with a core strategy in health promotion practice regarding the development of personal skills to improve self-efficacy. Zimmerman, Israel, Schulz & Checkoway's (1992) definition of psychological empowerment as integrating "perceptions of personal control, a proactive approach to life, and a critical understanding of the socio-political environment and an active engagement in it" (p. 708) is similar to how critical health literacy has been described in the literature.

## 2.9 Understanding health literacy in the context of social practices

The social practices viewpoint has arisen out of the ‘New Literacy Studies’ tradition (Gee, 1991, 2015; Street, 2003) whereby the focus is less on the acquisition of literacy skills, and more on what it means to think of literacy as a social practice. The social practices perspective of health literacy challenges the view that health literacy can be reduced to the measurement of abstract skills through individual performance tests (Papen, 2008). It is argued that this stance disregards the contextualised nature of reading and writing in health care settings. This viewpoint argues that health literacy needs to be understood as a situated social practice and that is a shared resource frequently achieved collectively by groups of people (such as families) (Papen, 2008). Papen and Walters (2008) undertook a study with forty-five adult literacy, language and numeracy (ALLN) students to examine the relationships between literacy, learning and health utilising a concept of health that includes cognitive aspects (skills), social relations and context as well as the emotional and psychological aspects of health and health care (Dray and Papen, 2004; Papen, 2008). The study identified a wide range of health-care system oral and literacy demands that were placed on students and offset by a variety of strategies used to cope with these difficulties. A key finding was the use of ‘brokering’ or ‘mediation’ involving the use of friends, family, key workers or health professionals to assist with reading and understanding English texts and familiarity with the working processes and structures of the healthcare system. Such findings suggest that health literacy is often distributed (Papen, 2008; Edwards, Wood, Davies, & Edwards, 2015) and, therefore, is not simply a property of the individual but it is a shared knowledge and expertise that resides in the person’s social network. Distributed health literacy refers to the way health literacy is dispersed throughout a group, such as in a family or in an individual’s social network, and is used as a collective resource to handle health information, make choices, and manage health (WHO, 2019). This view of health literacy as being collectively achieved challenges individualised notions of responsibility and risk which underline many current policies. Health literacy has emerged as a means to developing health promoting practices that has meaning in social contexts (Renwick, 2017).

The work of Samerski (2019), which focusses on the narratives of participants from socially and culturally diverse backgrounds, lends further support to this viewpoint. The social practices viewpoint is expanded further to challenge the dominant Western viewpoint of individuals as solely autonomous, rational agents (reflected in the idea that health literacy is the capacity to obtain and process information and make informed choices). An alternate analysis of human action, deemed more appropriate for issues of health and illness, is that of practice theory whereby what people know, say and do are neither the result of individual choices nor of structural determinants but are embedded in and governed by social practices. Study findings show health literacy as a situational, dynamic and multidimensional social practice that is embedded in networks of ‘doings and sayings’ (Samerski, 2019). Similar to other studies of health literacy as a social practice (Papen, 2008), study findings also indicated that even those individuals who might be classified as lacking health literacy, succeeded in accessing health information and making sense of it by mobilising social relations and networking. Information seeking and health related actions were determined firstly by concrete situations and the perceived need to gain agency, and secondly by interpersonal relationships with informal or professional helpers (Samerski, 2019). The author advocates that an effective patient-centred model of health care requires the acknowledgment of the social realities of patients and recognition of their heterogeneous and multidimensional knowledge.

## 2.10 Philosophical assumption underlining research design: critical realism

The longitudinal qualitative research study design draws on critical realism which functions as a general methodological framework for research but is not associated with any particular set of methods. One of the most important tenets of critical realism is that ontology (i.e. what is real, the nature of reality) is not reducible to epistemology (i.e. our knowledge of reality). Drawing on critical realism, it is possible to explore how health literacy unfolds in complex social and health systems contexts. These contexts shape how the phenomena (health literacy practices) are manifest, as well as how development may be facilitated or hindered. Critical realism is a philosophical approach that was developed in response to the limitations of positivism and relativism (Bhaskar, 1978). It is considered to be a theory of being which includes as *real entities*

the properties of the social world such as the reasons that individuals use to guide or produce individual behaviour or change.

A key tenet of critical realism is that things do not simply happen by chance or without a reason; rather there are always powers generating the occurrence of events and courses of events. Critical realism is concerned with these inherent properties which are referred to as 'causal powers' and which are understood to exist whether they are being exercised (to generate an event) or not. Critical realism posits then, as its ontological base, that all social structures possess causal powers or 'generative mechanisms' and liabilities (Bhaskar, 1978; Sayer, 2000; Danermark, Ekström, Jakobsen and Karlsson, 2002). These are 'potentialities' inherent in an object or structure that enable or constrain it from acting in certain ways (Psillos, 2007).

Critical realism also sets out the idea of a differentiated and stratified reality (within which these generative mechanisms are housed) consisting of three different domains of reality. At the most basic level is the domain of the 'real' where the mechanism exists, existing irrespective of whether they produce an event or not. When the mechanisms do produce a factual event, this then comes under the domain of actual (whether it is observed or not). It is when such an event is experienced that it then becomes an empirical fact and so comes under the domain of the empirical. Mechanisms may also belong to different strata of reality (including the psychological and social strata) and new mechanisms are continually being created in these strata, referred to as 'emergent powers'. In other words, the world is understood to be characterised by emergence (Sayer, 2000). Bhaskar contends that people's reasons and accounts are emergent phenomena and are thus the best guide to understanding both the material/immaterial structural influences that provide important controlling mechanisms in people's lives.

Social events (social practices, including health literacy) are the products of a range of interacting mechanisms, operating in an open system whereby the generative mechanisms under study are involved in a complex interaction with other mechanisms (either cooperatively or as a barrier). Phenomena are deemed to have emergent properties or characteristics that under the right conditions may result in a certain outcome (Pawson, Tilley & Tilley, 1997). These ideas can be applied to the concept of health literacy as a dynamic construct. This aligns with the concept of health literacy

as an asset which can be developed. All individuals have the potential for further health literacy capacity development but this potential, depending on contexts, may not be realised. A good example of this is described by Rubinelli, Schulz and Nakamoto (2009) where they examine different examples of how and when the capacity for health literacy is put into action. The point here is that while a quantitative measure of health literacy may present one story (levels of health literacy ranging from low to excellent) this alone does not necessarily predict how, or even if, that health literacy capacity might be put into practice. While the link between health literacy and behaviours is recognised, it is the priority of an “existential goal of health enhancement” (Rubinelli et al., 2009, p.308) which is required to build this link. The authors argue that for health literacy to be important to healthy choices and behaviour it has to be *internalised* (Schulz and Nakamoto, 2005) and integral to the lived experience of the person. This understanding is applied to the meaning of critical health literacy which is about contextualising health knowledge for one’s own good health; deciding on a certain action after a full appraisal of what that specific actions means for the individual in ‘their own world’ (Rubinelli et al., 2009). Further, this critical reflection is viewed as a crucial step for the application to concrete action of any knowledge that would otherwise be ‘external’ to the person and of any skill that would otherwise remain in its potentiality.

Similarly the work of Papen (2008), advocating that health literacy needs to be viewed as a social practice also sets out examples of how capacity for health literacy can exist but remain in its potentiality due to contextual factors. These include issues of power, authority (in the health care context) or cultural/social issues (in wider social contexts) as well as the very real aspect of the ‘emotional side of health literacy’ which has received scant attention in the research literature. Papen also argues that health literacy is always ‘situated’ or context specific and so must also take into account the role of health care providers in terms of communications strategies (Rudd & Keller, 2009; Rudd et al., 2012). Using a social practices lens for health literacy means recognising the importance of context and the many approaches that individuals use to access, understand appraise and use health information.

Drawing on a critical realist perspective lends support to the use of predominantly qualitative methods to examine the contextual factors that are at work for individuals

as they navigate health and wellbeing issues within complex health and social systems. Further, a longitudinal study design, is appropriate to explore how health literacy capacities can develop over time within these contexts.

### 2.11 Summary

The findings of this review of the literature have highlighted the importance of having an understanding of the breadth of health literacy. The relevance of health literacy across the domains of health care, disease prevention and health promotion are clear. While some qualitative research has been undertaken in the past, this is minimal. In order to gain a greater understanding of how health literacy develops, and how this can be facilitated, a nuanced account of peoples' experiences over time is needed in the context of how people manage their health and illness. The current study sets out to do this and focusses specifically on participants of a CVD risk reduction programme. This population provides the opportunity to explore health literacy capacities in both social contexts (in terms of making lifestyle changes) and the health care context (ongoing interactions with the health care system). While many studies have focussed solely on the measurement of health literacy at the functional level, this study takes a much broader stance by going beyond measurement to examine developments in health literacy over a twelve month period. The qualitative nature of the study allows for a detailed understanding of what contributes to developments or impediments for health literacy capacities.

## CHAPTER 3: METHODS

### 3.1 Introduction

This chapter sets out the methodological approach and study design undertaken to answer the research question, aim and objectives of the study. It begins with an overview of the methodological approach undertaken, which includes a brief overview of critical realism as the underlying philosophy (this is presented in more detail in Chapter 2) and the theoretical framework underpinning the study. Next, the data collection and analysis procedures for the study are set out. Reliability and validity issues relevant to the study as well as ethical considerations are presented in the final section along with an account of reflexivity on the part of the researcher.

### 3.2 Methodological approach

#### 3.2.1 Philosophical assumptions for the research design

A critical realist lens is congruent with the longitudinal question frameworks used in the analysis of the study data (see Tables 5 and 6). Drawing on critical realism, it is possible to explore how health literacy unfolds in a complex social/ health systems context which shapes how the phenomena (health literacy capacities) are manifest as well as how development may be facilitated or hindered.

#### 3.2.2 Theoretical framework

This qualitative study was underpinned by the Sørensen et al., (2012) HLS empirically validated conceptual model. Health literacy is recognised as a process involving the consecutive competencies of accessing, understanding, appraising and applying health information. The model also links health literacy to its antecedents and consequences (Sørensen et al., 2012). According to the model, application of the competencies provides individuals with the abilities to take control over their health by overcoming personal, social, structural and environmental barriers to health. This is discussed in further detail in section 2.4 in Chapter 2.

### 3.3 Study design

A longitudinal qualitative (LQ) study design was undertaken to address the research questions. Longitudinal qualitative research seeks to uncover and understand processes of change over time (Corden & Millar, 2007) and therefore, is consistent with the critical realist approach outlined in Chapter 2. The method is based on repeat interview methodology. Qualitative longitudinal methods have been used across a wide range of disciplines including anthropology and community studies, education, psychology, health studies, sociology and policy (Holland, Thomson & Henderson, 2006). It is particularly suited to the area of health literacy as it allows individuals to create the narrative of their own experiences in terms of accessing, understanding, appraising and applying health information over time.

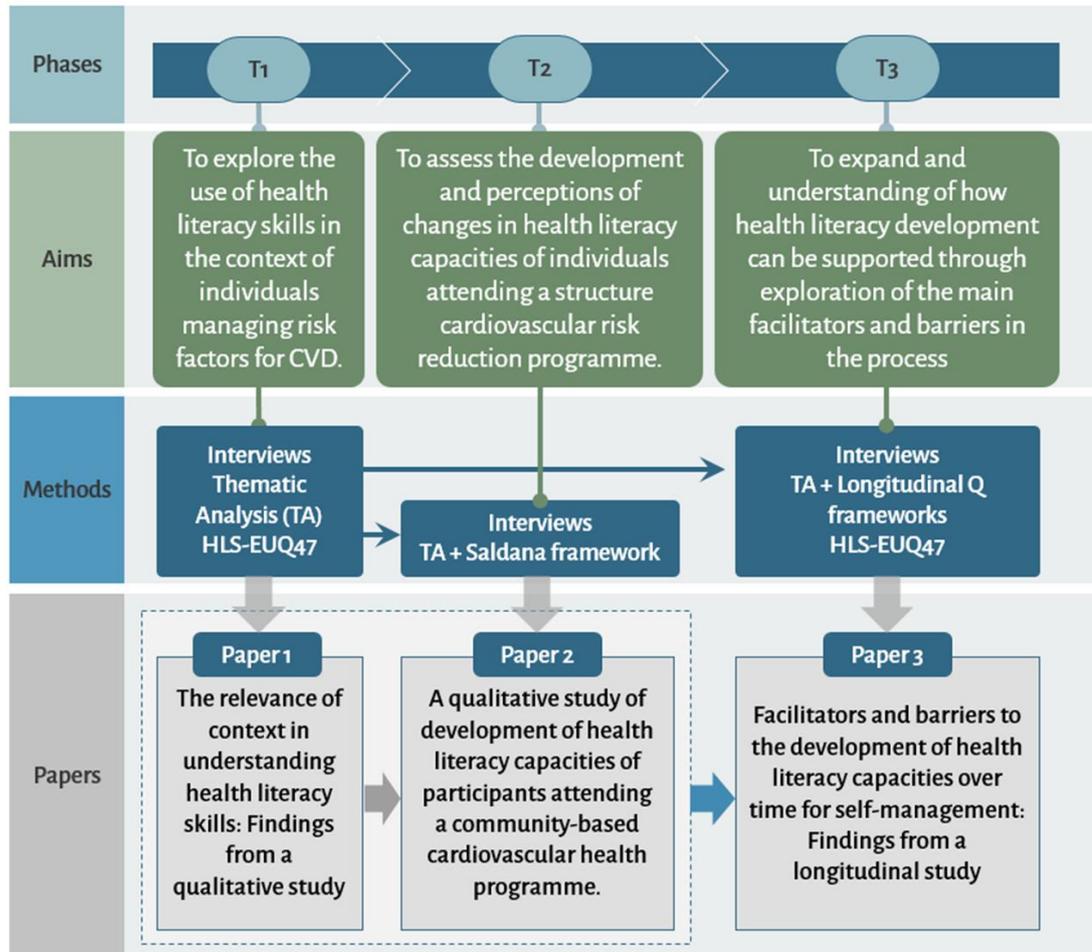
Longitudinal qualitative research is distinguished by the “deliberate way in which temporality is designed into the research process making change a central focus of analytical attention” (Thomson, Plumridge & Holland, 2003, p. 185). In this study the LQ design involved three separate waves of data collection, which corresponded to time points in a cardiovascular disease (CVD) risk reduction programme. These were: (i) at baseline before the programme commenced, (Phase 1); (ii) at 12 weeks, following completion of the programme, (Phase 2); (iii) at 12 months after programme start, (Phase 3). The HLS-EU-Q47 survey was administered at baseline (Phase 1) to obtain data on health literacy levels of the participants as they began programme participation. The survey was also re-administered at Phase 3 to provide an indication of any changes in health literacy levels over the 12 month time period. See Table 1 below for an overview of the study design).

Table 1 Application of methods across the different phases of the study.

Time points	Focus	Methods used	
Phase 1: (Baseline: Beginning of programme)	To explore individuals' experiences of using health literacy capacities in the management of health and illness.	Interviews with 26 participants in the structured CVD programme.	HLS-EU-Q47 survey completed (n = 26)
Phase 2: (End of programme@ 12 weeks)	To monitor developments and changes in the use of health literacy capacities since Phase 1.	Follow-up interviews with 19 of the 26.	
Phase 3: (One year follow -up @ 12 months)	To examine developments and changes in the use of health literacy capacities over time (12 months) and to explore the barriers and facilitators in this process.	Follow-up interviews with 17 of the original 26 participants.	HLS-EU survey completed (n = 17)

A flowchart of the different phases of the study, (together with the papers that report on the findings for each phase of the study) and the methods of analysis are presented in Figure 3 below.

Figure 3. Study phases, aims, methods used and papers



### 3.3.1 Sample

The concept of purposeful sampling is used in qualitative research whereby the inquirer selects individuals or sites for study because they can purposefully inform an understanding of the research problem and central phenomenon of interest in the study (Creswell, 2013). Purposeful sampling is a specific qualitative approach to case selection (Patton, 2002, 2015) with a focus on the selection of information-rich cases for in-depth study. Purposeful sampling was employed in this study in order to purposefully select individuals who were attending a structured cardiovascular risk reduction programme. This sampling approach was used to obtain the views and experiences of people with a range of risk factors for cardiovascular disease (CVD) as well as those with established disease. Selection of this group was congruent with the theoretical model of Sørensen et al., (2012) as this sample permits insights into the three domains of health care, disease prevention and health promotion outlined in the model. It is also congruent with the relevance of health literacy for the self-care plans necessary to manage chronic illness and engage in health promotion behaviour and lifestyle changes (Pleasant, 2014).

Appendix 4 outlines the implementation of the risk reduction programme from the point of initial assessment through to the end of year assessment. For the purpose of defining a cohort in this study, all participants coming on to the programme over a two-week period were identified as one specific cohort (i.e. baseline). The entire data collection process took place across multiple different cohorts to account for baseline, 12 weeks and 12 months. The programme was used as a 'vehicle' to engage individuals as they managed their health and illness over a 12-month period. An important feature of the programme is that participants (those identified with risk factors 'RF participant') may complete the programme alongside a partner (individual who is significant in the life of the 'RF participant'). In order to capture this important feature in the study design both referred participants and their partners were recruited. The programme nurse invited all applicable individuals to take part in the study. The programme operated on a rolling intake and over a three month period, an average of three individuals per week were invited to take part. Of these, a total of 10 individuals declined to take part in the study. Data saturation was reached at 26 interviews.

### 3.3.2 Sample size

Qualitative research findings do not aim to be generalizable. Longitudinal qualitative research, like qualitative work in general, seeks to generalize on analytic dimensions that establish a framework by which to authentically interpret a group, setting, or situation. This objective tends to require a sample smaller than the samples customarily found in survey research, since the aim is not statistical generalization. Specific sample size is answerable by the aims of the given research, in the context of these guiding principles (Small, 2009).

Qualitative research is about examining people's lives in rich detail and to achieve that goal small numbers of people are often chosen through purposive or purposeful sampling strategies (Braun and Clarke, 2014; Sparkes & Smith, 2014). Lewis et al., (2014) point out that qualitative research cannot be generalised on a statistical basis,

it is not the prevalence of particular views or experiences, not the extent of their location within parts of the sample, about which inferences can be drawn. This is also not the objective of qualitative research. Rather the value of qualitative research is in revealing the breadth and nature of the phenomena under study (Lewis, 2014, p. 351).

This study drew on the factors set out by Morse (2000) to determine sample size in qualitative studies. These include the scope of the study, nature of topic, quality of data, study design and research methods to be used. In this longitudinal study each individual completed three interviews. Corden and Millar (2007) have highlighted the fact that a substantial amount of data is generated by repeat interviews in LQR. However, consideration must also be given to the issue of retention in a longitudinal study design. For this study, it was planned to conduct interviews with up to 26 individuals to generate an overall data set of 78 interviews.

The number and frequency of serial interviews that compose a longitudinal study is dependent on how a given research problem is posed and so will vary from study to study. Decisions on how much time should pass before successive interviews were conducted, drew on the work of Hermanowicz, 2013 and Saldaña, 2003, to ensure a sufficient amount of time to examine relevant change from one point to another. In this study the longitudinal element covered 12 months, which is an appropriate

timeframe to discern developments (Holland, Thomson & Henderson, 2006). The times chosen were not arbitrary as these coincided with programme delivery points which facilitated meeting with participants. Having an additional contact between Phases 2 and 3 was considered as there was a nine month gap between these phases. However, this was not feasible from a resource perspective. On the other hand, the nine months was a useful time period to see if changes were sustained and/or developments continued without any further research interactions to potentially influence these.

While addressing the issue of retention it is also necessary to consider the issue of data saturation. Qualitative research is based on an interactive process through which information emerges and this study drew on guidelines to support decision-making on when to cease information gathering (Cleary, Horsfall & Hayter, 2014). Saturation of information refers to the situation where no new concepts or themes are emerging from sequential interviews. Ultimately, sample size within the qualitative tradition can be justified based on the quality of the data rather than on the quantity of the data (Cleary et al., 2014). In this study data saturation was reached in terms of inductive thematic saturation (analysis focus) and data saturation (data collection focus) as outlined in models of saturation put forward by Saunders et al., (2018). In addition, phases three-five of Braun and Clarke's (2006) methodology for thematic analysis (searching for, reviewing, defining and naming of themes) were applied, involving a process of checking for theme saturation to ensure that all data fit the themes and that no new themes were identified.

### 3.3.3 Participants

The 12 week CVD risk reduction programme integrates the care of individuals with established heart disease and those at high multi-factorial risk of developing the disease, into a local community-based programme (Gibson et al., 2014) that was originally developed at Imperial College London following the EUROACTION trial (Connolly et al., 2011). The programme is delivered by a multidisciplinary team comprising nurse specialists, dieticians and exercise specialists and incorporates weekly group exercise classes and educational workshops. The workshops address a range of topics including the risk factors for coronary heart disease and stroke, healthy eating, alcohol use, weight management, physical activity, stress management, food

labels, maintaining change and cardiac medications. Participants also have weekly meetings with the multidisciplinary team (Gibson et al., 2014). Initial recruitment took place in conjunction with the programme nurse, who identified individuals who were cognitively able to participate and were able to communicate through the English language. Twenty-six individuals completed interviews at Phase 1; 19 at Phase 2 and 17 at Phase 3. A table detailing the demographics of attrition is in Appendix 5. Overall, a total of five partners were included in recruitment at Phase 1 with two partnered couples remaining for the 12 month duration of the study. Profiles of the participants for each phase of the study are documented in Table 2 below.

Table 2 Profile of participants across Phases 1, 2, and 3 of study.

	<b>Phase 1</b>	<b>Phase 2</b>	<b>Phase 3</b>
<i>Participants (n)</i>	26	19	17
<i>Gender (n)</i>	M: 10 F: 16	M: 8 F:11	M: 7 F:10
<i>Age (mean, range)</i>	49 (36-76)	61 (36-76)	59 (36-76)
<i>Education (n, %)</i>			
Primary School (PS) level (low)	3 (11.5)	3 (16)	2 (12)
Incomplete PS (low)	1 (3.8)	1 (5)	1 (6)
Secondary-intermediate level (low)	7 (27)	7 (37)	7 (41)
Completed secondary (medium)	5 (19.2)	3 (16)	2 (12)
Diploma/certificate (medium)	5 (19.2)	2 (11)	2 (12)
Primary degree (High)	1 (3.8)	1 (5)	1 (6)
Postgraduate/higher degree (High)	4 (15.4)	2 (11)	2 (12)
<i>Social class (n, %)</i>			
I (High)	1 (4)	1 (5)	1 (6)
II (High)	7 (27)	5 (26)	5 (29)
III (Medium)	1(4)	0	0
IV (Medium)	3 (17)	1 (5)	1 (6)
V (Low)	4(4)	3 (16)	2 (12)
VI (Low)	3 (17%)	2 (11)	2 (12)
VII (Low)	7 (27%)	7 (37)	6 (35)

<i>Health service access (n/%)</i>			
Private health insurance	13 (50)	10 (53)	8 (47)
<i>Medical card only<sup>1</sup></i>	7 (27)	7 (37)	4 (23)
<i>Private AND medical card</i>	4 (15)	2 (11)	3 (18)
<i>Neither</i>	2 (8)	0	2(12)
<i>General HL level (from HLS-EU1-47) measure</i>			
Limited	17 (65%)	13 (68%)	5 (29%)
Adequate	9 (35%)	6 (32%)	12 (71%)
<i>Smoking</i>			
(% Current Smokers)	12		
<i>Diet</i>			
Mean Mediterranean Diet Score (optimal score $\geq$ 9)	5		
<i>Physical activity</i>			
% NOT achieving targets (> 5x/week $\geq$ 30 minutes)	81 (n=21)		
<i>Anthropometrics</i>			
% BMI $\geq$ 25kg/m <sup>2</sup> (overweight)	27 (n=7)		
% BMI $\geq$ 30kg/m <sup>2</sup> (obese)	65 (n=17)		
% Waist Circumference NOT at target	96 (n=25)		

<sup>1</sup> A medical card allows access to GP services, community health services, dental services, prescription medicines and hospital care free of charge under the General Medical Services Scheme for sub-groups of the population based on income levels/specific medical conditions (Department of Public Expenditure and Reform, 2016; Health Service Executive, HSEa, nd).

Male $\geq$ 94cm & Females $\geq$ 80cm			
<i>Blood pressure</i>			
% BP NOT to target (>140/90mmHg for high risk individuals & >130/80mmHg for coronary/diabetes)	62 (n=16)		
<i>Cholesterol</i>			
% Cholesterol NOT to target (TC >5mmol/L & LDL > 3mmol/L for high risk individuals and TC >4.5mmol/L & LDL >2.5mmol/L for coronary/diabetes)	42 (n=11)		
% with other illness related risk factors (heart attack, stroke, Diabetes; Hypothyroidism, Psoriasis, Cardiac arrhythmia, heart disease (stents fitted), heart failure	73 (n=19)		

### 3.4 Data collection instruments

#### 3.4.1 Interviews

Rigorous data collection methods were ensured through the use of the conceptual model developed by Sørensen et al., (2012) to inform the development of the interview guides so that the four dimensions of information processing associated with health literacy (i.e. accessing, understanding, appraising and applying health information) were explored. The semi-structured interview guide is the most frequently used interview technique in qualitative research (DiCicco-Bloom & Crabtree, 2006) and in a healthcare context (Gill, Stewart, Treasure & Chadwick, 2008). Semi-structured interviews were used in this study to explore the development of health literacy and to identify changes in knowledge, attitudes and experiences over time (see Appendix 6 for the interview protocols used for Phases 1, 2, and 3). The core elements of the interview protocols focussed on questions about how the individual accessed, understood, appraised and acted on health information. In addition, the individual was asked to describe interactions with their health care provider and their perceived ability to be able to make changes beneficial to health was also explored. Engagement with one's community was also examined. The interview protocols were broadly similar across the three phases with questions for Phases 2 and 3 exploring developments in the intervening time periods in relation to the competencies of accessing, understanding, appraising, and applying health information.

The rigidity of the interview guide structure, including question ordering, wording and inclusion/omission can be varied depending on the study purpose and research questions (Kelly 2010; Robson, 2002). This allows the interviewer to improvise follow-up questions based on participant's responses (Polit & Beck, 2010). This method was deemed suitable to address the research questions. For example, in this study, questions were added as appropriate to further explore topics that the participant brought up such as: asking questions about why a participant decided to stop taking certain medications; how s/he could find out about a treatment plan; how positive/negative health care provider interactions impacted on the participant. While acknowledging the advantages of the interview in qualitative research, it is also important to acknowledge potential challenges, which are also inherent. A fundamental issue is recognising that power is present in the interview transaction (Nunokoosing, 2005) and often this is shifting back and forth from interviewer (seeker

of knowledge and has methodological expertise) and the interviewee (privileged knower). Further consideration of this issue is addressed in the section on reflexivity (3.9)

Within LQR it is important that key questions on change itself are explored. Saldaña (2003) considers key questions on change for the different time points in the data collection. Adaptions of these questions were used to refer specifically to the description of changes in health literacy practices. The following questions were incorporated into the interview guides in this study:

What changes in yourself do you hope will result from this experience? (Phase 1)

What changes in yourself do you see or feel over the past 12 weeks? (Phase 2)

What kinds of changes in yourself do you see or feel over the past 12 months? (Phase3)

Interviews for the second round of interviews incorporated some preliminary analysis of data generated from the first round of interviews and typically began with a brief summary of what the participant reported at Phase 1. In LQR the issue of time is explicitly placed within the interview (Calman, Brunton & Molassiotis, 2013), so that it involves looking both forwards and backwards in time in order to move away from linear notions of time. This included asking participants to reflect on the content of their previous interview and by encouraging participants to engage in reflexivity (Calman et al., 2013). These procedures were used throughout the interviewing process.

Another important aspect of LQR is the emphasis on a layered approach in order to fully contextualise the individual so that behaviours and experiences can be embedded in the specifics of circumstance, relationship and setting (Saldaña, 2003). According to Saldaña (2003); a LQ study should begin with the collection of baseline data including “essential demographics, particular categories, or other descriptive qualitative data for future reference, implied by the research questions/ areas of interest that launch the study, to assess any future change”. (p. 18). To this end health literacy, demographic and health behaviour data were obtained at baseline interview (see Appendix 7). Demographic questions were chosen based on those used in the Survey of Lifestyle, Attitudes and Nutrition (SLAN) 2007 (Morgan et al., 2008) and the health outcomes questions included in the European HLS-EU survey (2012).

Additional clinical and health behaviour information was also collected from the community-based organisation at Phase 1. This information covered: Mediterranean diet score, physical activity targets, anthropometrics, blood pressure, cholesterol. These data are reported in Paper I.

All interviews took place in rooms of the organisation delivering the CVD programme. In one case, a Phase 2 interview took place by telephone as the participant did not live close by and had no means of transport to attend the interview in person. Another Phase 2 interview took place in the researcher's office. Average interview times were: 30 minutes (T1) 50 minutes (T2) and 40 minutes (T3).

#### 3.4.2 Administration of the HLS-EU-Q47

Participants' health literacy levels were assessed using the HLS-EU-Q47-Item Questionnaire (HLS-EU Consortium, 2012) to provide a guide on health literacy levels as outlined above (see Appendix 7). The use of this measure added perspective to the qualitative data and allowed for comparison with levels recorded for the overall Irish population (Doyle, Cafferkey & Fullam, 2012) (presented in Paper I). The instrument addresses the domains of health care, disease prevention and health promotion and yields scores for general health literacy, as well as for health care, disease prevention and health promotion. The scale comprises eight scales as outlined below:

Scale 1: A general HL scale comprising all items and providing a general picture and overview;

Scales 2-4: Three dimension-specific scales covering healthcare, prevention and health promotion; and

Scales 5-8: Four information-processing specific scales covering the different stages of information processing.

Appendix 8 shows the general and specific HL scales and their respective items as well as the scoring formula used.

The HLS-EU-Q47 uses a four-point rating scale, with integer response categories from 1 (very easy) - 4 (very difficult) where higher scores indicate lower health literacy. Scales are based on the inverted categories of the items (thus a higher value denotes

better health literacy) with the following numerical values: 1=very difficult; 2=difficult; 3=easy; 4=very easy.

The HLS-EU instrument distinguishes between four ranges of health literacy:

Inadequate level of health literacy: 0-25

Problematic level of health literacy: >25-33

Sufficient level of health literacy: >33-42

Excellent level of health literacy: >42-50

In this study limited (Inadequate + problematic health literacy) and adequate (sufficient + excellent) levels of health literacy are reported with scores ranging from 0-33 and 34-50 respectively.

In terms of collecting the survey data, best practice in the area of literacy dictates that these are administered in a face-to-face context with the researcher present. This also corresponds to the methods employed in the HLS-EU study (HLS-EU Consortium, 2012). The aim of the study was discussed and the researcher checked that participant had read the Participant Information (PI) sheet and understood what was involved (see Appendix 9). The researcher read through the survey with the individual and clarifications were provided as needed on any questions.

### 3.5 Data collection process

#### 3.5.1 Pilot

Interview and survey administration was piloted prior to commencement of data collection with eight individuals attending the structured programme. The pilot process was particularly useful in the identification of problems with the initial operationalization of the research process. Although attempts were made to implement a follow up system with the researcher following the initial assessment meeting with the nurse, this did not happen in many instances. As a result, the researcher did not know who was presenting for participation until the day and a valuable opportunity to

enhance participation was lost (whereby the research could do a 'meet and greet' phone call before meeting the individual to keep their interest).

The initial plan was to collect data at the time of meeting for the initial assessment. Attendance at week one of the programme was very good with participants generally arriving early. However, participants did have to meet with the nurse for assessment and the timing of these meetings varied. As a result, in some cases there was limited time remaining to conduct the survey and interview.

In some cases (particularly post week one), participants were late attending or on some occasions did not present at all. In situations where an interview had been arranged, this meant that no data collection took place.

A minimum amount of clarification was requested on HLS-EU items related to health literacy. Clarifications were required on some of the demographic questions. The pilot also indicated that the survey as administered took too long to complete. In some instances it was not possible to finish the demographics section in full. All of these issues were reviewed in full following the completion of the pilot and demographics questions were removed that were not clearly understood or that people were unable to answer. This entailed removing the self-perceived social class question as well as the question on income amounts, which individuals were reluctant to answer.

The recruitment and follow-up process was also discussed with the organisation team and agreement reached on a revised system whereby the researcher would be notified of potential participants ahead of beginning data collection. The nurse requested consent from participants to provide contact information to the researcher to make phone contact prior to completing the survey. This ensured that participants understood information on the PI sheet and times for meeting could be verified independent of the date and time of the initial assessment meetings.

At the end of the pilot phase, a total of eight persons completed the survey and two individuals completed interviews. The interviews were transcribed verbatim by the researcher and the transcripts were read through a number of times by the researcher and supervisor and initial codes developed. Agreement was reached that interview questions were appropriate to the research question.

The final protocol for data collection was developed following the findings of the pilot and is set out below:

- At initial assessment meeting with participant, the nurse will briefly introduce the study, provide a written PI sheet and request permission to provide their contact details to researcher.
- After one week the researcher contacted the potential participant by telephone, answered any queries and invited participation in study. If participants agreed to study participation a suitable time to meet was set up and the survey was administered.
- Following survey completion a suitable time was arranged to conduct the interview.
- 

#### 3.4.2 Timeline

Recruitment and data collection for Phase 1 interviews began in January 2014 and were completed in December 2014. Phase 2 interviews began in April 2014 and were completed in February 2015. Phase 3 interviews began in January 2015 and were completed in December 2015.

### 3.6 Analytical strategy

#### 3.6.1 Organising data to analyse change

Due to the breadth of data involved in longitudinal studies it is necessary to use a comprehensive system of data management. For this purpose all transcription data were imported into NVivo (version 11) computer software for data management and for use in data interrogation. The usefulness of such software for LQR is advocated by Saldaña (2003) as useful “storage and management systems with multiple facilities and functions that allow you to store, chunk, label, organise and manipulate data for your reflection and analysis” (p. 61).

In this study, the software was used to facilitate data management, coding, determining the frequency of quotations for specific codes, clustering codes into broader categories, and retrieval during analysis and write-up. Once initial codes were

developed each code was imported to Word and saved as a separate file. Each code document was printed out and read through in order to gain an in-depth understanding of what data were contained under each initial code and to ascertain which codes could be combined to form one code to start the process of theme identification (see section on thematic analysis below).

### 3.6.2 Longitudinal analysis

There is limited documented literature on the analysis of longitudinal data (Lewis, 2007) and Saldaña (2003) has noted the absence of “prescriptive, systematic, or universal formulas for analysing longitudinal qualitative data” (p. 62). However, a number of interpretive and analytic frameworks do exist which can act as guidelines in the longitudinal qualitative analytic process. The work of Saldaña (2003) is to the fore in its focus on the *analysis of change through time* and he has developed an analytic framework which incorporates framing, descriptive, analytic and interpretive questions that can be applied to the data. Saldaña’s longitudinal question framework is informed by the conceptual framework of Wolcott (1994), which delineates three levels of description (when and what kinds of changes occur in whom), analysis (explaining how and why those changes might have occurred), and interpretation (explaining the nature and meaning of those changes) of qualitative data. Lewis (2007) explains that the analysis of qualitative longitudinal data employs the following approaches typically used in cross-sectional studies:

- Exploring diversity, deviant, negative or atypical cases and alternate perspective.
- Using iterative questions to search deeper into the data.
- Drawing out explicit and implicit explanations.
- Exploring conceptual and thematic linkages.
- Identifying patterns.
- Constant comparison.

However, the multi layered nature of longitudinal qualitative research means that its reading is necessarily more complex involving multi-dimensional analysis (Lewis, 2007). The longitudinal analysis in this study involved three stages (Thomson and Holland, 2003 Holland et al., 2006). The first was a within time analysis (cross-sectional), which entailed thematic analysis of each data set at a particular time period

(i.e. Phase 1, 2, 3), and this is outlined in the thematic analysis section below. The second stage involved a repeat cross-sectional analysis which focussed on identifying changes between points in time for individual cases (see Table 3 below). The third stage used a trajectory approach for a longitudinal analysis that focused on changes over time (Table 4 below). The longitudinal question frameworks of Saldaña (2003) and Lewis (2007), (Tables 5 and 6 below) were also applied to support data interrogation (see Table 9 in Chapter 4 for samples of question application). A matrix format (Miles and Huberman, 1994; Miles, Huberman and Saldaña, 2014; Grossoehme and Lipstein, 2016) using Xcel (2013) was employed to facilitate the ordering and summarising of data for each participant across Phases 1 to 3 drawing on the trajectory approach advocated by Grossoehme and Lipstein (2016) (Tables 3 and 4 below). The trajectory analysis focuses on changes over time for an individual or small group of individuals and was deemed most suitable to meet the aim of the current study (to understand individuals' experiences over time). Once coded, the data were organised into matrices (A) with one matrix per unit of analysis (individual participant). Each matrix is organised with themes along the y axis and time along the x axis (see sample below).

Table 3: Sample matrix A for each participant

Theme	Phase 1	Phase 2	Phase 3
A: Access			
B: Understand			
C: Appraise			
D: Apply			
+themes identified inductively			

The second step involved the longitudinal analysis of change over time. An overall matrix (B) was constructed with participants listed on the y axis and the summary of

changes over time for themes listed across the x axis. (See Appendix 10 for a sample of the data ordering).

Table 4. Sample matrix B

Participant	A: Access	B: Understand	C: Appraise	D: Apply	+themes identified inductively
1					
2					
3...					

Preliminary analysis took place between interviews at Phases 1 and 2 and between Phases 2 and 3 to allow for reflexivity on the part of the researcher (Carduff, Murray and Kendall, 2015), as well as to focus on process and changes rather than on snapshots (Calman, Brunton & Molassiotis, 2013). This preliminary analysis allowed the researcher to identify key issues that could then be returned to for further exploration in subsequent interviews. This meant that the following interview could build on the narrative and include questions or prompts based on developing interpretation and knowledge of what had gone before (Lewis, 2007). The current study drew on the following frameworks for the analysis of Phase 2 and Phase 3 data. The bolded questions in Table 5 refer to questions used at Phase 2 analysis.

Table 5: Saldaña (2003) framework questions

<p>Framing Questions (situate the context of the data)</p> <p><b>What is different from one round of data to the next?</b></p> <p>When do changes occur through time?</p> <p><b>What contextual and intervening conditions appear to influence and affect participant changes through time?</b></p>
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<p>What are the dynamics of participant changes through time?</p> <p><b>What preliminary assertions about participant changes can be made as data analysis progresses?</b></p> <p>Descriptive Qs (7)</p> <p><b>What increases/emerges through time?</b></p> <p>What is cumulative through time?</p> <p>What kind of surges/epiphanies occur through time?</p> <p>What decreases/ceases through time?</p> <p>What remains constant or consistent through time?</p> <p>What is idiosyncratic through time?</p> <p>What is missing through time?</p>
<p>Analytic and interpretive questions (4)</p> <p>What changes interrelate through time?</p> <p>What changes through time oppose or harmonise with natural human development or constructed social processes?</p> <p>What are participant or conceptual rhythms e.g. cycles through time?</p> <p>What is the through-line of the study?</p>

Table 6: Lewis (2007) framework questions

Questions about	Focussed/directed questions
Description	What is the type, extent and timing of any changes
Location	Who showed changes, when, and in what contexts

Explanations (Drivers for change)	What were the factors that influenced the changes?
Evaluation	What influenced the experience of participants in use of HL capacities and change/lack of change?
Consequences	What was the effect of further changes, new directions, loss of opportunity
Personal meaning	What was the perceived importance of the change?
Policy meanings	Applied to Sørensen framework
Researcher reflection	Reflexivity

### 3.6.3 Thematic analysis

Thematic analysis is a useful method in longitudinal qualitative research (Calman et al., 2013; Kennedy, Harcourt & Rumsey, 2012; McCaughan, Prue, Parahoo, McIlpatrick & McKenna, 2012). In this study it is used as a specific method, as advocated by Braun and Clarke (2006), alongside Saldaña's interpretive frameworks for longitudinal data analysis (2003). The flexibility of the approach is particularly relevant to the longitudinal study format, as it can provide a rich and detailed account of the data collected at the various time points. Thematic analysis can provide rich insights into complex phenomena, be applied across a range of theoretical and epistemological approaches and expand on or test existing theory (Braun and Clarke 2006). However, one criticism directed at this approach is that it lacks depth and results in sections of the data being fragmented from the original, which can result in misinterpretation of the data (Attride-Stirling, 2001). The application of rigour in the use of computer software, as well as collaboration with other researchers in discussion of codes, categories and rationale for theme development should serve as a countermeasure to such criticisms. In addition, a number of criteria to ensure credibility of findings were applied in this study (see section 3.7 below).

There are a number of ways to analyse qualitative data within a longitudinal study, including grounded theory, framework approach and thematic analysis. Each of these methods were considered in detail before deciding on thematic analysis as the most appropriate overall method for the research design and research questions. However, some aspects of the other methods were also utilised as set out below during the thematic analysis of data at Phases 1, 2 and 3

This study does draw on ideas from the grounded theory approach to lend rigour to the analysis, namely constant comparison and theoretical or analytical memos. Although both memoing and the constant comparison have a basis in the grounded theory approach, both of these have become more mainstream and are used extensively in qualitative research (Hewitt-Taylor, 2001; Boeije, 2002; Fram, 2013). Constant comparison refers to the process of constantly comparing instances of data labelled as a particular category with other instances of data in the same category. It allows for the 'meaning and construction of concepts to remain under review... and for a more nuanced understanding of what that category might consist of' (Urquhart, 2013, p. 17).

It “assures that all data are systematically compared to all other data in the data set. This assures that all data produced will be analysed rather than potentially disregarded on thematic grounds” (O’Connor, Netting, & Thomas, 2008, p. 41).

Theoretical memos are now widely used in qualitative research, and simply refer to breaking off during the coding process to record ones’ thoughts about the data. This proved particularly useful for distinguishing between potential overlaps in data coding, for example between instances of appraising and using information. It was also used extensively for phases four and five of the thematic analysis which involved reviewing, defining and naming final themes. This is seen as being fundamental to the inductive practice of developing codes and themes and bringing meaning to these. In this study, memos were initially recorded manually in the coding diary and then written up in Microsoft Word to be imported into NVivo. In this way the memos then become part of the study data set.

The framework analysis approach (Ritchie & Lewis., 2003; Pope, Ziebland, & Maya, 2006) was also considered initially for its potential usefulness as a comprehensive data management system for the large body of data generated in a longitudinal study. It is essentially a matrix-based method for ordering and summarising data. However, this approach is better suited to structured topic guides and studies, which incorporate a largely deductive approach. Nonetheless, cognisant of the usefulness of using matrices to display qualitative data, particularly for longitudinal studies, (Miles and Hubermann, 1994; Miles et al., 2014), a matrix format (Grossoehme & Lipstein, 2016); using Xcel (2013) was employed to facilitate the ordering and summarising of data for each participant across Phases 1 to 3.

Baum and Clarke (2006) describe six key phases in the process of thematic analysis. In this study this process was applied to data for study Phases 1, 2 and 3. The six phases are documented below and examples of their application to data at Phase 1 is provided. The process began with the researcher repeatedly reading the interview transcripts in order to become familiar with the depth and breadth of the content (1: data familiarisation). This process continued by examining the transcripts, line by line, and developing initial codes (as closely related to the raw data as possible). The initial coding strategy involved a number of phases. Firstly, generating as broad a set of codes as possible from which to work which are linked to specific segments of the data set

(interview transcript). Each code was assigned a definition. Data collection and analysis was a concurrent process in this study (due partly to the nature of rolling intake which set the time parameters on recruitment). In the first phase of coding, the researcher decided to assign data segments to multiple categories, in some instances, rather than have mutually exclusive categories. This process was further refined in later stages when themes were developed (see Appendix 11 for coding samples).

Secondly initial codes were checked again against the transcript data. The query function in NVivo was used to collate all data coded under 'getting information' etc. Transcripts were reviewed again to check that no data had been overlooked. Some data were subsequently coded into different categories. The researcher went back to each of the initial codes and sought to generate sub-categories (which formed the basis of later theme development). This process also involved the collapsing/integrating of some codes. An example of this is where transcripts were initially coded for the two separate categories of 'medication use' (defined as 'references of participant to medication use/questioning use of med/stopping medication and self-management of medication') and 'self-management' (defined as 'references by participant to self-management of various conditions such as diabetes). Following the phase (b) coding it was decided to collapse these two categories into 'self-management' to encompass medication use and treatment decisions

While each in-vivo code could initially form a potential category, these were grouped together, to form broader categories as coding progressed. Similar categories were then eventually brought together to form the initial themes (3: searching for themes).

Meetings were held between the researcher and supervisor to discuss the transcripts, coding and preliminary findings and to reach a consensus on the final themes (4: reviewing themes). The researcher initially categorised data within the four themes of access, understand, appraise and apply. This process involved movement back and forth through all of the initial codes generated above further categorising the initial codes until final themes and sub-themes were developed. This resulted in the four previously defined themes (access, understand, appraisal and use), each with subthemes and the additional key themes of being in control and communication which the researcher considered as central aspects of health literacy practices.

Each theme was reviewed for suitability (5: defining and naming themes). Themes were verified by checking intrinsic codes and cross referencing to the data under that specific code (within NVivo software). Defining and naming themes involved reviewing the names assigned to the themes. Some were amended to reflect the data they denoted. This process resulted in the decision to incorporate the health literacy competencies of accessing, understanding, appraisal and application within the overall theme of 'Using health literacy capacities for self-management of health and illness'. The final sets of themes (together with sub-themes and categories) identified for all three time points are set out in the Results chapter and in each of the three papers. The final step of thematic analysis involved selecting compelling extract examples, which were believed to clearly elucidate the main patterns and key findings of the data and writing up the findings (6: producing the report). The same process of data familiarisation, initial code generation, searching, reviewing, defining and naming of themes was undertaken for data sets at time 2 and time 3.

### 3.7 Rigour in qualitative research

Without rigour, research is worthless, becomes fiction, and loses its utility (Morse, Barrett, Mayan, Olson, & Spiers, 2002). In the past, a number of leading qualitative researchers argued that reliability and validity were terms pertaining to the quantitative paradigm and were not pertinent to qualitative inquiry (Altheide & Johnson, 1998; Leininger, 1994). However, the current study uses analytic processes and strategies that fit qualitative inquiry while also remaining consistent with concepts used by the larger social science community as advocated by Morse, 2015.

Lincoln and Guba (1985) suggest that the quality criteria for qualitative data means it must be credible, transferable, dependable and confirmable.

#### 3.7.1 Reliability and validity measures

Qualitative validation criteria were applied in this study in line with established guidelines including those of Creswell & Miller, (2000), Guba, (1981) and Maxwell, (1992) and these are set out below:

Validity measures for qualitative data are advocated which includes the strategies used to check the accuracy of the qualitative findings. These may include triangulating data

sources, member checking, detailed descriptions or other sources (Creswell & Miller 2000). Rolfe (2006) suggests that researchers should leave an audit trail recounting not only the rationale underpinning the research decisions and processes but also an on-going critique and self-appraisal process of the researcher. Finlay (2002) supports this view stating it increases the reliability and trustworthiness of the research. In this study participants' perspectives were reported as accurately as possible and the participants' own voices were used. Review and refinement of themes through a consensus process was undertaken among the researcher, supervisor and another academic qualitative researcher. The credibility of findings was enhanced by returning to the original transcripts and through discussions between the researcher, supervisor and an academic qualitative researcher. A sample of transcripts was also read by the research supervisor, and initial codes and final themes were reviewed with both the supervisor and another academic qualitative researcher. In addition, a sample of ten transcripts from Phase 1 was independently coded by another experienced qualitative researcher and consensus was apparent. The following specific strategies for credibility were also employed:

**Triangulation:** Convergence was sought among multiple sources of information (interview transcripts, memos, relevant theory, and researchers' analysis) to verify interview data and to develop themes. Also, by considering the findings in the context of the extant literature the study seeks to illuminate themes and perspectives (Creswell, 2007).

**Member checking:** A level of member checking was achieved where key issues and themes arising at Phase 1 were reviewed with the participants at the start of Phase 2 and Phase 3 interviews.

**Peer debriefing** is where the analysis process is assessed on a continuous basis by one's peers which can assist with the development of both design and analysis of the study where the exercise of having to formulate presentations or report to a peer fosters credibility (Robson, 2000). Peer debriefings were carried out within the supervisory structure of the NUI, Galway PhD programme and included annual PhD presentations and Graduate Research Committee (GRC) meetings and report submissions.

Rolfe (2006) suggests that a 'detailed reflexive research diary' (pg. 309) should be kept for research quality purposes. A detailed research logbook was kept which was a useful tool for improving the overall research process by exploring what went well

and what needed to be changed. This was particularly useful during the operationalisation of data collection methods during the pilot stage of the study. Preliminary analysis between the different phases allowed the researcher to reflect on personal assumptions related to health literacy and social contexts. Researcher reflexivity is also set out in more detail in section 3.8 of this thesis.

**Descriptive validity:** Multiple reading of the transcripts took place and recordings were listened to in line with the methodology of thematic analysis as advocated by Braun and Clarke (2006).

**Interpretive validity:** The study participants' voices were relied on as much as possible for interpretation of meaning alongside the meaning attributed by the researcher.

**Theoretical validity:** The findings are clearly set out within relevant theory in the field of health literacy.

### 3.7.2 Transferability, dependability & confirmability

Transferability refers to the provision of thick descriptions, which specifies everything the reader may need to know to understand the findings (Robson, 2000, Creswell, 2007). Information from complementary data sources can enhance validity and promote understanding and transferability (Polit & Beck, 2010). All aspects of the study are clearly outlined from the theoretical underpinning to the detailed methodological considerations and processes of the qualitative phases.

A credible research process is also considered to be dependable (Robson, 2000). Confirmability refers to a clear audit trail where various categories of information is available e.g. raw data, processed data, data construction, process notes, materials relating to intentions and dispositions and instrument development information. All of the above were recorded throughout the project, reviewed regularly, and are securely stored and accessible.

## 3.8 Ethical considerations in this study

Ethical approval for this study was granted through the Research Ethics Committee of NUI, Galway in May 2013 (see Appendix 12 for approval letter).

### 3.8.1 Informed consent

Due to the nature of longitudinal research, consent should be viewed as process rather than as an initial act (France, Bendelow and Williams, 2000). In this study, consent

was requested from each individual at the beginning of all phases of the study. The Participant Information (PI) sheet specifically set out that the all participation was voluntary and that participants were free to opt out of the study at any point. See Appendix 9 for copies of the consent form and the PI sheet.

All participants were given a PI sheet at initial recruitment. The researcher checked that this had been read and understood and whether the participant had any additional questions prior to proceeding with the survey and interview. The PI sheet was again provided to participants prior to interviews at T2 and T3.

### 3.8.2 Confidentiality and data protection

All participants were given unique identifiers to ensure anonymity. All recordings and transcripts of interviews and paper format documents were stored in a locked filing cabinet in the Health Promotion Discipline at National University of Ireland Galway. Electronic data were stored on a password-protected computer. In compliance with National University of Ireland Galway regulations, data will be stored for five years following study completion before being destroyed.

## 3.9 Reflexivity

Researcher reflexivity can be referred to as ‘thoughtful, self-conscious awareness’ (Finlay, 2002, p.532). Mason (2002) expands on this by describing it as:

thinking critically about what you are doing and why, confronting and often challenging your own assumptions, and recognizing the extent to which your thoughts, actions and decisions shape how you research and what you see.  
(p.5)

It involves a continual internal dialogue and critical self-evaluation of the researcher’s positionality ((Bradbury-Jones, 2007; Guillemin and Gillam, 2004; Pillow, 2003; Stronach, Garratt, Pearce, & Piper, 2007). Reflexivity is situating the researcher as non-exploitative and compassionate towards the research subjects (Pillow, 2003). An important aspect of the process involved considering my own personal characteristics in terms of my social position, gender, personal experiences, political and professional beliefs, values etc. and emotional responses to participant. During Phase 1

interviewing, a number of participants became emotional recalling experiences where delays in diagnosis and/or treatments meant that it was difficult to cope and to understand what was happening. Having a well-developed sense of empathy and being able in some instance to identify with the feelings reported meant that I could appreciate what the participant was telling me without becoming overwhelmed. At the same time, I was aware, particularly at the analysis stage of the study, of the importance of remaining balanced and neutral meaning that I did not give undue prominence to issues that I could identify with. Drawing on the work of Berger (2015) I recognised that in some instances I shared aspects of experiences of the study participants, while in other instances I did not have any personal familiarity. Again, I was aware of the importance of remaining unbiased towards more familiar experiences at all times during the interviewing and analysis processes.

In engaging with participants, I was aware of my own experiences of being a patient and/or accompanying others on illness and health management journeys. From the beginning I became aware of the very emotional aspects of the conversations with participants where people became emotional describing experiences of illness, coping and grief. I was aware of my own experiences and the need to keep boundaries and to explore the participants own experiences only. It was necessary to examine my standpoint as a researcher to accurately reflect the points of view put forward by the participants and to not be influenced by any similar experiences/feelings of my own. On the other hand, I felt that my experiences provided an empathy to my interactions with participants and allowed us to quickly establish a rapport which allowed them to be comfortable in opening up to me. My training in psychology, health promotion and in social science research allowed me to comfortably explore the broader aspects of health and illness and to be considerate in the discussion of any sensitive issues. I also considered my stance as a researcher and the issue of power relations in the research process (Karnieli-Miller, Strier and Pessach, 2009). Cognisant of this, I made it clear that each participant was the expert in terms of their own experiences and I did not make any judgements or use leading questions. I was also aware of the importance of building relationships with the participants (as we would be engaging with each other on multiple occasions) whereby each individual felt comfortable to meet with me on multiple occasions.

In addition, the use of memos throughout the data collection and analysis process allowed me to record reflections and thinking processes in keeping with the views of Miles et al., (2014). Within LQR they are particularly useful for recording thoughts on participant changes as analysis proceeds (Saldaña, 2003). In this study the researcher used memoing throughout the research process to capture thoughts and connect ideas about participant changes.

## CHAPTER 4: RESULTS

### 4.1 Introduction

The results of this study contributed to three peer reviewed articles, which have been published in three different journals (Appendices 1-3). In this chapter, the key findings from each study phase are discussed as reported in papers I-III. Furthermore, unpublished findings in relation to study phases are also included. Quotations not included in the published papers are presented here to provide a broader view of the data collected. To conclude, the main findings from the study are summarised at the end of the chapter.

### 4.2 Summary of the key findings from the three papers

#### 4.2.1 Paper I: The relevance of context in understanding health literacy skills: Findings from a qualitative study

This paper presents findings from Phase 1 of a qualitative exploration of how individuals use health literacy in the context of their everyday lives in managing their health and illness, including risk factors for CVD. As outlined in Chapter 3, the study used the Sørensen et al., (2012) conceptual model of health literacy to examine individuals' experiences of accessing, understanding, appraising and applying health information and explored the barriers and facilitators in using these skills. It also described the experience of information exchange in health consultations. Findings are reported from Phase 1 of a longitudinal qualitative study design to examine developments in health literacy over time. The aim of this paper was to explore the use of health literacy in the context of individuals managing risk factors for CVD. The objectives of Phase 1 were to:

- Describe individuals' experiences of accessing, understanding, appraising and applying health information.
- Explore the context (i.e. the barriers and facilitators) to using these skills.
- Describe the experience of information exchange in health consultations.

The methods for this study are outlined earlier in the methods chapter. Findings from the HLS-EUQ47 indicated that participants had a high level of limited health literacy (n= 17; 65%), which is higher than levels reported in the overall European survey (Sørensen et al., 2015), which ranged from 28.7% in the Netherlands to 62.1% in Bulgaria. The level reported is also higher than that reported for the Irish sample of

the European survey at 40% (Doyle, et al., 2012). This high level of limited health literacy may be linked to the fact that the individuals were managing chronic illness. Findings from the HLS-EU study indicated that higher levels of limited health literacy were associated with vulnerable groups, including those with poor health status and those managing more than one long-term illness (Sørensen, et al., 2015).

In this study, participants had an adequate level of health literacy for the health care index and limited levels of health literacy for both the disease prevention and health promotion indices. This finding may be indicative of individuals who are frequent users of the health services due to their health conditions. The demographic details of participants are set out in Table 2 in Chapter 3 and indicate that the sample was mixed across demographics. Statistical tests for differences in general health literacy scores for education and social class were not significant ( $p = .265$  and  $.389$ , respectively).

Thematic analysis of the interviews yielded rich data on contexts as well as the different facilitators and barriers which can impact on health literacy practices. Findings also highlighted experiences and strategies that individuals used for accessing, understanding, appraising and applying health information across the functional, interactive and critical levels of health literacy. Overall, four themes were identified. These themes and subthemes are presented in Table 7.

Table 7: Themes identified in Phase 1 analysis

Theme	Sub-theme	Categories
Using health literacy capacities for self-management of health and illness  (Functional; Interactive levels)	Health information seeking	Keeping motivated  Active and passive information seeking  Appraising information  Making sense of information
	Side effects of medication use	Decisions about treatments  Concerns re QoL
Psychological factors that impact use of health literacy capacities  (Critical level)	Perceptions of control	Being confident and proactive  Not having control  Dealing with family history
	Emotional reactions	Anxiety and coping
Structural factors that impact use of health literacy capacities  (Critical level)	Being able to access health services	Health service access  Having/not having health insurance  Waiting lists  Fragmentation of services
	Environment	Living environment (rural, urban)  Affordability
Quality of relationship with the HCP  (Interactive level)	Qualities of the HCP	Listening, good rapport, trust, feeling cared for
	Accessing and appraising information with the HCP	Positive and negative experiences  Seeking referrals

		Active and passive relationships
	Communicating	Positive experiences Negative experiences

The study found that participants were actively attempting to use the health literacy competencies of accessing, understanding, appraising and applying health information to manage their health and illness (Sørensen et al., 2012). The first theme in Table 7 includes seeking out health information (accessing), making sense of and appraising information (understanding and appraising). Insights on the psychological and structural factors are related to the extent to which the competencies can be influenced by these factors. These factors can impact on how health information is applied.

Some participants were less active than others in terms of asking questions and accessing information. For example, one participant didn't actively engage in seeking out information instead preferring to *'trust the doctors for ... guiding me the right way ..., and I go along with it'* (P18ML). Participants readily acknowledged the challenges of putting knowledge into action and motivation was reported as an ongoing challenge for many. Participants who were at the beginning stage of the community-based risk reduction programme recognised that it would likely contribute to motivating them to engage in health promotion practices believing that *'you need something like that that would have a follow up kind of thing. It's no good saying you'll do it yourself because you won't'*. (P5FL)

Participant concerns about the side-effects of medications were identified as an important issue with implications for whether or not a treatment may be taken up, despite medical advice. For some participants, their fears were discussed further with the GP, however, not all reassurances were taken on board, *'I read up on them; the tablets I'm taking you're not supposed to be taking these. I asked him about it, Dr X, he said it's no harm in taking a few of them, you're alright. I still didn't want to take them. I still have them in the house there'* (P10ML)

Psychological factors, including perceptions of 'being in control', emerged as an important factor that could impact on the use of health literacy capacities. For some

participants, being in control and being responsible for their own health was important. For others, a feeling of having little control over health issues contributed to a more fatalistic attitude. A number of participants had experienced delays in receiving important diagnoses, which impacted on confidence and the control they felt over their health. Study findings showed that being in control or having limited control are central to how health literacy capacities may be utilised in the management of health and illness. Feelings of being in control are associated with greater confidence for more proactive engagement with health information and health services such as being able to ask questions and seek solutions. The psychological aspects of managing illness can impact on abilities to access, understand, appraise and use health information. Stress and fears associated with a diagnosis or treatment can impede individuals from moving forward: *'I was very, very nervous, 'I was very nervous. Absolute dread, yeah. Just couldn't go any place without somebody being with me, constantly sick, constantly thinking the same thing is going to happen again'*. (P9FA)

In addition to psychological factors, structural factors, which could impact on use of health literacy capacities, were also identified by participants. The timeliness of being able to access health services was an important topic, with participants having experience of both public and private systems of health care. While long waiting lists were associated with public access, some felt that the aftercare provided in the private sector was poorer than in the public system: *'There is no follow up on private. So that in actual fact, if you can get in on the public system, I think it's a much better caring system really'*. (P25ML)

In the absence of private health insurance, public access was seen to work better in emergency situations but was lacking in terms of preventative care: *'I think the health services work very well if you're in crisis; possibly it would be great if they had the money to invest more in preventative stuff; that can be a bit slow'*. (P25ML)

Being able to apply health information, such as engagement with health practices was viewed as being dependent on environmental facilitators such as access to safe walking and cycling areas. A lack of facilities in rural areas was seen as challenging. In addition, the issue of affordability in terms of being "fortunate enough" to afford a lifestyle that promotes wellbeing, accessing health services and costs of medication were also concerns that were raised in the study. Medication costs in the Irish

healthcare system are addressed to some extent by the Drug Scheme<sup>2</sup> (HSEb, nd) but costs can still be significant: *'The drug scheme is a waste of time. I mean I've to pay €140 per month before I benefit from that. So my prescription per month is about €110 so I really don't benefit from it at all... at the moment I can afford the medication right, but I mean if I was on the threshold basis, like that you know struggling, it would be a huge stressful factor like for people that are ill and have to take medication, like the cost is a huge stress factor, do you know'*. (P16MA)

Findings from this study have highlighted the crucial role of the health care provider, and the GP in particular, for helping individuals to navigate health information in terms of being able to access, understand, appraise and apply health information. In this way the health care provider plays an important role in impacting on the potential of individuals to develop health literacy capacities in these areas as well as playing a role in the empowerment of the individual in their own healthcare. Positive experiences were contingent on the quality of the interaction and the perception of trust and being cared for that the participant felt: *'He's very good, he is good. We've sort of got a very good relationship and he can give out to me and I can give out to him; he is good. And he will sort of sit me down and say look, you need to do this and take my advice for once'*. (P11FL)

As shown in Paper I, overall findings show evidence of widespread use of health literacy capacities and efforts to engage with health issues, despite the fact that the majority of participants appeared to have limited levels of health literacy. The findings have generated a number of important insights into contextual factors influencing how health literacy capacities may be used. Health care providers having a more nuanced appreciation of their patient's understanding of, and attitudes to, family medical histories as well as their management of the side-effects of medication, and their perceptions of control are highly relevant. These can make an important contribution to enriching the patient-provider relationship as well as promoting opportunities for optimal health outcomes for individuals regardless of health literacy levels.

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<sup>2</sup>The Drug Scheme: Under the Drugs Payment Scheme (DPS) an individual or family will pay no more than €124 each calendar month for: approved prescribed drugs and medicines; rental costs for a continuous positive airway pressure (CPAP) machine; rental costs for oxygen.

#### 4.2.2 Paper II A qualitative study of the development of health literacy capacities of participants attending a community-based cardiovascular health programme

This paper presents findings from Phase 2 of the longitudinal study, which comprised a repeat interview methodology at 12 weeks post baseline. The study explored developments in health literacy for nineteen participants, following attrition of seven participants, who were attending the community-based CVD risk reduction programme. See Chapter 3, Table 2 for the demographic profile of the participants. The study objectives at Phase 2 were to:

- Explore perceptions of changes in interactions and information exchange within health consultations.
- Identify the facilitators associated with changes in health literacy capacities.
- Assess any developments in engagement with the broader contexts for health literacy capacities.

The Phase 2 study was concerned with a broader focus of health literacy that moved beyond the realm of functional health literacy. Semi-structured interviews were used to explore the development of health literacy and to identify changes in knowledge, attitudes and experiences over time. Thematic analysis of the interviews was undertaken and this was also informed by a specific framework for longitudinal analysis developed by Saldaña (2003) as outlined earlier in the methods chapter (Chapter 3). Thematic analysis of the interview data identified five themes, which are set out in Table 8 below.

Table 8 Themes identified in Phase 2 analysis

Theme	HL level	Sub-theme	Categories
Re-engagement with health information	Changes in functional HL	Qualities of communicator	Engaging Supportive
		Forum/methods	Multiple methods used
Increased understanding of risk and protective factors	Changes in functional HL		Food and nutrition Exercise Medication and treatments Side-effects of medication Cholesterol; BP
Changes in interactions with HCP	Changes in interactive HL	More at ease in communicating with the HCP Reinforcement/reassurances	Increased knowledge and therefore confidence
Enhanced psychological insights	Changes in critical HL	Increased insights of personal control limits and opportunities	Self-efficacy and confidence Dealing with stress
		Emotional issues Facilitators of motivation	Anxiety/fear Peer comparisons
Understanding the broader determinants of health	Changes in critical HL	Sharing information Infrastructures to support health	Safe access-walkways; cycling Food manufacturing/culture Government lobbying

Developments in terms of the health literacy competencies of accessing, understanding, appraising and applying health information were evident here. Re-engagement with health information is related to developments in accessing, understanding and appraisal of health information whereby participants found this easier to do based on how the information was presented to them. Developments in terms of understanding the risk factors for their conditions, as well as new insights regarding the broader issues that contributed to health and illness, were also apparent. These positive developments, in terms of knowledge acquisition and understanding, were also related to increases in confidence which were highlighted in reports of improved communication and interactions with health care providers. Enhanced psychological insights stem from developments in understanding and an improved

ability to apply health information to manage stress. Understanding the broader determinants of health is also linked to using or applying health information as individuals reflect on barriers and facilitators to the use of health information in their everyday lives.

Analysis also identified that participants developed health literacy capacities that incorporate changes in the functional, interactive and critical levels of health literacy within the five identified themes. Findings highlighted that changes in functional health literacy, including improvements in understanding and engagement could be attributed to the methods used to communicate health information. The practical nature of the information delivery and its relevance and applicability to everyday life was also perceived to be a facilitating factor. This is important in relation to accessing information for lifestyle issues that are integral to self-management of health and illness: *'They had screens there and everything was displayed, you know you could talk till the cows come home but if you have a diagram of something up there it helps to make it register'*. (P13MA)

Participants reported acquiring new insights into their health care management, including understanding what medications were for, how they actually worked and understanding side effects: *'Also I learnt a few things about medication. I was on medication for the last number of years but you know, why you were taking what and what it was doing. And when to take medication and how it reacted with you, you know, learnt a bit about that'*. (P16MA)

Participants had developed more confidence in their interactions with HCPs due in part to the acquisition of new knowledge and understanding and also from their positive experiences with health care staff on the community-based programme. One participant, who was previously very reluctant to discuss treatments due to fears and anxieties, was now actively pursuing information and discussing it with her HCP: *'Dr X he's kind of said "I'm glad you are reading about it" because I was reading kind of the downside as well. He said "look I'm glad you are reading around the whole thing, the upside and the downside of it" you know'*. (P21FL). Findings also indicated evidence that participants were actively 'cascading' or sharing their newly acquired information with their family and wider community. Some participants were actively

sharing health information with extended family/friends and some were actively trying to change the health practices of others:

*I'm passing it along because there's 13 of us so I'm passing it on to them and their wives and their kids. So there's a whole bundle of people out there that's getting the information as well. Even the booklets that I get here I pass them on there and they're all reading them. Some things they might change, some they mightn't. You know that they are trying themselves as well because like a few of us started doing a few changes and you see them doing it as well; even like there's a few of my brothers and they've given up salt altogether. (P1FL)*

*I do especially say to immediate family. I did, I spoke to my niece about it, and I spoke to my sister. I'm very much a kind of pass it on, I think that's important. The more people who know, you know ... Passing it on, kind of giving people, say my sister, both sisters actually and also my sister's partner because he had a stent put in; I suppose I rang him then just this week and said are you aware that you really should have a blood test on a regular basis; well he was but he hadn't, so that kind of thing. (P8FL)*

A key finding in this paper related to participants' increased psychological insights regarding personal control, emotions, motivation and self-efficacy. Participants saw that enhancements in these areas could impact positively on their abilities to fully utilise their health literacy capacities. Findings also indicate that participants were becoming increasingly empowered as they navigated ongoing management of their health and illness. Developments here are indicative of moving towards critical health literacy as attempts are made to address and control aspects of personal and social determinants of health: *'I think I was having a mental block as well. I was using all these excuses but I didn't realise it. So I started making time and doing stuff And then every day I make sure I get my hour to go out walking, doesn't matter what's happening, I get an hour of walking for myself'. (P1FL)*

Participants were increasingly reflecting on the broader determinants of health, such as issues related to environment infrastructure, and policies in relation to labelling of food products. Overall, it was apparent that participants were more engaged with these issues compared to Phase 1 findings. For example, one participant reflected on the

adverse effects of a car culture particularly for mothers doing school runs and after school activities, which she linked to a lack of school based extra-curricular activities compared to the UK's school system: *There's a lot of after school stuff so you're kind of jumping in and out of the car dropping them here, there and everywhere whereas that was all part of the curriculum when we were growing up. So living in a city I think is easier in terms of keeping yourself fitter you know. But the car I think is desperate here you know. Women particularly I think are always in it. (P8FL)*

As shown in Paper II, findings provide important insights into how health literacy capacities develop over time and support the development of health literacy capacities across the functional, interactive and critical health literacy domains. This paper provides increased insight into how the development of health literacy can be facilitated which has important implications for health promotion programmes as these can explicitly address developing health literacy capacities. Over time individuals can develop confidence and self-efficacy regarding use of health information and an increased awareness of the social and environmental factors that can impact on health, as well as identifying ways in which they can act on such factors.

#### 4.2.3 Paper III: Facilitators and barriers to the development of health literacy capacities over time for self-management: Findings from a longitudinal qualitative study

This paper presents the findings from Phase 3 of the overall longitudinal qualitative study, which aimed to examine any developments or changes in health literacy capacities over a twelve month period. The paper addressed the following research questions:

Does health literacy develop over time in the context of prevention and health promotion interventions? What are the main barriers and facilitators to health literacy development?

##### *Attrition of participants*

A total of nine participants were lost to longitudinal analysis and seven of these were lost to Phase 2 follow up. Characteristics of the nine participants are outlined in Appendix 5. Three participants had a reported adequate level of health literacy and the remainder had a limited level of health literacy. The average age of the participants

was sixty years. The group comprised two males and seven females. Attempts to contact all participants by email and telephone resulted in contact with five of the participants. These had decided to leave the programme due to either time constraints or illness. Despite repeated attempts at contact, there was no response from four of the participants. See Chapter 3 for the participant profiles of the seventeen participants included in Phase 3. In order to profile the participants further in the context of health literacy, the HLS-EU-Q was administered again at T3 to provide a general overview of health literacy levels as well as to provide an indication of developments/changes over time. Specific longitudinal question frameworks were utilised to interrogate the qualitative interview data to examine developments and changes over time and examples of their application are presented in Table 9 below:

Table 9 Application of longitudinal question frameworks

Saldaña (2003)	Lewis (2007)
Framing Questions (situate the context of the data)	Description questions
What is different from one round of data to the next? (differences in confidence, perceived sense of control)	What is the type, extent and timing of any changes (linked to framing questions above)
When do changes occur through time?  (What is the timing of changes?)	Location questions
What contextual and intervening conditions appear to influence and affect participant changes through time?  (What external events are happening; what illness experience occurs?)	Who showed changes, when, and in what contexts (linked to framing questions above)
What are the dynamics of participant changes through time? (Make comparisons between participants in relation to changes and HL levels, changes and illness experiences. What were the	Explanations (Drivers for change)
	What were the factors that influenced the changes? (changes in confidence; external events)
	Evaluation
	What influenced the experience of participants in use of HL capacities and change/lack of change?

<p>effects of intervening factors on changes and comparisons of these across participants?)</p> <p>What preliminary assertions about participant changes can be made as data analysis progresses?</p> <p>(empowerment across time points becoming apparent)</p> <p>Descriptive Qs (7)</p> <p>What increases/emerges through time?</p> <p>(need to focus on self)</p> <p>What is cumulative through time?</p> <p>(confidence, self-efficacy)</p> <p>What kind of surges/epiphanies occur through time? (role of HCP)</p> <p>What decreases/ceases through time?</p> <p>(fears and anxieties abated for many)</p> <p>What remains constant or consistent through time?</p> <p>(engaging with health information; reluctance to change providers)</p> <p>What is idiosyncratic through time?</p> <p>(Is HL development orderly or consistent? How does HL play out in different circumstances?)</p> <p>What is missing through time? (limited changes for some)</p>	<p>(Relationship with HCP; being able to use information; confidence).</p> <p>Consequences</p> <p>What was the effect of further changes, new directions, loss of opportunity (more positive outlooks, enhanced HCP interactions, increased interactive and critical HL apparent)</p> <p><i>Personal meaning</i> What was the perceived importance of the change (very positive)</p> <p><i>Policy meanings</i> Applied to Sørensen framework</p> <p>Researcher reflection</p> <p>Reflexivity</p>
<p>Analytic and interpretive questions (4)</p> <p>What changes interrelate through time?</p> <p>(illness, adverse life experiences and confidence, sense of control)</p>	

<p>What changes through time oppose or harmonise with natural human development or constructed social processes?</p> <p>(Expected changes at T2 but were generally sustained over following nine month period).</p> <p>What are participant or conceptual rhythms e.g. cycles through time?</p> <p>(participants dealt with new diagnosis, changing symptoms and ongoing management)</p> <p>What is the through-line of the study?</p> <p>(perceived control is central to HL development)</p>	
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Overall, four themes were identified at Phase 3 which are set out below, together with sub-themes and categories

Table 10: Themes identified for Phase 3 analysis

Theme	Sub-theme	Categories
Gaining control and becoming empowered	Psychological impacts of external events	Dealing with stress Dealing with pain Past negative healthcare experiences/delayed diagnosis
	Self-efficacy	Ability and confidence to make lifestyle changes
	Looking after self	Need for psychological supports Fears and anxieties Dealing with grief
Embedding knowledge, health practices and motivation	Accessing and using information	Awareness of limitations Knowledge on diet and exercise
	Environment	Urban/rural Facilitator/Barrier to health promotion practices
	Food literacy (what shapes food choices)	Marketing Food labels Family/social aspects
Dynamics of relationship and Support of HCPS	Communication, rapport, trust and approachability	Positive/negative outcomes Non paternalistic

Treatment decision-making	Managing and challenging side-effects  Decisions about treatment	Fears and misconceptions  Logistical and practical considerations
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Overall, participants reported gaining a greater sense of control over their health over the 12 month period which facilitated the positive development of health literacy competencies (accessing, understanding, appraising and applying health information). This included having a clearer perception of the limits of control, as well as having increased confidence related to the developments in understanding, appraising and applying health information: *‘I’ve just figured out that you can’t, it’s not an all or nothing situation either. You can’t have perfect health all of the time or it’ll completely fall apart. You just have to have the best health you can have, at any particular moment in time. And..., just feel a bit more prepared for the process and at the same time, appreciating that you can’t control everything’*, (P2FA)

Developments in accessing, understanding, appraising and applying health information were also reflected in the theme of ‘embedding knowledge, health practices and motivation’. The facilitators and barriers identified are linked to the competencies of accessing, understanding, appraising and applying health information and the extent to which these are influenced by structural factors. In addition, developments in the competencies were also apparent as participants engaged in decision-making on treatments and in developments in their relationships with HCPs. Increased knowledge and understanding were also related to increased confidence in interactions with healthcare providers.

An important finding was in relation to an increased emphasis on taking care of one’s mental health in order to be able to manage health and illness: *‘I suppose physical health I always knew...because you can see it, but the mental health you can’t see it. And you know I have good conversations with my mum about it. So I think my mental health is good – well it’s getting better...But I think I say things – before I’d internalise it, and it would be kind of stressed. I have a good group of friends now’*. (P8FL) While the importance of the availability of psychological support was acknowledged, so too were the difficulties in accessing these services.

However, findings also elucidated the role of adverse circumstances (illness and demanding life events) on abilities to effectively use and develop health literacy capacities and in this way acted as a barrier. Participants were continuing to embed health knowledge and practices over time within the everyday contexts of their lives. This included, for example, having an increased understanding of the importance of combining both diet and exercise for the greatest health benefits: *‘I find it very hard to be vigilant around eating when I’m not exercising, that is a big challenge for me, once I’m exercising, that’s fine. So that’s something I may need to work on, if my ability to exercise is compromised’*. (P2FA)

Participants indicated that they had sustained an awareness of the broader determinants of health, evident in the importance placed on the living environment, which was perceived to impact on health practices and health outcomes. Participants continued to reflect on their environments in terms of local community, living space and availability of facilities to engage in health pursuits (walking, swimming, gym). The environment and access to facilities also impacted on motivation to engage in health practices. Rural environments were seen, on the one hand as peaceful and a positive environment for raising children that contribute to a natural healthy way of life, but were also viewed as being challenging, in terms of transport and access to facilities to engage with health practices.

Developments continued across relationships with HCPs. Participants reported confidence in interactions with HCPs: *‘My GP is very helpful, we discuss things. She would make recommendations and refer me on, if she feels I need referring on. In terms of, the consultants and things like that, I have had two consultants that I’ve dealt with and I have found both of them very helpful. Very open, very, prepared to sit down and discuss things and to answer any questions that I have. And to take the time to do that, so I haven’t any complaint with them. I’ve been very happy with them’*. (P2FA)

An interesting finding was that individuals often chose to remain with a GP even where they were dissatisfied with the service provided. *‘At the moment I don’t see him for very much, only for, he does the Warfarin... but, that’s about it like, anything just, you know something on a general line. But I mean if I went in now he wouldn’t kind of say “well we’ll do the blood pressure, and we’ll do A, B and C” like you’d have to go in and ask for it. He’s not really proactive in any way’*. (P5FL)

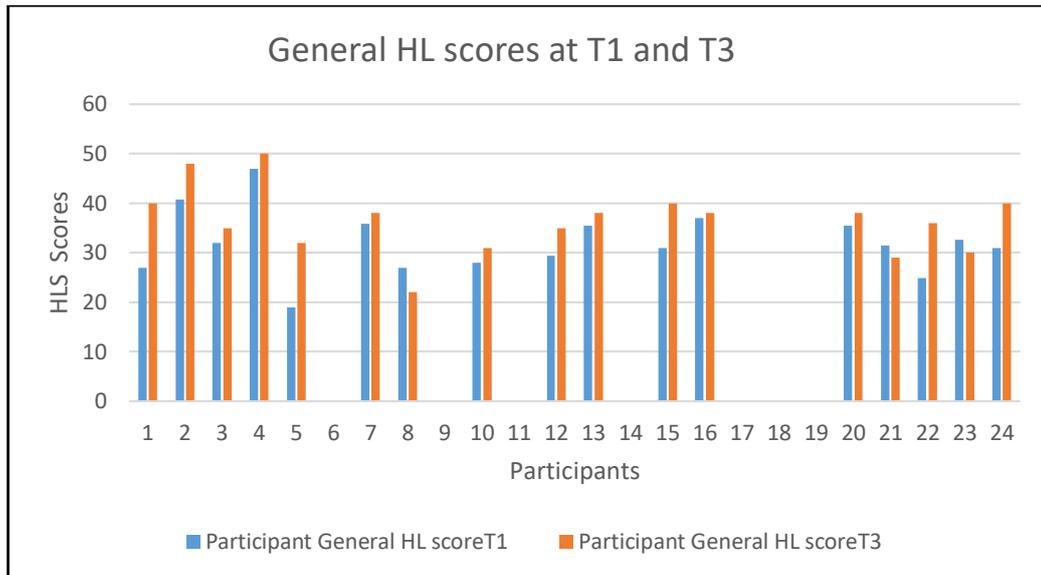
Findings showed that individuals, despite overall increases in confidence, can continue to have concerns over medications and treatment plans: *'When I went to Dr [name] the last day and I had told him I was getting very sick, and I stopped taking the cholesterol tablets. So he told me they have a new programme in the hospital, and they're doing this, it's an injection for your cholesterol once a month. I've just a dread of cholesterol tablets'*. (P20FA). Having limited access or understanding of information on a particular treatment could lead to delays in taking up treatments or avoiding them altogether.

As shown in Paper III, findings indicate that while developments occurred across all three levels of health literacy, there was variation in these developments reliant on both individual experiences and contexts. Findings from Paper III provide an increased understanding of health literacy challenges experienced in the management of health and illness over a period of time and of the strategies individuals use to address such challenges. The findings have important significance for health care providers, especially in relation to self-management programmes, in order to highlight specific areas where more supports may be necessary to facilitate positive developments in their health literacy. In particular, the need to address the psychological as well as the physical aspects of illness management were apparent. Additional supports maybe required to assist people in translating health information into health promoting activities by supporting them to address barriers they are facing.

Changes in health literacy scores:

Twenty-nine per cent of the participants had a limited level of health literacy at T3, and the majority showed an increase in score compared to scores from T1 (see Figure 4 below). The average health literacy score for general health literacy had increased from 32 (limited) at T1 to 36 (adequate) at T3. Using a significance level of 0.05, a Wilcoxon signed-rank test (utilising exact significance) showed that the General HL score is significantly different across time with higher scores at T3 than T1 ( $z = -2.832$ ;  $p = .003$ ). Although the average scores across the healthcare, disease prevention and health promotion indices had also increased, Wilcoxon signed-rank tests showed that the increases were not significant: Health promotion  $z = -1.890$ ,  $p = 0.059$ ; Disease prevention:  $z = -1.762$ ;  $p = 0.083$ ; Health care:  $z = -2.540$ ;  $p = 0.010$ .

Figure 4: General HL scores over a 12 month period



Based on the health literacy score changes over time participants were grouped into the following four categories:

- Change from limited to adequate health literacy level over time
- Adequate health literacy increased score over time.
- Limited health literacy increased score (remained in limited band) over time.
- Limited health literacy score decreased over time.

To gain a greater understanding of the changes, it is useful to consider the nature of these changes and how they reflected individual participants' experiences. A trajectory longitudinal approach as outlined in the methods chapter, allowed for an exploration of the experiences over time for each of the participants. Within each group, examples of the participant experiences are presented.

**Change from limited to adequate health literacy level over time:** Six participants moved from a limited to adequate level of health literacy score. Although they continued to monitor health issues they did not experience any major new symptom or illness over the twelve month period compared to some other participants. They were engaged in ongoing strategies to promote health by increasing activity levels, monitoring diet and mental health (such as recognising the importance of physical

activity for mood enhancement). Two of these participants were partners to referred participants, although one did have significant risk factors to address. In one case the participant had experienced a number of potentially stressful life events (moving home and pregnancy) however, these were perceived as positive life events and served to further motivate her in her health promotion pursuits.

P1: Female aged 36 years (referred following gestational diabetes during pregnancy). She also had a high body mass index (BMI) and blood pressure (BP) readings at T1. This participant was very concerned about a family history of heart disease and diabetes and was unsure of how to find out answers to the queries that she had. Her demeanour was reticent at T1 and came across as low in confidence and quite fearful about how to protect herself and her family from diabetes and heart disease. The participant engaged very well with programme and enjoyed all aspects of it. As a result she felt that her motivation and overall mental health and mood improved. She was able to engage with exercise and dietary changes and able to see what facilitated behaviour change (such as changes in her living environment). She was able to access and understand information that was relevant to her. She also showed overall improvement in BP (was able to come off blood pressure medication) and BMI score. As time went on she also actively engaged in sharing health information with extended family members.

P15: Female aged 75 years, widowed. At Phase 1 interview it was apparent that she was quite anxious as she had experienced a transient ischemic attack (TIA) a few months before beginning the programme. She was very fearful of aftermath and trying to understand what had happened. She was very apprehensive about the possibility of having another episode. She had chosen not to let her immediate family know about the TIA as she felt that they would worry about her. As a result, she did not have support in terms of coping with the diagnosis. She was hoping to get more information on what her risk factors were and why she had become ill. In addition, she was still coming to terms with the death of her husband a number of years earlier. Over the 12 month period there was a marked increase in her confidence, and she became very engaged with health promotion strategies. She had acquired a much better understanding of the TIA diagnosis. She had also shared information on her diagnosis with her family members and had become-much more active socially. In particular,

she was very engaged with looking after her mental health as she realised that this was an area she had neglected in the past.

P12. Female aged 50 years. Engaged with reducing cholesterol and quitting smoking. This individual was resistant to use of medication to lower cholesterol and was using a diet based approach to doing this. She was very confident and proactive in her engagement with HCPs and was able to question treatment plans and to question the side-effects of same. She was also a carer for older relatives and drew on their experiences in health service access and use to question some of the structural determinants in terms of health care access.

**Adequate health literacy increased score over time:** Overall, there were six participants included in this category. Below are examples from two of these participants. Both of these participants began with high scores which increased over the twelve month period. Both were extremely confident and proactive in their dealing with the health care system.

P4: Female aged 59 years. This participant was the partner of a referred individual and so engaged with general health promotion over the 12 month period. She was able to increase her knowledge and motivation over the time period and saw improvements in diet and exercise. She was confident and proactive in engaging with health care providers. In particular she moved towards a greater engagement with the broader determinates of health, for example, in questioning issues around food availability and structural barriers to activity levels for children.

P2: Female aged 43 years. This participant was very confident and proactive in her dealings with the health care system and in managing health and illness for herself and her family. Although she had to deal with a number of health issues and stressful life events over the twelve month time period, her confident approach in dealing with health care services and providers may have contributed to a maintenance of adequate health literacy throughout (in comparison, for example, to the experiences of P8 detailed below). She had also developed good coping mechanisms for dealing with stress.

**Limited health literacy increased score (remained in limited band) over time.**

Three participants were included in this category.

P5: Female aged 65 years. Although this participant remained at a limited level of health literacy over the time period, she did show a substantial increase from a score of 19 up to 32, which brought her score to the cusp of adequate health literacy. This individual did experience very serious ill-health over the 12 month period and long periods of hospitalisation. As she was diagnosed with a new illness between the T2 and T3 time periods she had to find, understand, access and use new information regarding the condition. She did demonstrate useful strategies for doing this. For example, she found it useful to access information regarding use of oxygen equipment through both the specialist nurse and the company supplying the oxygen.

P10: Male aged 65 years. This participant was not very proactive in dealing with health services and had experienced difficulties in accessing information. He had also experienced serious ill-health over the twelve month period as well as dealing with decreased mobility which made it very difficult to sustain health practices around exercise. It was apparent at Phase 1 that his engagement with community-based leisure activities and regular walking were an important part of mental health promotion for him. Therefore, not being able to engage with these activities, had a negative impact on his mental health. The participant was not very proactive in dealing with health services and had experienced difficulties in accessing information. In addition, he experienced an increasing stressful living environment over the 12 month period which impacted on his mental health.

**Decreasing health literacy score over time: limited health literacy score decreased over time.**

Two participants who initially had a limited health literacy score showed a decrease in their score over time. One participant had experienced illness and very stressful life events over the time period including taking on additional caring role for older family members. She attributed these events to having a sense of limited control over her life and the ability to engage positively with health issues. She recognised that she needed to be able to manage stress better in order to make positive life changes.

P8: Female aged 58 years. This participant had a history of TIA, high BP, high BMI and cancer. She struggled with managing stressful life events over the 12 month period. She also struggled with illness and managing her own time due to family caring commitments. She felt that she had limited control over ability to make changes in life due to life circumstances which had become more complicated over the 12 month period.

P21: Female aged 59 years. At Phase 1, this participant was coping with a recent diagnosis of heart failure. It was apparent that she was very fearful of some of the treatments required. She was also very unsure of what she could/could not do in terms of exercise. Her mood was quite low. She also recognised that she needed psychological supports which were difficult to access. Following completion of programme (Phase 2) she was more confident in relation to managing her condition. However by 12 months she had experienced more serious illness and was finding it difficult to cope. Her mood was quite low as she was frustrated with the inability to fully engage with health behaviour change because of illness/life circumstances. She reported feeling that she had a sense of limited control over being able to manage her circumstances. In terms of her more recent illness setback, she reported that she had not understood the symptoms of an illness which led to it becoming more serious and as a result she had to be hospitalised.

### 4.3 Summary

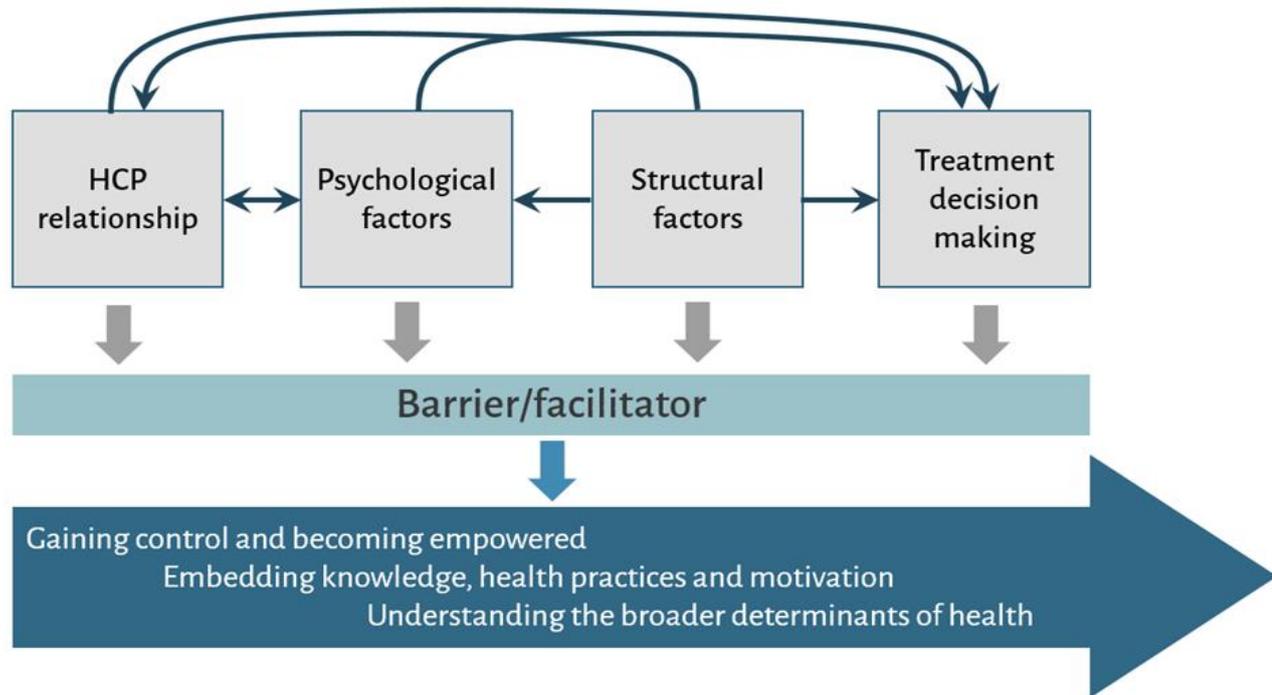
Facilitators and barriers to health literacy and its development over time were identified in this study. Participants demonstrated developments in knowledge and motivation used to access, understand, appraise and apply health information. These developments were related to increased perceptions of having control and being empowered over time. However, this was also found to be impacted by external life events. Study participants were also found to be embedding health knowledge, motivation and behaviours over time within the everyday contexts of their lives. The relationship with the health care provider permeated all aspects of health literacy capacity development including aspects of treatment decision-making. Participants identified the need for psychological supports and the increased importance of looking after their mental health. Findings from this study support many aspects of Sørensen's health literacy model. The core aspects of knowledge, motivation and competences are central to the development of health literacy capacities over time.

These findings show that self-efficacy plays an important role in the use of health literacy capacities. In the main, participants experienced increased confidence and perceptions of control in being able to manage their health. The focus of the cardiovascular risk reduction programme contributed to an increased ability to access appropriate information as well as having a better understanding of that information. This is also linked to improvements in appraisal, as participants could question information and could discuss it with health care providers. The study findings have also highlighted the importance of both psychological and situational contexts that can impact on health literacy capacities and this also supports the Sørensen et al., (2012) framework.

Findings from these papers have elucidated the contexts for use of health literacy capacities and demonstrated that health literacy can develop over time. However, developing health literacy can be facilitated or hindered by a number of factors pertaining to the individual (psychological, such as perceived sense of control) and broader social factors (structural, such as health service access; lived environment). Longitudinal findings underscore the importance of the health care provider in supporting the development of health literacy capacities over time.

Figure 5 below depicts the overall findings regarding the main barriers and facilitators identified by respondents from the interviews conducted.

Figure 5 Thematic map: key findings from the three articles



The main findings from the three study phases can be summarised as follows:

#### Paper I

The identification of important insights into contextual factors influencing how health literacy capacities may be used. The health care provider, and most often the GP, emerged as being central to the process of navigating health information and, therefore, activities to enhance the quality of the patient-provider relationship were viewed as being important.

Psychological factors, including perceptions of control over one’s health, including the impact of structural factors were also identified to act as either barriers or facilitators in the use of health literacy capacities.

Participants generally reported actively seeking out information and working towards understanding, appraising and using it. However, concerns about medication use and possible side effects were apparent.

## Paper II

The findings generated important insights into the factors that can support the development of health literacy capacities for individuals with varying health literacy needs.

Findings support the development of health literacy capacities across the functional, interactive and critical health literacy domains.

Participants developed increased confidence in their interactions with health care providers drawing on the supports gained from community-based programme participation.

Developments in perceptions of personal control and self-efficacy were also observed in relation to how participants managed their health, with increased ability to use health information to make lifestyle changes.

Increased engagement with health knowledge was also found that went beyond personal health management to an awareness and appreciation of the social determinants of health and how they impacted one's health and wellbeing.

## Paper III

Study findings revealed developments across the functional, interactive and critical levels of health literacy among study participants, together with a progression in personal empowerment.

Findings support the main components of the Sørensen et al., (2012) model. The core aspects of knowledge, motivation and competences (to access, understand, appraise and use health information) are central to the development of health literacy capacities over time. However, the role of the health care provider could be made more explicit in future conceptualisations of health literacy

Over the twelve month period participants had acquired an increased understanding of the importance of having positive mental health in facilitating their overall management of health and illness.

Positive developments in health literacy were found, however, these could also be adversely affected by negative changes in life circumstances including increased stressful demands on an individual. This may contribute to low motivation and feelings of limited control.

There is value in health care providers having an increased insight into vulnerable aspects of individuals' lives where there may be a need for additional supports.

These findings lend support to the need to integrate health literacy into medical and other health care provider curricula to raise awareness of the concept of health literacy.

Over the twelve month period, individuals continued to have concerns about treatment and medication side-effects. Being able to access accurate information and communicate concerns is important.

## CHAPTER 5: DISCUSSION

### 5.1 Introduction

Findings from this longitudinal qualitative study have revealed the lived experiences of people who are managing health and illness, demonstrating developments in health literacy including how they learn about health issues (accessing health information), how they go about understanding and appraising health information, and the factors that can assist or impede action on this information

The study has also identified the perceived barriers and facilitators in the process of developing health literacy capacities. This chapter begins with a brief overview of the three phases of the study related to the published papers. The main findings from the thesis addressing the research objectives will then be discussed in the context of extant literature. This will be followed by an interpretation of the findings, methodological considerations, implications of study findings for research, practice and policy, and an overview of the study strengths and limitations. A brief summary will conclude the chapter.

#### 5.1.2 Overview of the study phases in relation to the published papers

This longitudinal study took place over a 12 month time period, following a group of participants in a cardiovascular risk reduction programme. Each phase of the overall study was linked to a particular time point in the programme. At Phase 1 (time point 1) participants were about to embark on a community-based cardiovascular risk reduction programme. The study focussed on exploring and describing how these individuals practice health literacy in their everyday management of health and illness. It also examined the barriers and facilitators identified in the process (Paper I). The second phase of the study (time point 2) collected data after 12 weeks of attending the programme. This allowed the study to examine any developments in health literacy capacities over the time period (Paper II). The final phase of the study (T3) examined overall changes in the 12 month time period (Paper III). Across all three study phases, it was apparent that the role of the health care provider was central in terms of initial descriptions of interactions (T1) and in terms of perceived changes in interactions and relationships (T2, T3). The longitudinal nature of the study provided a unique perspective on the experiences of participants in managing their health and illness.

## 5.2 Discussion of main findings in context of extant literature

### 5.2.1 Developments in health literacy over time

Study findings have demonstrated that health literacy can develop over time and that this potential exists for varying levels of health literacy needs.

The study was informed by a critical realist approach and findings are in line with this approach as it was clear that the potential for health literacy development can be impacted both positively and negatively within complex health and social system contexts. These systems can shape how health literacy capacities are manifest as well as how development may be hindered or facilitated. In this study these included those factors that are both intrinsic and external to the individual such as feelings of confidence and perceptions of control, as well as the types of health services and built environments that individuals had access to, all of which could either hinder or facilitate health literacy capacity development in different ways. Findings in terms of capacities for developments are similar to the concepts put forward in the health capabilities framework, where health outcomes are viewed as the opportunities that people have and the choices they make relative to these chances (Weaver, Lemonde, Payman, & Goodman, 2014). These findings highlight the necessity for efforts to address health literacy to balance activities focussed on individual agency with those aimed at addressing the broader social and structural determinates of health (Razoum, Weishaar and Schaeffer, 2016).

Another important finding is the heterogeneity in terms of the attitudes and experiences of those across both adequate and limited levels of health literacy. Similar to findings in the study by Gerich and Moosbrugger (2018), some participants in the current study with adequate levels of health literacy possessed qualities of high confidence and being proactive while others with less confidence exhibited high levels of trust in their medical teams. Although a number of participants experienced ill health and stressful life events between Phases 2 and 3 of the study, it was those who had indicated a perception of having limited control at Phase 3 that showed a decrease in the health literacy score over time. This suggests that perceptions of limited control can contribute to a reduced ability to effectively use health literacy capacities, particularly in relation to the application of health information. This presents important insights into vulnerable periods where additional support may need to be provided by

health care providers to maximise positive developments in health literacy and ultimately in health outcomes. Such support could include provision of access to psychological and social services as needed. These findings in relation to developments overall, as well as specific aspects set out below, offer important insights into how health promotion interventions can ensure that positive health literacy capacities can be progressed. This could be achieved through a focus on developing self-empowerment and coping skills in managing illness and maintaining health.

### 5.2.2 Impact of contextual factors-barriers and facilitators

Findings across all three phases (Papers I-III) of the study have shown that situational factors and stressful life events can impact on the development and effective use of health literacy capacities and that there is a need for health care providers to have a greater understanding of the social and emotional needs of their patients. Shaw, Ibrahim, Reid, Ussher, & Rowlands (2009) have also highlighted the importance for health care providers to have an understanding of the patient's perception of the problem as well as its social and emotional impact. Findings have indicated that structural or contextual factors are likely to affect both health literacy and health outcomes across different contexts and this is supported by other literature (Mantwill and Diviani, 2019; Jordan et al., 2010). The psychological aspects of managing illness can impact on the person's abilities to access, understand, appraise and use health information. Health information that is provided during stressful situations (such as news of a diagnosis) may be difficult to interpret. Likewise, fears associated with certain treatment plans may cause individuals to refuse a treatment altogether. Such barriers can be addressed by incorporation of shared decision-making models into consultations where patients have the opportunity to discuss their fears and beliefs about treatment options (Edwards et al., 2012; Lopez-Vargas et al., 2014; Shaw et al., 2009; Gainer et al., 2017). The concept of the teachable moment, which describes how naturally occurring life transitions or health events can motivate individuals to spontaneously adopt risk-reducing health behaviours, is also relevant here (McBride, Emmons, & Lipkus (2003). Success of the teachable moment is contingent on the health care provider's ability to identify and explore the importance of patient concerns and recognise opportunities to link them with unhealthy behaviours (Cohen, Clark, Lawson, Casucci & Flocke, (2011).

Study findings have highlighted the impact of illness-related anxiety and fears on the participants' ability to fully utilise health literacy capacities, which concurs with patient experiences in other studies (Jordan et al., 2010; Edwards et al., 2012). Where concerns were alleviated over time, (Paper III), participants reported being able to more effectively engage with and use health information similar to findings in other studies (Dunn et al., 2017, Morgan et al., 2016; Jordan et al., 2010).

Study findings highlighted the impact of structural barriers, such as access to health services, to effectively use health literacy capacities (Paper I). This study had a mixture of public and private access patients and there were differences experienced in terms of timely access to health care and treatments. Spending long periods of time on a waiting list is disempowering and can lead to reduced potential for positive health outcomes. Therefore, it is likely that health literacy may have limited impact. The 2030 Agenda for Sustainable Development emphasises the need for Universal Health Coverage across all countries, which would address such issues as unequal access to health care as well as acknowledging the opportunities for positively impacting on health literacy (WHO, 2016). Similar to findings from a study which conceptualised health literacy from the patient perspective (Jordan et al., 2010), findings from the present study indicate that an individual's health literacy development is dependent on the relationship between individual health literacy capacities, the healthcare provider/health system and broader society. This means that it is important that health systems work to address the health literacy needs of service users. A systems approach is considered an appropriate means to address health literacy in a coordinated and consistent manner utilising a 'universal precautions approach' (Willis et al., 2014; Walsh, Shuker, & Merry, 2015). This approach advocates that health care providers and health care organisations assume that all patients and caregivers may have difficulty comprehending health information. Based on this understanding, health care providers should consistently communicate in ways that anyone (regardless of health literacy needs) can understand and confirm comprehension; support ease of navigation within the health care organisation and support patients' efforts to improve their health ((Brega et al., 2015).

### 5.2.3 Role of the health care provider

The study findings show that health care providers played a central role in both the access and appraisal of information and could facilitate or impede service users in gaining new knowledge (such as through the referral process). This finding is supported in other studies that found that face-to-face practitioner time was perceived to be the most valuable method of communication (Shaw et al., 2009) and that patients want a patient-centred and positive approach, and if they do not get it they are less satisfied, less enabled, and may suffer greater symptom burden (Little et al., 201).

The relationship with, and perceived support from, the health care provider were also important and interactions with health care providers were seen to permeate all aspects of health literacy capacity development from accessing information through to support for use of health information (Papers I-III). An important finding in this study was the participants' reported willingness to remain with a GP even where there were concerns over the level of care and services provided (Paper III). This is an important issue as GPs are generally the first point of access to healthcare services and play a key role in building patients' health literacy (Lausen et al., 2018). Health literacy capacity developments may be impeded where an individual is reliant on a local health service provider who they do not have confidence in or with whom they are not wholly comfortable. This highlights the importance of having access to independent sources of health information as well as the skills necessary to access and use such information. Study findings highlighted the central role of the General Practitioner (GP) in particular, for navigating health information. While the health care provider was often seen as the most trustworthy source of information, it was also evident that less than optimal relationships also existed. Findings in Phase 1 (Paper I) showed that perceptions of not being listened to or not having one's opinion taken on board contributed to less productive relationships (Paper I). These findings are supported by other research that shows that a positive response in the health care encounter to information brought in by patients is important for enhancing patient-provider relationships (Murray et al., 2003). The overall communication style of the health care provider could either facilitate or act as a barrier to information exchange (Edwards et al., 2012). Over time it was apparent that participants had developed a greater awareness of the importance of addressing psychological issues as part of their overall self-management plans (Papers II and III). This is supported by models of self-

management which include a focus on an emotional component (e.g. Lorig and Holman, 2003). Overall, challenges to self-management identified in this study also correspond to challenges that are based on individual, relationship and environmental factors identified by Vallis, 2009. The GP is well placed to identify where additional supports may be needed at vulnerable points in their patients' lives and this can be facilitated by health care providers having an understanding of the patients' perception of the problem, including its social and emotional impact (Shaw et al., 2009).

Overall, participants reported positive developments in their interactions with health care providers. These were attributed to having increased knowledge and understanding of their condition as well as a sense of increased confidence regarding communication with the health care provider (Papers II and III). The findings also support the view that the relationship with the health care provider can have both social and medical dimensions (Samerski, 2019).

5.2.4 Health literacy, perceptions of personal control, empowerment and self-efficacy  
The longitudinal findings (Paper III) emphasised developments in terms of empowerment of all participants due in part to the positive communication experiences with health care providers in health care and community programme settings and this is concurrent with the literature (Edwards et al., 2012; Nutbeam, 2008). Findings support the fact that perceptions of being in control or a sense of having limited control are central to how health literacy capacities may be utilized. A sense of being in control is linked to greater confidence/self-efficacy and therefore, presents a greater likelihood of engaging in proactive health activities.

At T1 (Paper I) many participants perceived having limited control/power across situations, which shifted towards having an increased sense of control as time went on (Papers II and III). Although overall increases in confidence can be equated with self-efficacy and positive health literacy developments, in some cases developments were adversely impacted or even stalled by the onset of illness, excessive stress, changed life circumstances and/or poor communication experiences with health care providers.

The broader contexts of the everyday life experiences of participants impacted (both positively and negatively) on their ability to use health literacy capacities and to

sustain motivation and health practices over time. Longitudinal findings show that over time there were developments in perceived control and self-efficacy whereby participants were becoming more empowered and this supports conceptualization of health literacy as an instrument in the empowerment process (Cron Dahl & Eklund Karlsson, 2016). Other studies have examined the role of self-efficacy and health literacy in improving health outcomes and have highlighted the need for self-management programmes to promote the development of self-efficacy (Huynh-Hohnbaum, Marshall, Villa and Lee, 2015). As stated earlier, health care providers, particularly those in the primary care setting, are in a good position to recognise when psychological supports might be needed and how they could be made available. Health care providers are also well positioned to support patients to develop greater self-efficacy around their health-related activities, as this contributes to enhancing motivation and empowerment. This is particularly relevant for patients with low health literacy (Lausen et al., 2018).

#### 5.2.5 Developments across functional, interactive and critical levels of health literacy and application to the broader determinants of health

Taken together, the longitudinal findings indicate developments in health literacy across the functional, interactive and critical levels of health literacy and engagement with health information that goes beyond personal health management to the social determinants of health (Sørensen et al., 2012; Nutbeam, 2000). Findings indicate that individuals developed personal and social skills, in addition to acquiring new knowledge that fit with the concepts of interactive and critical health literacy.

All participants reported having acquired increased understanding of issues relevant to their self-care. Findings indicated that participants had a new level of engagement with their health concerns, (such as an increased understanding of the impact of hypertension on their cardiovascular health) as they often were exposed to a new perspective or information presented in a new way. One of the most important findings was in relation to participants' understanding of medications and side effects. It was noteworthy that participants continued to question the use of statins and continued to favour lifestyle approaches (where benefits seen). This understanding can be attributed

to a combination of knowledge acquired both through the programme and through their own information-seeking (Papers II and III).

Findings from this study have generated important insights into factors that support developments for health literacy capacities and suggests that those with varying levels of health literacy can engage with self-management programmes. This is similar to findings from other studies (specific to diabetes) where all participants benefited from self-management programmes, regardless of their health literacy level (Kim, Love, Quistberg, & Shea, 2004; Vanderbosch et al., 2018).

Although this study did not involve a health literacy intervention, findings do indicate positive developments in health literacy following participation in the programme. In this regard it lends support to embedding an explicit health literacy intervention in this type of self-management programme to increase health literacy of individuals. Such an intervention could focus on health literacy as an outcome of self-management training, regardless of participants' initial health literacy levels.

An important finding in the current study is the engagement of participants with broader factors that can impact on health and the contextualisation of health concerns. In terms of health literacy, this represents a shift towards critical health literacy whereby individuals start to address the demands and complexities of their social contexts (De Wit et al., 2017). These findings compare favourably to those reported by Rowlands, Shaw, Jaswal, Smith, & Harpham, 2017, where social determinants, social activity and the local community were viewed as influencing the translation of knowledge into health behaviours. Participants were able to reflect on how physical and structural factors can directly affect their health and wellbeing. Other research has used the term 'risk regulators' to describe mediating structures, such as walkability of the local environment, that link the social determinants of health with health behaviours and actions (Glass & McAtee, 2006). Participants' responses also indicated that they are capable of locating responsibility (for health) beyond the individual level (Sykes et al., 2013) and are making sense of knowledge within their own 'social space' (Renwick, 2017), for example, within their own family and community environments. This indicates that developments in health literacy have moved beyond the acquisition of knowledge to use of health literacy as a resource for engaging in health at the community level (Renwick, 2017, Sykes et al., 2013). This engagement includes the

sharing of health information and knowledge with extended family and community, which was apparent in the study. Edwards et al. (2015) in their study used the term health literacy mediators to describe individuals who passed on their health literacy skills. This is linked to distributed health literacy, though in this instance it is about supporting others to become more health literate (rather than being supported). Study findings support the idea that health literacy is linked to specific environments and social contexts (Kickbusch, Pelikan, Apfel, & Tsouros, 2013; Nutbeam, 2017).

Interactive and critical health literacy are acknowledged to play an important role in the successful management of chronic illness (Heijmans et al., 2015). The broader definition of critical health literacy put forward by Sykes et al., (2013) is relevant for the realities of the daily management of health and illness highlighted in this study. This includes having the ability to appraise and analyse health information in a critical way and apply it to the context of their own lives (Sykes & Wills, 2018). This is evident in some of the issues raised by participants in this study such as the questioning of food marketing practices and treatment and medication implications.

### 5.3 Interpretation of findings

This study was underpinned by the HLS model empirically validated by Sørensen et al., (2012), whereby health literacy is recognised as a process involving the consecutive competencies of accessing, understanding, appraising and applying health information. In the model the antecedents (such as societal, environmental, situational and personal determinants) and consequences (such as influences on health behaviours and use of health services) are also addressed (Sørensen et al., 2012). According to the model, application of the competencies provides individuals with the abilities to take control over their health by overcoming personal, social, structural and environmental barriers to health. In this study participants identified barriers and moved towards addressing them such as the need for better walking facilities and the need to look after their mental health. Study findings also support the contention that health literacy is a dynamic construct and that the skills and competencies of health literacy develop over the life course as contextual demands change over time (Levin-Zamir et al., 2017; Sørensen et al., 2012). Findings from this study support many aspects of Sorensen's health literacy model. The core aspects of knowledge, motivation and competences

are central to the development of health literacy over time. Findings show that self-efficacy plays an important role in the use of health literacy. In the main, participants experienced increased confidence and self-efficacy in being able to manage their health. The focus of the cardiovascular risk reduction programme contributed to an increased ability to access appropriate information as well as having a better understanding of that information. This is also linked to improvements in appraisal, as participants could question information and could discuss it with health care providers. The study findings have also highlighted the importance of both psychological and situational contexts that can impact on health literacy and this also supports the Sørensen framework. While the model sets out empowerment as a possible outcome of health literacy, our findings suggest that empowerment as a process is also very important for the development of health literacy. Another important finding, which is not explicitly addressed in the Sørensen model, is the role of health care providers in the process of developing health literacy. Study findings expand on the model's implicit reference to the interactive, relational nature of health literacy as they illuminate the fit of personal capabilities to the complexity of situational demands (Parker, 2000; Kickbusch et al., 2013). This is seen through varying capacities for development amongst the study participants. Study findings have shown that an increased perception of control and self-efficacy provided improved confidence and motivation to be able to access, understand, appraise and apply health information more proactively, particularly through interactions with health care providers. This was evidenced through reports of, for example, having greater confidence in asking questions and appraising various sources of information to draw on in the consultation. Other examples include, participants having an increased understanding of the side effects of medications and treatments, as well as gaining knowledge and understanding on the reasons to take medications and how medications worked. Additional developments included increased motivation to seek out psychological supports and an understanding of the importance of using exercise to promote mental health.

Findings support a conceptualisation of health literacy as a multidimensional, complex and heterogeneous concept (Sørensen, 2019). Study participants demonstrated developments across the functional, interactive and critical levels of health literacy,

which are congruent with the typology advocated by Nutbeam (2000) and contained within the HLS-EU model. Findings correspond to a complex understanding of health literacy, which acknowledges a wide range of skills that are developed and applied in interaction with social contexts (Mårtensson & Hensing, 2012).

This study also supports the conceptualization of health literacy as an asset (Nutbeam, 2008) and provide an increased insight into how the development of health literacy can be facilitated. Over time individuals can develop confidence and self-efficacy regarding use of health information and an increased awareness of the social and environmental factors that can impact on health. Findings indicate that health care providers can play a critical role in supporting individuals to move towards development of critical health literacy through improved communication and shared decision-making practices.

## 5.4 Methodological issues

### 5.4.1 Use of a longitudinal qualitative methodology

This study employed a longitudinal qualitative methodology, which used a repeat interview approach at three separate time points over a 12 month period to follow a group of participants in a CVD risk reduction programme. This method provided a unique perspective on participant experiences of managing their health and illness, and of how health literacy capacity developments can be both hindered and enabled. The findings in this study could not have been captured in a once off cross-sectional qualitative study. For example, data collected at Phase 1 explored experiences in managing health and illness concerns only. Additional follow-up at different phases in the study allowed for the examinations of developments in health literacy over time. The application of robust longitudinal question frameworks (Saldaña, 2003; Lewis, 2007) focussed the analysis on determining where changes were occurring, what was contributing to these changes, as well as identifying where no change was occurring. A longitudinal qualitative methodology is an important means of capturing the dynamic nature of health literacy. Within a longitudinal qualitative research study, social actions and circumstances within time are understood to be contextual, and therefore, change is also contextual (Saldaña, 2003). Analysis yielded rich data on change processes that could not have been achieved using a stand-alone cross sectional study.

The use of a longitudinal qualitative approach allowed the exploration of highly situation-specific experiences, understandings and perceptions that mediate the ways in which people deal with and respond to their health issues over time. This also made possible the identification of developments in health literacy as individuals dealt with stressful life events that unfolded over time. The study design is highly sensitive to contextual issues, and can illuminate important processes, such as the ways in which people subjectively negotiate the changes that occur in their lives such as, dealing with new illness or caring for older relatives. Longitudinal qualitative methods can offer fresh perspectives into how health literacy is used and it develops over time across different health and social contexts. Embedding a longitudinal qualitative study within a larger quantitative study would maximise the robustness of findings. However, significant resources would be required to conduct repeat interviews across a larger sample. Longitudinal qualitative research emphasises the value of a layered approach (Saldana, 2003). To this end, the HLS-EU measure was used to provide a guide on health literacy levels of the participants at the beginning and at the end of the 12 month period. As such this study was unique as it combined data on health literacy levels with qualitative experiences of individuals. Findings from the HLS-EU measure indicated overall changes which lend support to the qualitative findings. The inclusion of individuals with varying levels of health literacy allowed for a more nuanced understanding of developments over time. The trajectory approach used provided insights into health literacy developments for individuals with different health and social circumstances over time. Overall, these findings lend further support to the qualitative findings that developments can occur in health literacy regardless of whether one started with a limited or adequate level of health literacy. However, this is dependent on situational contexts and supports available to individuals. Clearly, participants had variable experiences, which either facilitated or impeded their ability to utilise health literacy and engage with health issues. In all cases, it is likely that health care provider awareness of such vulnerable points in patients' lives and the provision of additional psychological and social supports would be beneficial for enabling positive actions on health information. Therefore, there appears to be some potential to examine how health promotion programmes could best facilitate increasing changes in these areas. The use of health literacy interventions could be an integral part of such programmes.

#### 5.4.2 Use of the HLS-EUQ47

As stated earlier, the HLS-EU was originally developed as a population measure and, therefore, may not be appropriate for individual measurement or for measuring change over time. At the outset of this research study the HLS-EU measure was the most robust and validated measure available within the European context. It was also the only available measure that incorporated the breadth of health literacy across the health service, disease prevention and health promotion domains. In addition, it offered the opportunity to place study findings in the context of national and European data (Doyle et al., 2012; Sørensen et al., 2015). Although the sample size used was too small for detailed quantitative analysis and there are questions on the sensitivity of the measure for individual measurement, there does appear to be some evidence for the usefulness of the HLS-EU at the individual level. As this is the first time that the measure has been used in a longitudinal study, it is feasible that further research in this area is warranted. In a paper illuminating the design and development process of the HLS-EU-Q, Sørensen et al., (2013) have highlighted that “it is evident that further research is needed to enhance its quality and applicability in the future” (p. 8). It is also important to note that the HLS-EU-Q is a subjective, self-report measure. It is possible that self-report measures of health literacy assess participants’ confidence in their capacity to comprehend and use health materials, rather than their actual ability (Muscat et al., 2019). The study did not use a measure specific to CVD. However, as the participants were involved in both primary and secondary prevention, and lifestyle change and management was a core element of the programme, the researcher deemed that the HLS-EU-Q was appropriate. The measure also addressed the disease prevention and health promotion domains of health literacy.

#### 5.4.3 Qualitative research and health literacy

Qualitative research findings, including those of the current study, can expand our understanding of what health literacy is and how it develops. Similar to statements in the Calgary Charter of Health Literacy (Coleman et al., 2009), the current study findings demonstrate that health literacy is not just about having/not having certain skills but also emphasises what one does with the skills that are available. An example provided in the Calgary Charter is that knowing that an individual reports not finding information very often does not reveal which specific skills an individual may be lacking or not using. For example, it could be due to having poor reading skills, not

knowing how and where to search for information or, not having a high level of need or motivation to search for information. Qualitative study findings allow us to identify these possible reasons through more nuanced accounts and can allow researchers and health care providers to collaborate to plan for effective health engagement using more focussed interventions.

#### 5.4.5 Attrition of study participants

In this study, a total of nine participants were lost to the longitudinal analysis. The attrition of participants from time point 1 to time point 3 of the study was problematic. The characteristics of those who left the study are detailed in Appendix 5 and indicate that the majority had a limited level of health literacy. The majority of the participants left following time point one (seven participants), having also left the risk reduction programme. Due to time and resource constraints, there was no structured follow-up built into the study design. Ideally it would have been useful to include a focus group session between time points 2 and 3 to check in with participants. However, only two participants left between time-points 2 and three. It must be considered that those who completed the programme and follow up were more engaged with their overall health than those who did not complete the programme. Such bias needs to be acknowledged in terms of how the findings are interpreted. It is also noteworthy that those who did participate through the 12 month duration of the study all reported positive experiences regarding programme participation. Again, this may point to a group of participants who were particularly engaged with and interested in their health concerns.

#### 5.5 Implications for research, practice and policy

The current study addressed the development of health literacy over time and identified the barriers and facilitators in that process. Through a longitudinal qualitative research design, the study examined contextual factors that can facilitate or impede the process of health literacy capacity development. This study makes a number of important contributions to existing health literacy research as outlined below:

This is one of a small number of health literacy focussed, qualitative, longitudinal studies that follows individuals over time to examine developments in health literacy as they manage their health and illness in the context of their everyday lives. There is a paucity of such longitudinal qualitative studies in the current health literacy

literature. The longitudinal nature of the study has provided increased insights into how the development of health literacy capacity can be facilitated. Findings are relevant for health-care providers in order to enhance the patient-provider relationship. Findings have highlighted the central role of the GP in supporting health literacy capacity development. The qualitative longitudinal approach used in this study is crucial to examine the complex nature of health literacy and addresses its breadth beyond a functional health literacy focus, to one that encompasses health interactions and health contexts. The study has highlighted the importance of having a sense of perceived control in terms of being able to effectively access, understand, appraise and use health information in the management of health and illness and thus underscores the need for empowerment focussed interventions. It has also highlighted the importance of addressing psychological supports as part of self-management as an overlooked area. While current research in mental health literacy is predominantly focussed on knowledge and beliefs about mental disorders to aid their recognition, management or prevention (Jorm et al., 1997), this needs to be more focussed on positive mental health promotion which could be included in self-management programmes. This concurs with work by Kutcher, Wei and Coniglio (2016) which emphasis the need to include understanding of how to obtain and maintain positive mental health and that mental health literacy should be more integrated into overall health literacy activities. The study has also contributed to a qualitative validation of the HLS model as the findings support the model constructs.

#### 5.5.1 Implications for future research

This study did not examine the development of health literacy in the context of a health literacy intervention. However, findings do indicate the importance of interventions being aware of, and responsive to, the social, cultural and psychological context of participants (Banister, Begoray & Daly, 2011). Study findings indicate that some participants struggled to cope with stressful life events which impaired their ability to engage fully with health promotion practices. Study findings emphasised the role of contextual factors in health literacy capacity development. As people are embedded into complex environments, context related health literacy interventions, that are relevant to peoples' lived experiences, should be developed, implemented and evaluated (Rowlands et al., 2019). In keeping with best practice, such interventions

should include public/patient involvement (PPI) to ensure that the patients themselves are involved in the development process.

The current study tracked individuals over a twelve month period. A longer follow-up period, including more detailed accounts of health care interactions over the time period would be useful. It would also be valuable to have included the health care provider perspective particularly in regard to patient understanding regarding side effects and need for psychological supports in order to expand on how best these issues could be addressed.

Future research should use findings from qualitative research to explore the nuanced set of capacities/skills/activities that individuals actually use to access, understand, appraise and use health information. Such findings could be incorporated into the design of health literacy measures and interventions by focussing on the issues that are most relevant to populations. An example here might be the provision of information on specific reliable health websites to discourage general web searches regarding health concerns.

In this study developments indicated a shift towards critical health literacy whereby participants were starting to identify and question the broader determinants of health. However, there were no findings in relation to collective action. Further community based research is warranted to assist people to identify and prioritise their own health priorities. Such research should include the participants of vulnerable groups in society as well as populations outside of clinical or structured programme settings, and focus on the development of interactive and critical health literacy (Nutbeam, McGill & Premkumar, 2017).

### 5.5.2 Practice implications

The study findings are useful for informing what health promotion programmes can do to support those with health literacy needs in progressing their health literacy. The findings in this study could be used in the design of programmes aimed at developing health literacy, improving self-management and health promotion skills. Findings also support the explicit inclusion of mental health promotion in programme design so that individuals can address both the mental and physical aspects of managing health and illness. Findings supported the development of health literacy in relation to the health promotion domain. The design of health promotion interventions should embed health literacy as a core outcome of health promotion interventions.

There is a need for health care services and health care providers to have a more comprehensive understanding of the contextual factors that can impact of use of health literacy regardless of initial levels of health level. This can enhance the patient provider relationship and assist in identifying where further supports might be necessary. Examples are: engaging with the patient when s/he brings in health information to a consultation to identify what their specific concerns or fears might be, having an appreciation of what is going on in their lives, such as, an awareness whether they are providing care to dependent relatives, or what barriers may exist for them in trying to implement behaviour changes. The findings lend further support to the key influence of the health care provider on the individual's ability to feel at ease and engage well in the consultation. Health care practitioners should have opportunities to participate in ongoing training to develop and maintain excellence in communication skills.

### 5.5.3 Policy implications

The impact of structural factors on health need to be built into health literacy programmes to ensure a balance between the role of the individual and the wider environment in developing health literacy to address health issues. Governments and policy makers need to be aware that health literacy is more than a solution to increase compliance in individuals (Razum et al., 2016). The challenges of managing health and illness in the context of broader social determinants, as identified in this study, need to be addressed. This could be achieved by incorporating specific models, such as that developed by Rowlands et al., 2017, which could incorporate the health

promoting and health inhibiting influences of individuals' social, community and work settings.

Findings can also be used to promote the development of more person-centred care. Individuals interacting with health care providers all have varying levels of health literacy, which in turn can impact on how health information is accessed. Positive developments in health literacy are important for the self-management of health and illness. The longitudinal findings in the current study underscore the importance of the health care provider in supporting the development of health literacy over time. By having an increased awareness and understanding of these contexts, more patient-centred care can be provided. Having an understanding of health literacy should be an integral part of training for all healthcare professionals and should be available throughout all years of study. In addition, health literacy training could also be part of continuing professional development. The management of chronic illness requires ongoing patient-provider engagement, which requires a high level of health literacy awareness among health care practitioners (Poureslami et al, 2017). However, research has indicated that, in general, many health care providers do not have sufficient training in health literacy awareness (Coleman, 2011; Coleman & Fromer, 2015; Kaper et al., 2018). In the UK an online cross-sectional survey of 206 GP trainees was undertaken to examine the extent of their health literacy-related competencies. Findings indicated that while they consistently overestimated the numeracy and literacy levels of the English population, they did not see their role in helping to improve patient health literacy. In addition, those skills relevant for patient decision-making (such as coaching, explaining risk and use of visual aids for clarification) were rated lower (Groene, Wills, Crichton, Rowlands, & Rudd, 2017). The recent WHO Roadmap document (2019) also identifies the need to build the capacity of health professionals, increase health literacy responsiveness and improve service quality. It specifically highlights actions including the introduction of health literacy concepts and implications into health professionals' education by carrying out government-led revisions of curricula for health professionals. In this study the community-based health programme acted as an alternate health service. Patients experienced very positive interactions with the programme staff. Findings show that a community-based approach to self-management can yield positive outcomes in terms of health literacy developments. In particular, participants welcomed the 'one-stop' and holistic

approach to accessing care. Exploring the wider availability of such programmes is warranted as the lifestyle factors addressed are common across many non-communicable diseases.

### 5.6 Strengths of the study

This study demonstrates innovative use of longitudinal qualitative research to explore the development of health literacy over time. By using a longitudinal qualitative methodology, focusing on individuals' experiences of managing health and illness, the findings of this study can make an important contribution to building an understanding of how the development of health literacy can be supported. By highlighting the variability of peoples' experiences over time, this study has demonstrated the diversity of people's health literacy needs and assets, both over time and across the dimensions of health literacy. The longitudinal element makes it possible to identify the contextual and intervening condition surrounding changes. It is also possible to identify the types of factors that contribute to positive developments in health literacy.

This study was underpinned by the Sørensen et al., (2012) model. This allowed for the exploration of experiences not just within the healthcare setting but also extended these to include experiences in terms of health promotion and disease prevention where broader determinants need to be addressed.

Individuals with limited health literacy are well represented in the study. In addition, the study focused on people's experiences outside of the clinical setting. Individuals with both public and private access to health services were represented in the study, providing a breadth of experiences. All participants were managing health and illness concerns. In addition, some participants experienced additional serious illness between Phases 2 and 3 of the study. The longitudinal element of the study was important in determining how health literacy was drawn on in these circumstances.

Positive developments at the end of Phase 2 could be attributed, to some extent, to recent engagement with the risk reduction programme. However, these were mitigated by the overall 12 month follow-up, which permitted revisiting participants at nine months post programme completion. This allowed the exploration of where developments were being sustained, continuing or where developments had not progressed.

## 5.7 Limitations

Ultimately study participation was reliant on individuals volunteering to participate. This raises questions of possible bias whereby those who are most engaged with health issues are most likely to volunteer. However, the fact that there was variation across health literacy levels and experiences among the participants could serve to counter this.

Attrition of study participants over the twelve month period meant that it was not possible to follow developments for the original twenty-six participants. Six of the nine did have limited health literacy and it is, therefore, important to acknowledge that their exclusion from overall findings may have impacted on the results. However, as the majority of participants began with limited health literacy levels, this group was well represented in the study. A more robust attrition contingency plan, with more structured follow-up, could have mitigated the attrition experienced.

The sample was restricted to those attending a cardiovascular risk reduction programme. While the individuals were referred into the programme through various health service pathways, it should be considered that their participation reflects a level of engagement with their health that may not have been present in a general community sample. The impact of this on study findings needs to be acknowledged. Future research could compare participants across two or more settings, such as those attending a structured programme and those in the general community. The fact that participants in this study were exposed to focussed information on specific health issues and the implications of this on study findings needs to be acknowledged. This may be particularly relevant for findings from Phase 2 of the study.

Bias in qualitative research is common. In this study both self-report and social acceptability bias need to be acknowledged. This was addressed through the non – judgemental phrasing of questions. In addition, the researcher clearly communicated to the participants that the researcher was not an employee or involved in any of the activities of the community-based organisation. In this study these biases were possibly mitigated as it was already apparent that participants were dealing with health and illness issues. The issue of researcher bias is also important. The section on reflexivity (Chapter 3) reports on how this was addressed. Social acceptability bias may also be linked to a tendency towards positive commentary on the part of the

interviewee. The use of more explicit questions to delve into negative issues such as ‘what was difficult?’, ‘what did not work well?’ could have elicited a more nuanced account of the participants’ experiences.

While a level of member checking was achieved with participants (revisiting topics raised in earlier interviews) it would have been useful to build in focus groups at the end of Phase 1 analysis to present findings and get additional feedback from participants to further validate the findings.

While double-coding of some Phase 1 transcripts was undertaken, this not occur for Phase 2 and 3 data sets, due to time and personnel constraints. However, transcripts were reviewed across all three study phases and codes and themes reviewed and discussed with research supervisor and another academic member of staff with qualitative research expertise.

While it is useful to have health literacy levels as a guide, further clarification is needed on the appropriateness of health literacy measures for individual health literacy measurement.

Men are underrepresented in this study. Notwithstanding the difficulties of engaging with this group, it is important that this cohort are included in health literacy studies, particularly in relation to management of chronic illness.

## 5.8 Summary

Health promotion recognises the inextricable links between persons and their environments (WHO, 1986). However, the responsibility for health is increasingly being shifted from society to the individual. It is imperative then, that health literacy professionals and policy makers counter this trend. The health promotion approach to health literacy emphasises the complex interdependencies between health understanding, health attitudes and behaviours, social determinants of health and the design and delivery of health services (Sørensen et al., 2012; Sallis, Owen & Fisher, 2008). This means the emphasis should not solely be on strengthening health literacy at the individual level but should also be actively addressing inequities in the structural determinates of health. In addition, there needs to be a greater emphasis on developing health literate services that can support service users in developing their health literacy. These study findings have underscored both psychological and structural

barriers faced by individuals across the spectrum of health literacy. Failure to address these challenges will result in poor engagement with health issues and ultimately, in poorer health outcomes.

## CHAPTER 6: CONCLUSION

### 6.1 Introduction

Based on study findings and building on the implications for future research, practice and policy set out in the previous chapter, this chapter presents recommendations across the areas of research, practice and policy. This will be followed by overall conclusions from the study.

### 6.2 Recommendations

#### 6.2.1 Recommendations relevant to research

- Longitudinal qualitative studies should be incorporated into the evaluation design of health literacy interventions in order to elucidate the most effective ways to support the health literacy needs of individuals.
- Community-based research should be prioritised to examine how health literacy developments can be supported for marginalised community groups outside of the realm of structured health programmes. This could also allow researchers to identify ways in which the development of critical health literacy can be supported.
- In addition to the recognition of the importance of health literacy in secondary prevention, its relevance for health promotion is also vital for primary prevention. Community-based health literacy interventions to support people with lower health literacy and to improve health literacy also need to be prioritised. Such efforts need to include the involvement of health organisations and systems to ensure responsiveness to community needs.

#### 6.2.2 Recommendations relevant to practice

Self-management and health promotion interventions should have an explicit health literacy component built into their design. In addition, there needs to be a clear focus on developing participants' self-empowerment and self-efficacy, thereby building skills across the interactive and critical levels of health literacy.

Both health care providers and organisations involved in the delivery of self-management programmes need to address how best to support individuals to recognise when psychological support may be needed. For example, how to assist people in devising coping strategies to address particularly stressful and/or vulnerable aspects

in dealing with health conditions. To this end, mental health literacy, incorporating the promotion of positive mental health should also be incorporated into programmes.

Increased access to alternate models of health care delivery is important. In particular access to community-based one-stop holistic services that are relevant across the spectrum of non-communicable diseases can make an important contribution to supporting individuals to manage long term health conditions.

### 6.2.3 Recommendations relevant to policy

Health literacy training should be embedded across all medical and allied health undergraduate curricula in order to firstly, raise awareness of health literacy, and secondly, to equip future health professions with the skills they need to support the health literacy needs of their patients to assist in maximising health outcomes.

Health literacy should be embedded into health systems to ensure that there is a system-wide awareness of health literacy issues. The adoption of a Universal Precautions approach, which promotes the assumption that all patients and caregivers may have unmet health literacy needs, is relevant here (Brega et al., 2015). As outlined earlier, more recent conceptualisations of health literacy now incorporate the health system and the health care provider into the health literacy framework (Poureslami et al., 2017). This recognition that health care providers have a crucial role and responsibility in the exchange of health information, lends support to the relevance and importance of providing training on health literacy to all healthcare professional trainees as well as to those already established in practice.

Policy makers should ensure that all policies are ‘health literacy proofed’ in order to minimise barriers for positive health literacy capacity development. This includes examining access to health services and environmental factors that can impede action on health concerns for individuals.

### 6.3 Overall conclusions

This study has shown that health literacy can develop over time through a range of health experiences. The findings also suggest the view that having a comprehensive understanding of health literacy is valuable for healthcare, disease prevention and health promotion (Pelikan, Ganahl, Van den Broucke & Sørensen, 2019). The qualitative longitudinal study design provided an increased understanding of health

literacy challenges experienced in the management of health and illness over a period of time and of the strategies individuals used to address such challenges. This is an important consideration for health care providers, especially in relation to self-management programmes, in order to highlight specific areas where more supports may be necessary to facilitate the shift from functional to critical health literacy capacity development. It is also useful for what programmes can do to support those with health literacy needs in progressing their health literacy. Although no statistical significance, due to a lack of power in the sample size, was reported for differences in health promotion, disease prevention, and health care scores from T1-T3, it was clear that scores had improved. Therefore, there seems to be potential to examine how health promotion programmes could facilitate expanding changes in these areas. The qualitative findings indicate that over time participants had acquired a greater awareness of the broader determinants of health and were embracing/engaging with health promotion issues. The Shanghai Declaration on Health Promotion (WHO, 2016) places specific emphasis on health literacy promotion in order to address the improvement of individual health and empowerment. Findings from the current study have supported this viewpoint. Embedding health literacy across all health services could have a positive impact on health literacy at the population level. This is imperative for the promotion of overall health and well-being as well as supporting best practices in self-management across the various non communicable diseases.

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ORIGINAL RESEARCH PAPER

WILEY

## **The relevance of context in understanding health literacy skills: Findings from a qualitative study**

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### **Abstract**

#### **Background**

Conceptualising health literacy as a relational concept, which involves how individuals interact with complex health and social systems, requires a greater understanding of the context of people's health experiences.

#### **Objectives**

To describe individuals' experiences of accessing, understanding, appraising and applying health information; explore the barriers and facilitators to using these skills, and to describe the experience of information exchange in health consultations.

## **Design**

A longitudinal qualitative methodology with thematic analysis of interviews was used. Health literacy levels were assessed using the HLS-EU-47-Item Questionnaire. Findings are presented from the first round of data collection.

## **Setting and participants**

Twenty-six participants purposefully selected from a CVD risk reduction programme at three separate time points.

## **Results**

Four key themes identified: using health literacy capacities for managing health; psychological and structural factors that impact on these capacities; and the relationship quality with the health care provider (HCP). Although limited health literacy was prevalent across the sample (65%), all individuals were very proactive in attempting to utilise health literacy skills. Findings emphasise the importance of contextual factors such as the quality of communication with the health care provider, perceptions of control, attitudes to family medical history, navigating structural barriers and being supported in managing treatment and medication side effects.

## **Discussion and conclusion**

Findings are relevant for health care providers in order to enhance the patient provider relationship and to ensure optimum health outcomes for all individuals regardless of health literacy levels.

Keywords: health literacy; health experiences; health care provider communication; qualitative

## **Introduction**

Health literacy concerns the capacities of people to meet the complex demands of health in modern society. It is viewed as an increasingly important component in the self-management of illness and the ability to effectively engage in health promotion activities.<sup>1</sup> While the research evidence consistently demonstrates poorer health outcomes associated with lower levels of health literacy, relatively little is known about how people develop their health literacy skills in the context of managing their health and illness, how this changes over time, and the barriers and facilitators that may be experienced in this process.<sup>1-7</sup>

Although the importance of the social context of health decision-making has been previously highlighted<sup>8-12</sup>, conceptualisations of health literacy have been slow to move away from framing health literacy primarily as a capacity of the individual. The main emphasis of health literacy studies to date has been on measurement development and this has occurred with little associated research into health professionals' communication skills.<sup>13-15</sup> The majority of studies have focussed on the functional level of health literacy as outlined by Nutbeam<sup>16,17</sup> with far less work exploring the communicative and critical levels of health literacy<sup>9</sup>. Chinn (2011) advocates the use of qualitative methodologies to explore 'how people actually interact critically with health information in real-life situations'.<sup>18(p64)</sup>

Lai et al. (2015) also argue that health literacy studies need to shift from a predominantly patient focus to one that encompasses health interactions and health contexts<sup>19</sup>. The current study sets out to do this and employs a qualitative methodology, incorporating the HLS-EU conceptual model<sup>15</sup>, to explore individuals' experiences. This is a recently developed comprehensive model of health literacy that emphasises the capacities necessary to be considered health literate and to make decisions about health: access, understanding, appraisal and application, which can be linked to functional, interactive and critical levels of health literacy.<sup>20</sup> The HLS-EU model proposes that individuals who possess all four capacities are more likely to be able to successfully navigate three key dimensions of the health continuum: the health care setting, the disease prevention system, and community-based health promotion.<sup>15</sup>

This paper presents findings from the first phase of a larger longitudinal qualitative study, consisting of three phase, which aims to examine developments in the health literacy of individuals over time. The objectives of phase one were to: describe individuals' experiences

of accessing, understanding, appraising and applying health information; explore the context (i.e. the barriers and facilitators) to using these skills, and to describe the experience of information exchange in health consultations. The overall aim of this paper was to explore the use of health literacy skills in the context of individuals managing risk factors for CVD.

### Study design

This paper describes phase one of a longitudinal qualitative study design, which employs repeat interview methodology at three separate time points (see Table 1) to examine developments in health literacy of individuals over time. Data on health literacy levels were collected at time points one and three and this contributed to a layered approach as advocated by Saldaña.<sup>21</sup>

Table 1: Overview of timeline and methods for overall longitudinal qualitative study

		<i>Methods used</i>	
<i>Time points</i>	Focus		
Phase 1: (Baseline: Beginning of programme)	To explore individuals' experiences of using health literacy capacities in the management of health and illness.	Participants interviewed	HLS-EU survey completed
Phase 2 (End of programme @ 12 weeks)	To monitor developments and changes in the use of health literacy capacities.	Participants interviewed	
Phase 3 (One year follow up @ 12 months)	To examine developments and changes in the use of health literacy capacities over time and to explore the barriers and facilitators in this process.	Participants interviewed	HLS-EU survey completed

### Participants

The concept of purposeful sampling is used in qualitative research to select individuals/sites for study because they can purposefully inform an understanding of the research problem and

central phenomenon in the study .<sup>22</sup>In this study, purposeful sampling was employed in order to select individuals attending a community-based structured cardiovascular risk reduction programme and so obtain the views and experiences of people with a range of risk factors for cardiovascular disease, as well as those with established disease (see Table 2). The twelve week programme integrates the care of individuals with established heart disease and those at high multi-factorial risk of developing the disease, into a local community-based programme<sup>20</sup> that was originally developed at Imperial College London following the EUROACTION trial<sup>19</sup>. The programme in this study is provided in a community setting. Initial recruitment took place in conjunction with the programme nurse who identified individuals who were cognitively able to participate and had an understanding of the English language. A unique feature of the programme is that partners of referred patients are also invited to complete the programme and in this study five partners were included. Recruitment took place between February and December 2014.

#### Profile of Study Participants

All of the participants were commencing a twelve week CVD risk reduction programme and were referred through various pathways including general practice and hospital departments such as cardiology, stroke, and endocrinology. Participant characteristics are summarised in Table 2.

Table 2: Profile of study participants

<b>Participants (n)</b>		26
<b>Gender (n, %)</b>		
Male		10 (38%)
Female		16 (62%)
<b>Age (mean, range)</b>		59 (36-76)
<b>Education: highest level attained to date (n, %)</b>		
Primary School (PS) level (Low)		3 (11.5%)
Incomplete PS (Low)		1 (3.8%)
Secondary-intermediate level (Low)		7 (27%)
Completed secondary(Medium)		5 (19.2%)
Diploma/certificate(Medium)		5 (19.2%)
Primary degree (High)		1 (3.8%)
Postgraduate/ higher degree (High)		4 (15.4%)
<b>Social class<sup>25</sup> (n, %)</b>		
I (High)		1 (4%)
II (High)		7 (27%)
III (Medium)		1(4%)
IV (Medium)		3 (17%)
V (Low)		4(4%)
VI (Low)		3 (17%)
VII(Low)		7 (27%)

<b>General health literacy level from HLS-EU measure<sup>23</sup> (n,%)</b>	
Limited	17(65)
Adequate	9(35)
<b>Health service access (n/%)</b>	
Private health insurance	13(50)
Medical card only	7(27)
Private AND medical card	4(15)
Public access only	2(8)
<b>Smoking</b>	
% Current Smokers	12
<b>Diet</b>	
Mean Mediterranean Diet Score (optimal score $\geq 9$ )	5
<b>Physical Activity</b>	
% NOT achieving targets ( $> 5x/week \geq 30$ minutes)	81 (n=21)
<b>Anthropometrics</b>	
%BMI $\geq 25\text{kg/m}^2$ (overweight)	27 (n=7)
%BMI $\geq 30\text{kg/m}^2$ (obese)	65 (n=17)
% Waist Circumference NOT at target Male $\geq 94\text{cm}$ & Females $\geq 80\text{cm}$	96 (n=25)
<b>Blood pressure</b>	
% BP NOT to target ( $>140/90\text{mmHg}$ for high risk individuals & $>130/80\text{mmHg}$ for coronary/diabetes)	62 (n=16)

<b>Cholesterol</b>	
% Cholesterol NOT to target (TC >5mmol/L & LDL > 3mmol/L for high risk individuals and TC >4.5mmol/L & LDL >2.5mmol/L for coronary/diabetes)	42 (n=11)
% with other illness related risk factors (heart attack, stroke, Diabetes; Hypothyroidism, Psoriasis, Cardiac arrhythmia, heart disease (stents fitted), heart failure)	73 (n=19)

### Data collection procedures

#### Interviews

Twenty-six interviews, with an average length of 30 minutes duration were conducted. Semi-structured interview guides were used to explore the development of health literacy and to identify changes in knowledge, attitudes and experiences over time (see Appendix 1). The development of the interview guide was informed by Sørensen's conceptual model of health literacy<sup>15</sup> in order to explore all the capacities associated with health literacy. For phase one of the study the interview guide focussed on the specific phase one study objectives. All Interviews took place at the community-based programme building and were conducted by the first author (VMcK). Participants' health literacy levels were assessed using the HLS-EU-47-Item Questionnaire<sup>23</sup> to examine initial levels of health literacy. The use of this measure adds perspective to the qualitative data and allows for comparison with levels recorded for the overall Irish population.<sup>20</sup> Interview and survey administration was piloted prior to commencement of data collection with a small number of individuals attending the structured programme.

#### Ethical considerations provide date

The study was independently reviewed and approved by the Research Ethics Committee, National University of Ireland, Galway in May 2013. All participants were provided with written and oral details of study participation and provided with written informed consent to participate in the study. Emphasis was placed on the voluntary nature of study participation, the removal of all identifiers and that all information would be anonymised.

## Data analysis

### Interviews

All interviews were audio recorded digitally, transcribed verbatim and analysed using thematic analysis, which was facilitated through the use of N-VIVO version 10 qualitative software. The study used a hybrid approach of inductive and deductive coding<sup>24</sup> and theme development employing a thematic analysis methodology as advocated by Braun and Clarke (2006).

Credibility of findings was enhanced by returning to the original transcripts and through discussion with the other authors (MB and JS). A sample of transcripts were also read by MB and initial codes and final themes reviewed with both MB and JS. In addition a sample of transcripts was independently coded by another experienced qualitative researcher.

### HLS-EU measure

This measure<sup>23</sup> was used primarily for descriptive purposes and to profile the participants further. The instrument is scored for four indices: a general health literacy index (reported in this paper) and three dimension specific indices (healthcare, disease prevention and health promotion-these will be addressed in the longitudinal study findings). The raw scores are categorised to denote the following levels of health literacy: inadequate, problematic, sufficient and excellent.<sup>1, 15</sup> These were further combined to yield scores for limited and adequate levels of health literacy. The HLS-EU has previously been validated<sup>23</sup> and good internal reliability was demonstrated in this study (General  $\alpha = .91$ ; Health Care  $\alpha = .80$ ; Disease Prevention  $\alpha = .80$ ; Health Promotion  $\alpha = .89$ ). The measure was administered by the first author (VMcK) in face-to-face meetings with participants.

## **Results**

General health literacy scores were calculated for all participants and indicated a high level of limited health literacy across the sample at 65% (n=17) with a lesser proportion having an adequate level of health literacy (35%, n=9). The limited level of health literacy reported here is significantly higher than levels reported in the overall European Health Literacy survey<sup>1</sup> (47%) and in the Irish sample of the European survey (40%).<sup>20</sup> These findings correspond with those for population subgroups with lower education and social class levels, and higher rates

of disease and health service use. <sup>1</sup>In this study the sample was mixed across demographics as depicted in Table 3 below. Statistical tests for differences in general health literacy scores for education and social class<sup>25</sup> were not significant ( $p = .265$  and  $.389$ , respectively).

Table 3: Mean health literacy scores across education and social class

<i>Health literacy level from HLS-EU measure<sup>2</sup></i>	<i>Limited (n=17; <math>\bar{x}</math> =29)</i>			<i>Adequate (n=9; <math>\bar{x}</math>=34)</i>		
	<i>Low</i>	<i>Med</i>	<i>High</i>	<i>Low</i>	<i>Med</i>	<i>High</i>
<i>Education level</i>						
	n=8; $\bar{x}$ =28	n=6; $\bar{x}$ =32	n=3; $\bar{x}$ =29	n=3; $\bar{x}$ =36	n=4; $\bar{x}$ =39	n=2; $\bar{x}$ =41
<i>Social clas</i>						
	n=7; $\bar{x}$ =29	n=7; $\bar{x}$ =29	n=3; $\bar{x}$ =30	n=4; $\bar{x}$ =36	n=1; $\bar{x}$ =35	n=4; $\bar{x}$ =41

### *Interview data*

The interviews yielded rich data relating to participants' experiences and strategies for accessing, understanding, appraising and applying health information across various health contexts. The data also identified barriers and facilitators which can impact on health literacy practices for the individuals and these are depicted in the four interlinked themes set out in Table 4 below.

Table 4: Themes and additional participant quotations

Participant number P1,P2 , P3...P26	Gender M: Male F: Female	Health literacy level A: Adequate L: Limited	Example quote label: P1FL
<i>Theme</i>	<i>Sub-theme</i>	<i>Categories</i>	<i>Examples of additional participant quotes</i>
Using health literacy capacities for self-management of health and illness	Health information seeking	Keeping motivated  Active and passive information seeking  Appraising information  Making sense of information	<i>So I would read anything. And if they give you anything in the hospital any time I have been in, I will keep it, and I will maybe read it when I come home, but I would read it again a week later, do you know? (P23FL)</i>  <i>Well sometimes the information, if you're not into the terms that the doctors in the hospital use it's just like you have to go looking up about this, say different words and then you're wondering. . And then you spend ages looking that up ... So it's kind of like, it's alright if you know the medical terms of everything; then if you don't you're like just, it's kind of like trying to learn a new language .(P1FL)</i>
	Side effects of medication use	Decisions about treatments  Concerns re QoL	<i>I did mention it a couple of times and she kind of said 'oh you're better off to stay on it' but I don't know to be honest. I feel it nearly makes you too passive or too, you know, you just, as I say, just let everything flow by you kind of thing. (P5FL)</i>
Psychological factors that impact use of health literacy capacities	Perceptions of control	Being confident and proactive  Not having control  Dealing with family history	<i>And as my own brother died with it... from a major heart attack, I would have you know more of an interest. And I have another brother that got a stroke two years later and they were only in their fifties. (P23FL)</i>

	Emotional reactions	Anxiety and coping	<i>Feeling that I could get into the car and drive and stay in somewhere like X or somewhere. I have a longing to say go to X and have a few days and I'm afraid to do it and that's not living, that's my big issue, yeah, that's terrible... I haven't met anybody, friends have said we'd meet in X and stay the night, I'm afraid to do the trip, I'm afraid to be away from home (P21FL)</i>
Structural factors that impact use of health literacy capacities	Being able to access health services	Health service access  Having/not having health insurance  Waiting lists Fragmentation of services	<i>It might be not the right word but I feel worthless and useless and demoralised. To think that if you haven't got the money your health is screwed; just ridiculous. It should be, in a perfect world, waiting lists shouldn't be three or four years long. Nothing I can do about it.(P11FL)</i>
	Environment	Living environment (rural, urban)  Affordability	<i>I'm on my own, I'm separated, I only work September till May, and so kind of from January to May you are saving to get the few extra bob for the summer – so, no, I can't afford private health, and I have no money to pay for it (P26FL)</i>
Quality of relationship with the HCP	Qualities of the HCP	Listening, good rapport, trust, feeling cared for	<i>Oh it's easy to talk to them, yeah. And I've a good GP like, and he'll refer me in, and I'll meet up with the doctor and ask all the questions you want (P17ML)</i>  <i>If something like that came up that I thought that maybe I shouldn't be using, I would ask him, you know, that I would take his, his word would be the most important to me (P23ML)</i>  <i>And he knows that I'm, as he calls it, highly idiosyncratic, that I'd be allergic to medication, and stuff, and everything. So he's very</i>

			<i>good at trying to find one that will work for me, you know, and he knows and I know that if I try it for a month, whether it's going to work or not (P26FL)</i>
	Accessing and appraising information with the HCP	Positive and negative experiences  Seeking referrals  Active and passive relationships	<i>Like I suffer with HS, I can never pronounce it correctly, Hidradenitis suppurativa, it's just abscesses and boils, all the time I suffer with and not many GPs really know a lot about it. I asked him to refer me to a dermatologist and he said 'what the hell do you want to see a dermatologist for'? I said because I need to see a dermatologist. But 'oh, you're looking at those sites again'. And I said but you can't give me the information I need and I would like to see a dermatologist. 'Ok, I'll refer you'.(P11FL)</i>
	Communicating	Positive experiences  Negative experiences	<i>He talks normal talk rather than doctor [talk] and I'm not being disrespectful .He goes down to your own level and that's what I like about him. Like there would be a name for a tablet there and it could be, you name it, forty letters long but he brings it down to a simple, do you know what I mean? And that kind of thing, once that's explained I know exactly where I'm going. (P13MA)</i>

The findings are presented in terms of these four themes as well as relevant sub-themes and categories.

### **Using health literacy capacities for self-management of health and illness**

#### Health information seeking

Participants in this study were managing a wide range of CVD risk factors as well as managing chronic illness and they varied in the detail of information they wished to know about their conditions. Some were very proactive in seeking out detailed information from different

sources while others preferred to view their doctor as the sole point of access to health information:

*I wouldn't be somebody that'd be going home and researching what the doctors are telling me. I just take them at their word. (P14MA)*

In responding to ill-health, participants demonstrated efforts to apply actions to prevent disease and promote health and highlighted the challenges of maintaining motivation to sustain those activities. Participants emphasised the gap between *knowing* and *doing* which was an on-going struggle for all participants. This included those who had established cardiac conditions and those undertaking more general lifestyle changes:

*I find that awful hard; that's the hardest part. Motivation is incredibly difficult for me. (P3ML)*

Participants used a variety of means to access health information including the internet, newspapers, radio, medical leaflets, doctor and pharmacist. For those who use the internet *Google* was the predominant method to search for information. Others combined accessing information with an appraisal process using multiple sites, making comparisons and bringing information back to the GP for further clarification. Participants expressed caution in over-reliance on the internet as the sole source of health information:

*I know if I'd anything seriously wrong I'd definitely check with the GP. I wouldn't fully rely on the internet at all. (P6FL)*

However, it was also viewed as a useful way to supplement understanding of information received from the doctor:

*You can go to a doctor... but to be able to go home then, Google it up, print it off, read it and study it, and then go back with some of the formative questions, is good. (P26FL).*

In terms of appraising health information, participants who regularly used the internet to access health information were able to differentiate between sites which are generally deemed to be trustworthy (medical sites) and other sites. Participants also stated that they preferred using medical sites over those which are predominantly based on patient experiences (such as patient forums).

*..there are some good sites there and some bad ones. So you have to, weed out the chaff from the wheat as it were. The Mayo clinic-they really explain everything spot on. (P3ML)*

Attempts to understand health information can be impeded by unclear instructions as depicted in the quote below where a participant describes the confusion she felt where there was conflicting information provided on a medical leaflet describing the timing of medication dosage for a colonoscopy procedure:

*I was in a real panic because I'd read this and it said you must not eat or drink anything from midnight the night before the test and then I read this leaflet and it said second dose at seven am the next day. (P8FL)*

#### Side-effects of medication use

Participants with both limited and adequate levels of health literacy engaged in self-questioning regarding the side-effects of various medications and it clearly influenced their decisions on whether or not to take up or continue with various treatment plans:

*I'd be afraid like, I mean all my blood tests that I get taken they're fine, they're perfect and if I were to go taking statins well who knows what'd happen?(P12FL)*

These concerns also impacted on decisions to change medication dosages or to cease taking medicines altogether:

*I was wondering about, was it wise for me to be taking all this poison? I would refer to it as. I just went off the tablets. (P7MA)*

Quality of life considerations were important in making decisions about treatment plans/medication use:

*So if I feel that the downside of a medication has the potential to cause me serious problems in another area, then I would ask for an alternative. (P19FA)*

## **Psychological factors that impact use of health literacy capacities**

### *Perceptions of control*

Participants described feelings of control and confidence in relation to managing their health, which could impact on how proactive or passive they were in activities related to using health literacy capacities. Perceptions of control were linked to how individuals engaged with health information /health services. For some, being in control was important and is related to personal responsibility for health:

*I don't accept what people will tell me about my health unless I'm happy about it myself ...no offence to the medical profession but they're not going to take the time to figure out all the nooks and crannies of my medical issues. So I'm responsible for that myself. (P2FA)*

This is linked to an awareness of personal characteristics needed to be proactive:

*I would be somebody who'd make the phone call, keep asking the questions until I find the right person to speak to. (P2FA)*

For others, a sense of limited control pervaded their attitudes to managing health issues. Having an awareness of a family history in relation to illness or risk factors and how one copes with that also has a bearing on the control individuals felt in relation to their health. Some participants referred to not having any choice but to get on and make behaviour/lifestyle changes, in some cases this was equated with 'doing what one is told'(PR06). Some participants reported having little control over their health situation. Some dealt with family history by attempting to disengage from it:

*I thought I could do whatever I wanted; I was perfect. I did know in the back of my mind about my mother but you know you kind of shrug it off...But I didn't look sick or anything like that. (P7MA)*

For others, an awareness of risk factors rooted in family history acted as an impetus to gain more knowledge about the condition:

*Find out more about diabetes really and heart disease because it's something that's big in our family...so that I'll know to take care of myself and my family. (P1FL)*

A number of participants described situations where they experienced long delays in getting a diagnosis despite their on-going health concerns and continued interactions with their doctor.

These experiences were linked to feeling quite powerless in relation to trying to manage health concerns when there was no clear diagnosis:

*I kind of blame myself because for ten years I thought I was complaining of a kidney infection and when it turned out to be ovarian problems, that was a bit of a concern that it hadn't been picked up. (P8FL)*

#### *Emotional reactions*

Psychological aspects associated with diagnoses and on-going treatment of illnesses are important influencing factors that can hinder the application of health literacy skills and the active engagement of individuals regardless of levels of health literacy. These factors include the anxiety and shock of coping with diagnoses, which can also impact on the control one feels in relation to health issues:

*The technician up in the x Clinic, he said have you been offered a CRTD? [Cardiac resynchronization therapy] and I said I have but I'm scared of it and I don't want the idea of something shocking me. (PR21FL)*

Difficulties in understanding information were sometimes linked to emotional barriers such as dealing with the shock following a diagnosis. Participants had devised strategies to overcome these barriers such as having another person in attendance and bringing notes and/or questions into the consultation. One participant described how the doctor's understanding of her anxieties and the involvement of a family member facilitated the communication process to ensure that the health information was understood correctly:

*When I was in my consultant's and she said to my husband I'm going to tell you now because she won't believe me... I wouldn't believe. I would go home with the worst scenario possible. (P9FA)*

Similarly, another participant described how the shock of her husband's stroke diagnosis impacted on her ability to process the information:

*He tries to explain to us...but..., when he got the stroke, some of it went over my head. (PP23FL)*

Another participant who had previously worked in the health service highlighted her realisation of the difficulties of taking in and understanding information when one is unwell:

*I'm sure there's bits I forget and taking in information when you're sick, I never realized how different it is. It's frightening....I just gave people out their pills and did not have a clue what they were going through. (P21FL)*

### **Structural factors that impact use of health literacy capacities**

In discussing their health management experiences participants identified a number of factors at the healthcare system and broader community and environmental levels that influenced their capacities to access, understand, appraise and effectively utilise health information.

#### *Being able to access health services*

Within the Irish Health Service some individuals with private health insurance have more timely access to consultants, diagnostic and treatment services compared to those without health insurance (public patients). Participants without health insurance described difficulties accessing needed health services. In the Republic of Ireland primary health care services are not free at point of access except for those holding a medical card. Some participants had experience of both public and private health services use and were able to reflect and compare experiences. Those with private health insurance highlighted the timely access to services and equated this with earlier diagnosis:

*And I know that I wouldn't be seen to, when I had that irregular heartbeat, that I'd be put on a waiting list and I mightn't get a good consultant then. .. that's why I got such good service because I had insurance. (P20FA)*

Some participants found that the limited integration of services can make the management of multiple appointments/health care interactions difficult to manage:

*There's nobody looking at all the whole file – you go in, they look at their little bit, they ask you the same questions you were asked before...there is no continuity at all through the hospitals. (P26FL)*

Participants who do not have health insurance highlighted the issue of long waiting lists to see consultants as well as the poor coordination of medical appointments across different geographic locations:

*I was referred to the pain clinic by Mr X maybe three years ago as an emergency and I'm still waiting. Two weeks ago they phoned me up to offer me an appointment in x*

*but it'll be on-going appointments so I'm not travelling to x because at the moment I'm travelling to y with other health problems .(P11FL)*

### *Environment*

Participants identified how their living environments (including community and working) could facilitate or impede engagement with health practices. Rural dwelling participants highlighted the positive aspects of rural living (fresh air, wide open spaces, safety for children) while also identifying challenging issues (no footpaths, reduced safety for walking and cycling, limited access to groceries nearby).

*I suppose in the countryside it's harder to stick with stuff and be more active apart from walking and stuff like that because there's nothing there; have to drive everywhere compared to in towns. Even with the shopping ... there's not that much choice in the countryside. (P1FL)*

A number of participants who had retired from work noted that it was much easier to engage in lifestyle changes outside of the work environment.

*It's a different environment actually ...when I was working I was on the road a good bit ...it would have forced me into a car rather than doing healthier forms of transport you know. (P16ML)*

### *Affordability*

Financial considerations were perceived as barriers or facilitators to being able to engage with health activities. Some participants (all with higher levels of health literacy) described themselves as '*fortunate enough*' and '*privileged*' to be able to afford

*All the things that promote wellbeing...they all cost money...you have to be able to afford to do it, you know. (P19FA)*

## **Quality of relationship with the HCP**

### *Qualities of the HCP*

The relationship with the HCP (mainly GP) and the quality of that relationship emerged as central in using health literacy skills. Characteristics of the HCP relationship could act as a barrier or facilitator to information seeking and appraisal as well as to the overall interaction

and communication experiences of participants. Trust, being listened to, having a good rapport and feeling comfortable and cared for were all important factors identified:

*It's so important for somebody to listen to you and for them to understand what the problem is and how the patient is coping. (P12FL)*

The perception of *caring* is clearly important and this is particularly relevant for those who are managing serious illness:

*When I was told that my heart function was so low I got so scared and Dr X phoned me several times...to see how I was, I'd never had calls from a cardiologist to know how I was, which was lovely. (PR21FL)*

#### *Accessing and appraising information with the HCP*

Many participants were involved in seeking and obtaining health information such as looking up specific information, asking questions of the doctor, having a strategy to keep information and putting the information to use. Many of these activities are also an important component of the appraisal process whereby the HCP is directly involved. Participants varied in their level of engagement with active information seeking. For some, information was obtained by attending talks (for example, through the diabetes clinic) and noting relevant information as it came up. Others were much more proactive in seeking out different sources of information, engaging and using the information in consultation with the GP. A common part of the appraisal process was bringing information found elsewhere into the consultation and some participants had experienced negative reactions to this:

*So I did a bit of research on the internet and I found that this particular drug, X, if it does give you a cough it means there's something wrong with your heart and I actually said that and she said 'ah, you're reading too much.' (PR21FL)*

Some participants, with both limited and adequate health literacy levels, had actively sought out a referral from their GP. One participant linked her insistence on a referral for a mammogram to the early detection of breast cancer:

*So I went to my GP and she examined me, now I know she couldn't feel anything, so she wasn't going to send me to anywhere. But I said "I want to go for a mammogram". So only for that I wouldn't have gone, and I had it. (P18FL)*

Another participant used her knowledge of the difficulties of detecting an underactive thyroid using blood tests to insist on a referral:

*Most thyroid readings come out as normal, but you can still have a lot of the symptoms of an underactive thyroid, which I have. So I insisted that my GP refer me to a consultant, and I was referred, and I am now on medication for my thyroid. (P19FA)*

Despite the overall high level of limited health literacy in the study sample, the majority of participants were active in seeking out health information. However, a small number described more passive interactions with health care providers and engagement with health information:

*I would never ask the doctor. If he says it to me that's ok like you know. I'm not a kind of a guy now that would be asking or looking for answers. If it comes, it comes, do you know what I mean? (PR10ML)*

Some participants described negative experiences in their interactions with HCPS that correspond with a more paternalistic model of communication:

*Well we do talk but sometimes I do feel that maybe it's kind of like, you know, 'what would you know, this is my area'. I'm not a confrontational person so I wouldn't like to kind of rock the boat. (P8FL)*

## **Discussion**

The overall aim of this paper was to explore the use of health literacy skills in the context of individuals managing risk factors for CVD. The findings of this study are consistent with a perspective of health literacy as a relational concept which emphasises individuals' interactions with complex health and social systems.<sup>26,27</sup> The findings have generated a number of important insights into contextual factors influencing how health literacy capacities may be used. These are relevant for health care providers in order to enhance the patient-provider relationship and to ensure optimum health outcomes for all individuals regardless of health literacy levels.

Study findings have highlighted that the health care provider (HCP), and most often the General Practitioner (GP), is central to the process of navigating health information and is

generally seen as the most trust worthy source of information, even where the internet is routinely used. However, some participants had also experienced more negative interactions where they felt that their opinion was not respected and this acted as an impairment to their relationship with the HCP which in turn may act as a barrier in using health literacies capacities. A positive response by the health care provider to information brought to consultations is recognised as an important factor in creating positive patient-provider relationships<sup>28</sup>. Study findings indicate that the communication style of the HCP can either facilitate or act as a barrier to information exchange and other studies have highlighted how this can subsequently contribute to empowerment or disempowerment of the individual<sup>29</sup>. Timely access to appropriate health services was another potential source of disempowerment identified in this study. Long waiting lists, highlighted in this study, can act as a barrier for individuals to engage with health issues and the timely uptake of treatment plans. Where people are managing multiple conditions the lack of a coherent service can be problematic. Health literacy skills may have limited impact in instances where structural barriers to health service access exist. Typically those with more limited health literacy are going to experience greater challenges in this situation and are also more likely to be impacted adversely by social demographic factors.<sup>30</sup>

The issue of empowerment is important to consider and is understood here to refer to psychological empowerment that includes the constructs of personal control, a proactive approach to life and a critical understanding of the socio-political environment<sup>31</sup>. It entails being able and motivated to bring about changes not only in personal behaviour but also in the social situations and the organisations that influence one's lives.<sup>32</sup>

The exact nature of the relationship between health literacy and empowerment continues to be contested in the literature. However, there is a growing consensus that while health literacy does not automatically lead to empowerment, it may well be understood as an instrument in the process<sup>33</sup>. Both concepts are regarded as distinct but closely connected through knowledge, skills, and power dimensions.<sup>33,34,35</sup> Porr et al. (2006) further consider that individuals' competencies, self-efficacy, critical thinking and reflection are important factors in the process.<sup>36</sup> Sykes et al. (2013) used a concept analysis approach to identify critical health literacy as being similar to empowerment, the key attributes of which were health knowledge, confidence, self-efficacy and empowerment.

Feelings of being in control or having limited control are central to how health literacy capacities may be utilised in managing health. Study findings highlight that being in control is associated with feelings of greater confidence which in turn can contribute to more proactive engagement with health issues. Barriers to control identified include those at the personal or

psychological level and those at the broader social and structural levels. The psychological aspects of managing illness can impact on abilities to access, understand, appraise and use health information. In this study participants described how information given during times of stress may be difficult to take on board and understand. In addition, individuals may refuse treatments altogether based on their fears associated with the treatment. Health care providers need to have an understanding of the contexts of such fears and be able to offer support in a caring way to allay these fears. Having regular reviews to discuss the implications of long term treatments routinely built into consultations, and providing individuals with information on making changes to medications/treatment plans as appropriate, is important in this regard. Such an approach corresponds with a model of shared decision-making where doctors and patients jointly participate in a treatment decision-making process and come to some negotiation of which treatment is chosen and implemented.<sup>37</sup>

Although participants in this study demonstrated the ability to be quite proactive in their interactions with HCPs, it cannot be assumed that all individuals have the skills to be proactive regarding issues such as requesting referrals or second opinions and/or questioning medication use. A routine and consistent approach to raising such issues in the consultation by the HCP could be beneficial in terms of improving adherence and health outcomes. Initiation of such discussions by the HCP could also mitigate concerns over time pressured consultations that may impact on individual's confidence to bring up issues. Another important element is the importance of having a clear understanding of how individuals interpret and understand their risk in relation to family history, which can be particularly relevant in the management of CVD risk factors. Familial risk models indicate that persons will attempt to either cope with or control disease vulnerability (Walter and Emory, 2005). Findings in this study identified that some individuals needed to attempt to exert control over familial risk factors and this may be linked to beliefs about the contribution of nature and nurture to disease.<sup>38</sup>

An important finding relates to individuals' concerns regarding the side effects of treatments. Greater knowledge on the part of HCPs of the health beliefs and attitudes of the patient will help to ensure that appropriate health information is provided. For example, treatments could be better tailored where there is knowledge about the patient's attitude to medication usage and more lifestyle focussed treatment plans could be incorporated where feasible. It is important that HCPs are aware of the extent of such concerns and the context for them in order to support the individuals to make appropriate care decisions. Lower levels of health literacy can affect key decisions-making outcomes<sup>39</sup> and the use of formal decision aids may be useful.<sup>40, 41</sup> Without adequate support in this process some individuals may have adverse health outcomes, for example, if they cease taking medications associated with particular side effects.

Strengths and limitations of the study:

One strength of this study is that it combines data on health literacy levels with the qualitative experiences of individuals. Individuals with limited health literacy are well represented in the study. The participants in the study were sampled from those at the beginning stages of a community-based CVD risk reduction programme and so differs from the healthcare-based patient samples used in other studies.

The study design could have been strengthened by using a stratified purposeful sample which would allow for a clear differentiation between groups with high/low health literacy. However, this was not possible due to the nature of recruitment (rolling intake) into the community-based programme. Ultimately, study participation relied on the voluntary participation of individuals and so it is possible that those individuals who were most engaged with health issues were more likely to take part.

### **Conclusion**

Participants in this study, with varied levels of health literacy, are striving ‘to make informed choices, reduce health risks and improve quality of life’<sup>42</sup>. Individuals interacting with HCPs all have different levels of health literacy which in turn can impact on how health information is accessed, understood, appraised and applied. HCPs need to have an increased awareness and understanding of these contexts. There were no clear patterns regarding health literacy levels and experiences discerned in this study in relation to either education or social class levels. However, what does seem to be most important are contextual factors such as the quality of communication with the health care provider, perceptions of control, attitudes to family medical history, navigating structural barriers and being supported in managing treatment and medication side effects. Capacity at the critical level of health literacy entails moving from an understanding of basic health information to being able to contextualise it and to use this to gain control and/or change the determinants of a particular outcome. Further research involving follow-up with participants as part of the larger on-going longitudinal study will offer increased insights into barriers and facilitators to developments in health literacy over time.

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## Appendix 2: Paper II

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### A Qualitative Study of the Development of Health Literacy Capacities of Participants Attending a Community-Based Cardiovascular Health Programme

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**Abstract:** Health literacy is a critical determinant of health, which can empower individuals and lead to engagement in collective health promotion action and is also a crucial component in the self-management of illness. The current study moves beyond a focus on functional health literacy and presents findings from a longitudinal qualitative (LQ) study consisting of three phases. This paper presents findings from the second phase of the study, which assessed the development of health literacy capacities of individuals attending a structured cardiovascular risk reduction programme in Ireland. The study objectives were to: explore perceptions of changes in interactions and information exchange within health consultations; identify the facilitators associated with changes in health literacy capacities; assess developments in engagement with broader contexts for health literacy capacities. A LQ study design was undertaken, which employed repeat interview methodology with 19 participants (aged 36–76 years) 12 weeks after beginning a structured cardiovascular risk reduction programme. Health literacy levels were assessed using the HLS-EU 47 item instrument in phase 1 (68% limited health literacy (HL), 32% adequate health literacy). A semi-structured interview guide, (informed by Sørensen’s conceptual model of health literacy), was used to explore the development of health literacy and to identify changes in knowledge, attitudes and experiences over time. Thematic analysis was used, informed by aspects of Saldaña’s framework for longitudinal

qualitative data analysis. All participants reported having acquired increased understanding of issues relevant to their health and self-care. Participants described health literacy capacities that incorporate aspects of all levels of health literacy (functional, interactive and critical). Core themes were identified corresponding to changes in these levels: re-engagement with health information and increased understanding of risk and protective factors (changes in functional health literacy); changes in interactions with healthcare providers (HCP) (changes in interactive health literacy); enhanced psychological insights and understanding the broader determinants of health (changes in critical health literacy). Findings support the development of health literacy capacities across the functional, interactive and critical health literacy domains. Participants are capable of locating responsibility for health beyond the individual level and are making sense of knowledge within their own social contexts. Individuals, regardless of their initial health literacy levels, are capable of engaging with broader issues that can impact on their health and can be supported to develop these critical health literacy capacities.

Keywords: health literacy; critical health literacy longitudinal qualitative research; determinants of health

## 1. Introduction

Health literacy is a critical determinant of health that can empower individuals and lead to engagement in collective health promotion action [1]. It is also a crucial component in the self-management of illness [2]. Regarded as an asset, it is seen as central to lifelong engagement with health, building cognitive and social skills as well as the motivation necessary to navigate healthcare systems, disease prevention and health promotion throughout the life course [3–5]. While there is increasing recognition of the need to support the development of individuals' health literacy capacities and minimise environmental demands in both healthcare and broader societal contexts [6–12], there is still relatively little known about the barriers and facilitators in this process [13,14]. Research has highlighted the need to move beyond a focus on functional health literacy capacities in order to gain a greater insight into how the social and cultural context of individuals' lives can facilitate the development

of health literacy capacities, [12,15,16]. Some recent studies have examined this in adult-based educational settings [17,18]. This paper draws on the health literacy model developed by Sørensen et al. [5] to explore the different dimensions of health literacy within healthcare, disease prevention and health promotion settings. In this study, health literacy is defined as being 'linked to literacy and entails peoples' knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course' [5]. The current study addresses health literacy 'capacities', which refer specifically to the skills, abilities and potentialities of individuals to effectively access, understand, appraise and use information [6,19,20]. This definition aims to capture and embrace the depth of health literacy as an asset.

Increased insight is needed into how the development of health literacy capacity can be facilitated. The current study sets out to do this and presents findings from a longitudinal qualitative study, consisting of three phases (see Table 1 below), which examines developments in the health literacy of individuals over time. This study entails an in-depth qualitative exploration of the development of health literacy over time for a group of individuals managing their health and illness in the context of their everyday lives. There is a paucity of such longitudinal qualitative studies in the current health literacy literature.

Table 1. Overview of timeline, sample and methods for overall longitudinal qualitative study.

Time Points	Sample	Methods
Phase 1: (Baseline: Beginning of programme)	26 Participants	HLS-EU survey and interview completed [21]
Phase 2: (End of programme @12 weeks)	19 Participants	Interview completed
Phase 3: (One-year follow-up @12 months)	17 Participants	HLS-EU survey and interview completed [21]

This study makes an important contribution to the field of health literacy research as it is a qualitative in-depth and longitudinal study that follows individuals over time to examine developments in health literacy as they manage their health and illness in the context of their everyday lives. Findings from the first phase have been previously reported [22] and indicated a high level of limited health literacy for the population sample (65%). Both psychological factors, including perceptions of control and confidence in managing health, and structural factors such as access to health services and the impact of urban/rural environments, were found to impact on individuals' use of health literacy capacities. Relationships with healthcare providers, mainly the general practitioner (GP), and the quality of that relationship, were also identified as being crucial in using health literacy skills. This paper presents on the second phase of the study, which assesses the development and perceptions of changes in health literacy capacities of individuals attending a structured cardiovascular risk reduction programme. The study aim was not to evaluate the impact of the programme per se. Rather, the programme was used as a 'vehicle' to engage individuals as they managed their health and illness over a 12-month period. The study objectives were to: explore perceptions of changes in interactions and information exchange within health consultations; identify the facilitators associated with changes in health literacy capacities; assess developments in engagement with broader contexts for health literacy capacities.

## 2. Methods

### 2.1. Study Design

This paper describes phase two of a longitudinal qualitative study design, which employed repeat interview methodology at three separate time points (see Table 1) to examine developments in the health literacy of individuals over time. Findings from time point 2 (T2) are outlined in this paper.

### 2.2. Participants

In this study, purposeful sampling was employed in order to select individuals attending a community-based structured cardiovascular risk reduction programme. Purposeful sampling is used in qualitative research to select individuals/sites for study that can purposefully inform an understanding of the research problem and central phenomenon in the study [23]. The sample in this study were selected in order to

obtain the views and experiences of people with a range of risk factors for cardiovascular disease, as well as those with established disease (see Table 2). Twenty-six individuals were interviewed in phase one and nineteen of these were subsequently interviewed again at the 12-week point due to attrition of seven participants. The 12-week programme integrates the care of individuals with established heart disease and those at high multi-factorial risk of developing the disease, into a local community-based programme [24] that was originally developed at Imperial College London following the EUROACTION trial [25]. The programme is delivered by a multidisciplinary team comprising nurse specialists, dieticians and exercise specialists and incorporates weekly group exercise classes and educational workshops. The workshops address a range of topics including the risk factors for coronary heart disease and stroke, healthy eating, alcohol use, weight management, physical activity, stress management, food labels, maintaining change and cardiac medications. Participants also have weekly meetings with the multidisciplinary team [24]. Initial recruitment took place in conjunction with the programme nurse, who identified individuals who were cognitively able to participate and were able to communicate through the English language. A unique feature of the programme is that the partners of referred patients are also invited to complete the programme, and three partners were included in phase 2 of this study. Recruitment for this study took place between May 2014 and March 2015.

### 2.2.1. Profile of Study Participants

All of the participants ( $n = 19$ ) had completed a 12-week cardiovascular disease (CVD) risk reduction programme and were referred through various pathways including general practice and hospital departments such as cardiology, stroke, and endocrinology. Participants had a variety of risk factors including hypertension and elevated cholesterol and many were also overweight or obese. In addition the majority of participants had experienced one or more of the following conditions: established heart disease (stents fitted), heart failure, type 2 diabetes, cardiac arrhythmia and stroke. Participant characteristics, including health literacy levels recorded at phase one, are summarised in Table 2. The raw scores of the general health literacy index are categorised to denote the following levels of health literacy: inadequate, problematic, sufficient and excellent health literacy. In this study these were further

combined to yield scores for limited (inadequate and problematic) and adequate (sufficient and excellent) levels of health literacy. The limited level of health literacy reported here (68%) is significantly higher than levels reported in the overall European Health Literacy survey (47%) and in the Irish sample of the European survey (40%) [2,26]. These findings correspond with those for population subgroups with lower education and social class levels, and higher rates of disease and health service use, which is consistent with this participant profile.

Table 2. Profile of study participants.

Participants (n)	19
Gender	n, %
Male	8 (42%)
Female	11 (58%)
Age (mean, range)	61 (36–76)
Education: highest level attained to date	n, %
Primary School	4 (21%)
Secondary School	10 (53%)
Diploma/certificate/Primary degree/postgraduate	5 (26%)
Social class 1	n, %
I–II (High)	6 (32%)
III–IV (Medium)	1 (5%)
V–VII (Low)	12 (63%)
General health literacy level from HLS-EU measure 2	n, %
Limited	13 (68%)

Adequate	6 (32%)
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Length of time with risk factors/illness	n, %
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6–9 months	7 (37%)
More than 1 year	12 (63%)
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Health service access	n, %
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Private health insurance	10 (53%)
Medical card only <sup>3</sup>	7 (37%)
Private AND medical card	2 (10%)

<sup>1</sup> [27];<sup>2</sup> [21] <sup>3</sup>A medical card allows access to GP services, community health services, dental services, prescription medicines and hospital care free of charge under the General Medical Services Scheme for sub-groups of the population based on income levels/specific medical conditions [28,29]. Please add the explanation of superscript 3.

### 2.2.2. Data Collection Procedures

#### Interviews

Twenty-six individuals were interviewed in phase one and 19 of these were subsequently interviewed again at the 12-week point. Retention issues and attrition of participants is common in qualitative longitudinal studies [30–32]. In this study, attrition was attributed to a combination of issues including limited engagement with the risk-reduction programme on the part of some participants and illness factors that prevented programme completion.

Semi-structured interview guides were used to explore the development of health literacy and to identify changes in knowledge, attitudes and experiences over time (see Appendix A). The development of the interview guide was informed by Sørensen’s conceptual model of health literacy [5], in order to explore all the capacities associated

with health literacy. Interview questions for phase 2, similar to phase 1, focussed on the areas of accessing, understanding, appraising and applying health information, and transcript data were initially categorised within these areas. In addition, questions were also included, in the form of probes, to explore further issues that had been identified in phase 1 (for example, concerns about upcoming treatment decisions). Saldaña's framework [33] (as outlined in Table 3 below) was used to guide the analytic process and to structure the data analysis. The interview schedule was piloted prior to commencement of data collection with a small number of individuals attending the structured programme. Only minor changes were made to the sequencing of questions.

Table 3. Saldaña framework [33] (aspects used in this analysis are bolded).

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<b>Framing Questions (5)</b>
What is different from one round of data to the next?
When do changes occur?
What contextual and intervening conditions appear to influence and affect participant changes over time?
What are the dynamics of participant changes over time?
What preliminary assertions about participant changes can be made as the data analysis progresses?
<b>Descriptive Qs (7)</b>
What increases/emerges over time?
What is cumulative?
What kinds of surges/epiphanies occur?
What decreases/ceases over time?
What remains constant or consistent?

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What is idiosyncratic?

What is missing?

Analytic and interpretive questions (4)

What changes are interrelated?

What changes oppose or harmonise with natural human development or constructed social processes?

What are participant or conceptual rhythms, e.g., cycles through time?

What is the through-line of the study?

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All interviews took place in a private room at the community-based programme building and were conducted by the first author (Verna B. McKenna).

### 2.3. Data Analysis

All interviews were audio recorded digitally, transcribed verbatim and analysed using thematic analysis, which was facilitated through the use of N-vivo version 10 qualitative software. Qualitative validation criteria were applied in this study in line with established guidelines [34–36]. These included:

**Credibility:** Participants' perspectives were reported as accurately as possible and the participants own voice used. Review and refinement of themes through a consensus among the three authors.

**Triangulation:** convergence sought among multiple sources of information (interview transcripts, memos, relevant theory and authors) to verify interview data and to develop themes. A level of member checking achieved where key issues and themes arising at time point 1 were reviewed with the participants at start of time point 2 interviews;

**Transferability:** Detailed accounts of the data and the context of data collection provided.

Descriptive validity: Multiple reading of the transcripts and listening to recordings in line with the methodology of thematic analysis.

Interpretive validity: Made clear through the use of the participants own voice alongside the meaning attributed by the researcher.

Theoretical validity: Findings clearly set out within relevant theory in the field of health literacy.

Researcher reflexivity: Preliminary analysis between time points allowed researcher to reflect on personal assumptions related to health literacy and social contexts.

The study used a hybrid approach of inductive and deductive coding and theme development, employing a thematic analysis methodology as advocated by Braun and Clarke [37] whereby core themes, subthemes and categories were identified. Aspects of Saldaña's framework [33] (bolded in Table 3 below) were used in order to ensure that analysis captured the process of development and changes rather than presenting cross-sectional findings only [32,33]. By linking back to the previous dataset it was also possible to determine what changes or developments had occurred in terms of health literacy capacities (accessing, understanding, appraising and applying health information). The Saldaña framework [33] will be used more extensively for the overall longitudinal analysis of the entire dataset (time points 1–3). Preliminary analysis took place between interviews at time points 1 and 2 to allow reflexivity on the part of the researcher [38] as well as to focus on process and changes rather than on snapshots [32]. This preliminary analysis allowed the researcher to identify key issues that could then be returned to for further exploration in the second interview. This process was facilitated through the use of memos and field notes.

The analysis occurred both within each case and as a comparison between cases across the two time points. As such, the focus is not on gaining snapshots across time but to 'ground the interviews in an exploration of processes and changes which look both forwards and backwards in time' [39] (p. 194), [40].

Credibility of findings was enhanced by returning to the original transcripts and through discussion with the other authors (Margaret M. Barry and Jane Sixsmith). A sample of transcripts were also read by Margaret M. Barry and initial codes, emerging

themes and final themes reviewed and refined with both Margaret M. Barry and Jane Sixsmith through a negotiated consensus process.

#### 2.4. Ethical Considerations

The study was independently reviewed and approved by the Research Ethics Committee, National University of Ireland, Galway in May 2013. All participants were provided with written and oral details of study participation and provided with written informed consent to participate in the study. Emphasis was placed on the voluntary nature of study participation, with the removal of all identifiers and assurance that all information would be anonymised. Due to the nature of longitudinal research, consent should be viewed as a process rather than an initial act [41]. In this study consent was requested from each individual at each time point. The Participant Information Sheet specifically set out that all participation was voluntary and that s/he was free to opt out of the study at any point.

### 3. Results

The interviews yielded rich data relating to developments in participants' experiences of accessing, understanding, appraising and applying health information across various health contexts. Themes are set out in Table 4 and described in detail below. Themes are also linked to changes across the functional, interactive and critical domains of health literacy and highlighted below. Reference to the literature to support the changes across levels is also included where appropriate. Quotation labels are numbered by participant (P) and partner (PP) and also denote gender (M: Male; F: Female) and health literacy level (A: Adequate; L: Limited).

Table 4. Overview of themes and corresponding changes in levels of health literacy.

Theme	Health Literacy (HL) Level	Subtheme	Categories
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Re-engagement with health information	Changes in functional HL	Qualities of communicator Forum/methods	Engaging Supportive Multiple methods used
Increased understanding of risk and protective factors	Changes in functional HL		Food and nutrition Exercise Medication and treatments Side-effects of medication Cholesterol Blood Pressure
Changes in interactions with healthcare providers (HCP)	Changes in interactive HL	More at ease in communicating with the HCP Reinforcement/reassurances	Increased knowledge and therefore confidence
Enhanced psychological insights	Changes in critical HL	Increased insights of personal control limits and opportunities	Self-efficacy and confidence Dealing with stress
		Emotional issues	Anxiety/fear
		Facilitators of motivation	Peer comparisons

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Understanding the broader determinants of health changes in critical health literacy	Changes in critical HL	Sharing information Infrastructures to support health	Safe access— walkways, cycling Food manufacturing/culture Government lobbying
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### 3.1. Re-Engagement with Health Information

Participants found it possible to re-engage with health information. This was attributed to how information was communicated, which was regarded as being central to facilitating developments across the health literacy capacities of accessing, understanding, appraising and applying health information. Involvement in the structured programme was perceived to be a positive experience overall for the participants. Despite the fact that the majority had been managing illness and/or risk factors for a number of years, individuals reported being able to find new ways of accessing, understanding, appraising and applying health information. This was particularly clear in relation to information pertaining to exercise, food and nutrition, and medication use. These findings are indicative of changes in functional health literacy whereby participants are increasing their ability to respond successfully to the communication of factual information on health risks [4,42].

In terms of the health information provided, comparisons were made to the more traditional or ‘boring sell’ (PP4FA). Although the information itself was not necessarily new, participants felt that it was the way it was delivered (more personalised and tailored health communication) that impacted positively on their ability to take it on board:

I would have read lots of stuff and you’d hear stuff on the radio about healthy eating and all the rest of it but by actually handing you the packet of cereal that you buy every week and saying if you really look at it; and so it was really, really pertinent to where we were at rather than saying you should eat more of this, eat more of that. (PP4FA)

Participants, who at phase one had a recent diagnosis or illness event, were able to reflect back on the experience during the phase 2 interview. One participant described

how she was now able to access information and reassurance regarding her husband's stroke and recovery that had not been available to her in the hospital setting including the knowledge that it was safe to engage in exercise:

So we got an awful lot of information the first day we came—where the stroke was—they said it was in the front part of his brain—we didn't know that from the hospital, you know. ... they said it was alright for him to do it (exercise), which was more—do you know we never got that from the hospital really—they never told us like from once he came home. (PP23FL).

Participants found that being able to communicate with programme staff helped them to understand and appraise information compared to reading information by themselves:

Because the books are great but then when you've somebody to talk you through it as well it's good. (P1FL)

Yes, I would, I'd find it easier alright now to kind of eliminate down and say well, yeah, now that is a thing that I really need to look into a bit more. (P5FL)

### 3.2. Increased Understanding of Risk and Protective Factors

There were reported changes and developments in terms of understanding and awareness, which also led to application, i.e., how information was used. This in turn was linked to developments in engagement with and management of illness and risk factors. This was particularly evident in relation to food and nutrition, managing blood pressure and cholesterol levels, exercise, medication and treatments plans. These findings are also linked to changes in functional health literacy whereby participants are increasing their ability to act on the communication of factual information on health risks [4,42].

#### 3.2.1. Food and Nutrition

Although managing diet is a crucial component of treatment plans for cardiovascular disease, participants had limited previous knowledge of how to correctly read and understand food labels. This was a key aspect of new learning for participants that they were then able to apply to their everyday lives:

Like checking out labels and food products and what's in some of the regular everyday foods that we just take for granted and don't even give a second thought to. Maybe sweet foods or not foods that you'd imagine would have sugars and fats and stuff in them. (P5FL)

They have it down as sodium or they have it down as something else and you're like, these are all the hidden things like. Then like the sugar, the way they have it under syrup or corn syrup or under; it can be under different names, just little things. (P1FL)

### 3.2.2. Medication Use and Managing Side Effects

Although many participants were on long-term medication/treatment plans (such as medications for cholesterol and blood pressure), they were able to acquire new learning in relation to their use of medications as well as improved understanding regarding side effects:

Just that there are different medications for the blood pressure and you don't have to stop at one; sometimes they combine two different things that you need, like two different tablets. (P1FL)

This participant also reflected on how her childhood experiences had influenced her view on medication use, which, although entrenched, had now shifted towards a prevention first approach:

Like I think because my own mam and dad, they were on loads of medication so as kids it was like medication would fix you and I think since here it's like why not prevent it before you get to the stage of medication ... (P1FL)

Participants in phase 1 had spoken about concerns regarding possible side effects of certain medications or treatment plans. They were now able to reflect on new learning regarding the possible side effects of different medications and how these could be managed. For others, this reinforced their opposition to certain medications:

I opted not to take (a statin) because I had read things about it... you know, I kind of feel I've gone from never taking anything to suddenly taking medication, you know... Yeah, I am always aware that I have responsibility but I will listen to research but I will also ask the question because I do, you know. (P8FL)

Well I started off with having high cholesterol and it was 7 this time last year and we had that conversation about statins and I wouldn't go on them and I went on my broccoli and my kale and it's down now to, presently, to 5.5 so I'm happy the way it's going. If I can keep bringing it down now it'll be great. (P12FL)

Others had seen positive changes in their medication regimens:

I'm off a lot of tablets I used to be on—a lot of my diabetic tablets that I was on have been more than halved. (P13MA)

So it's great that way and that way you can pass it on hopefully because I don't have to take my blood pressure tablets any more. (P1FL)

### 3.3. Changes in Interactions with HCP

Participants reported perceived changes in how they interacted with their GP. Participants identified increased confidence due to improved understanding of their conditions and/or having the reassurance of programme feedback to support them in their interactions with their GP. These findings reflect changes in the interactive or communicative level of health literacy whereby participants' motivation and self-confidence to act on information was increased. One participant reported that she felt better able to communicate with her GP because she now has more knowledge about health issues such as blood pressure:

Just like when we were talking about blood pressure I was like, I know how it is. ... Yeah, because I'd know more about it, I'd be able to say well this, that or the other. I'd be able to say no and isn't this that and he'd be like, yeah, I'd be more comfortable about it because then I'd know what I'm talking about. (P1FL)

Participants reported increased confidence in asking questions and felt that the credence of having attended a risk reduction programme supported their new found knowledge and helped in decision-making related to their treatment plans:

Probably because I'm not just dealing with my own GP, there are other influences and I can kind of, and other people that I've got contact with here and I suppose that can sort of say well this has been said and what do you think? That to me I think is important because you know sometimes you do feel you're at the mercy sometimes

of, you know, if you're just dealing with one person. .... I mean, that was the good thing of this, I kind of feel now I've got more than one area to pull on. (P8FL)

I suppose the reinforcement by the people here from what my GP was saying, you know, when you're dealing with one person I was able to kind of say to him 'can you leave me another month?' But they were very definite here, 'oh you actually need your medications increased.' So it was reinforced in two places. It was very definite, and I kind of knew they were right, you know. (P21FL)

Participants also commented on the contrast between the busy GP practice and the access to staff on the programme particularly for emotional support:

GPs are very busy, you know, you have so many things when you go in I feel of the medical type ... but really you are conscious that they are so busy and there is so many more waiting to come in, that, no, you know, I don't think it's a good place to sort out feelings. (P21FL)

Another participant acknowledged that her communication/interactions with GP were more relaxed as she was less anxious now regarding her health condition:

I was probably more relaxed this time than I would have been normally and I probably wouldn't, I probably allowed my GP to just get on with the job herself as opposed to interrogating the poor woman ... and at the same time, for example, I suppose I would have been less anxious in many ways; that would be an indication of me being more willing to trust that things are probably alright but no harm to check things out. (P2FA)

#### 3.4. Enhanced Psychological Insights

This theme refers to individuals' increased insight regarding personal control limits and opportunities and also encompassed the areas of self-efficacy, emotional issues and facilitators of motivation. Similar to the findings from interviews in phase one, this theme was important in terms of its impact on individuals' abilities to utilise their health literacy capacities to their fullest potential. Having the potential to fully engage with and use health information became more possible through gaining an increased understanding of their own situation. These findings also show that participants are becoming more empowered as they navigate illness and health management and are

increasingly using of critical health literacy skills in attempting to control aspects of personal and social health determinants.

#### 3.4.1. Perceptions of Control and Self-Efficacy

Participants were able to reflect on developments in terms of the control they felt over their situations. One participant reflected on earlier challenges:

Everything was kind of against me. I remember at one of the meetings now alright and what they kind of said to me well at least like, you're not in a great place but at least if you're doing something about it, you know, you should feel that bit better in yourself. You're trying to improve some of the situation anyway. (P5FL)

This participant also made the comparison to what she was then able to achieve:

Maybe with them telling you and explaining to you that I suppose every point you come down in something or every month you're doing something that it sort of helps you along the way. (P5FL)

Another participant reflected on the importance of developing a greater understanding of health issues and having the time or space to pay attention to them:

You see, I suppose for myself, you know, when you're busy, you're working you don't, I just didn't think about my health, you know. I'm realising because I've had a lot go on in the last while, if I want to live healthily and I suppose now too when I'm retired; I think when you're working sometimes you don't have so much control but now that I've retired I think my attitude has changed. (P8FL)

Another participant reflected on the role of stress and learning how to deal with it to have more control over health issues:

I let stress develop, it was like a cancer, it was eating away at me. So in the last few weeks I've started letting it go completely over my head, positive things have come out of it, you know. I'm totally relaxed, totally chilled out, which I wasn't, and maybe that's why my blood pressure was away, you know. (P13MA)

Some participants also demonstrated a more comprehensive understanding of their situations and the factors that determine their health:

I can control my amount of exercise and diet, certain things you can control, but there are certain things you can't in life. You know like your situation. Or if you wanted to go and live somewhere else, or live alone, or not having the stress of this that or the other, then there is some things you can't control, you know, financially and that kind of thing. (P21FL)

Developments in self-efficacy linked to exercise performance were also apparent. This was most evident for participants with mobility and illness concerns in phase 1. These participants felt reassured that exercise was both safe and possible:

I never was in a gym, I never used a gym before, or exercised with other people, or that kind of thing—I never realised how good you can feel after! I didn't know that! I feel a bit braver. It made me feel, you know, that I could do it, and it's nice to exercise. (P21FL)

I feel that I have enough information about my illness, my sickness, I wouldn't call it an illness either, but my health, that I feel I'm in safe hands. And if I reduced my chances of getting a stroke by 20 percent in 12 weeks, what can I do in another [12 weeks]? Like, they wanted to get my blood, my heartbeat up to a certain thing, and they've done that. (P20FA)

#### 3.4.2. Anxiety and Fears

While participants had previously referred to the impact of anxiety on dealing with illness, they were now able to reflect on how these fears had been assuaged.

One participant spoke about her fears following her husband's stroke and how this impacted her sense of control:

How do I put it? Like when the stroke came I didn't know what I knew anymore, or what, because he was such an unlikely candidate of getting a stroke. (PP23FL)

Participants also reflected on overcoming fears about illness:

So I just, I think I have a kind of a, I feel more confident that I'm not as bad as I thought I was, and that I know like that I can live a good life. I can look forward, I look forward now like to a better kind of a life for myself. (P20FA)

The symptoms that I presented with, were sort of symptoms that would be relevant to a mini stroke. And that sort of made me afraid. That if I take a long journey in the car or should, should I do this, should I do that, will I get more symptoms, will I get a stroke? That, it knocked my confidence. (P15FA)

This participant was now able to reflect with a more positive outlook, which she attributed to staff reassurance:

And they were all (saying) you know that might never happen again and your blood pressure is being monitored and your heart checks and cholesterol and diet ... it takes a while to readjust ... I'm smiling now and all that, but it did throw me ... But I've come out the other end now and I'm ok. (P15FA)

One participant with heart failure reflected on the fact that she was less fearful about taking part in activities:

And doing a bit more. But I'm not as nervous now about, say, taking off and doing more things by myself. Just up to the gym and keep doing it, and I knew that I could then, you know. (P21FL)

### 3.5. Understanding of Broader Determinants of Health

Participants demonstrated an increased ability to reflect on external factors that can impact on health. These were related to physical contexts, such as walkability issues and access to cycle lanes; health and public policies, e.g., in relation to childhood obesity, affordability of medicines; and legislation in relation to food labelling standards. These findings can also be related to changes in critical health literacy, as participants are critically analysing health information and using this in an attempt to exert greater control over personal and social health determinants [4,42].

#### 3.5.1. Physical Contexts

##### Walking—Access and Road Safety Issues

Similar to the phase one findings, rural-dwelling participants were most critical of the lack of safe places to walk:

Just somewhere for people to be able to go out walking that's safe, just a little footpath just for maybe three miles say and then everybody can go, because like it's there, it's safe. Women can bring their buggies, kids can go on bikes. (P1FL)

This participant went on to make a comparison between two different areas and the impact of having safe walkways:

So like there's loads of walkways and people are more motivated up there. You look out the window, every three seconds there's somebody walking by; always movement, people are running or cycling or something but back in our place all you see is cars. It's a different place ... It would be great for everywhere because I know, say cities have it all but out in the country there's really nothing. (P1FL)

Similarly, from another participant:

Paths would make lives better for people, a lot easier. So if you were walking with a child in a pram you just couldn't do it you know. And I mean an elderly person, my mother has one of those wheelers, she can't walk. Those little things would make life a lot easier you know. (P8FL)

Others, living in more urban areas appreciated access to scenic walkways and green spaces and not having to rely on a car:

But the effort of getting into a car and driving, you just won't do that, whereas where we are we don't have that excuse. We do not need to get into the car to go to somewhere specific to do exercise. (P4FA)

I actually love where I live, in that I'm beside a big green, I'm beside a big park, so I can walk, in five minutes from my house I can walk in a big field, and it's half a mile we'll say one way and the other, I can have a half mile to a mile walk. And that really is important to me. Or I can go down to a beach. And that is really a lifeline for me, being able to live where I'm living. So I think that really has an impact on your health, if you have somewhere nice to walk, I think, it's really important. (P21FL)

Cycling

Participants who regularly cycled commented on the lack of a completed cycling infrastructure, which impacted on safety:

Once you go outside the city area back on the country roads like I'd be nervous enough now cycling. It would make it safer. Because you are taking your life in your hands if you get up on a bike...the traffic is too busy. So from that point of view I would like to see something being done. (P16ML)

#### Food Culture/Food Manufacturing

A key learning in relation to food and nutrition was reading and understanding food labels, which led to reflection on broader issues such as the regulation of food labelling:

I think they'd want to get that system brought in for all food manufacturers. But there would be too much opposition from the ones who have the bad food. So there's a stalemate there. So it's up to the government to bring it in by law and that's the only way it can happen. If they bring it in by law then they're compelled to put that red label on and put their product, whether it's red, amber or green. (P3ML)

Another participant commented on the role of policy with regard to childhood obesity.

I would be very bothered about this new idea in the schools that they've a 'no running' policy now in 1 in 20 schools in the country. I think that's where it needs to start with the health. Now I know they do some of these sports things and that, but there should be an awful lot more. They're talking about having a sugar tax but then on the soft drinks and that but I think there should be a tax like cigarettes, you know, because it's ridiculous. (PP4FA)

#### Role of Government

One participant had taken part in a lobbying exercise to get the government to consider the provision of a medical card (free primary care access) for people with certain chronic diseases:

So I sent that in and wrote all my own views on it and the list of complaints that I have, all the heart problems I have, the liver and so on. And then the list of all the drugs I

have. In other words I pay the maximum of, it's over 1700 a year even with the allowance the government make, that's what it works out at. And I'm retired so you know I'd appreciate it if the government were to do that; give me a medical card for the drugs. So that's the one way I can appeal to the government. (P3ML)

Another commented on a lack of long-term health promotion planning at government level.

And the other thing is that they're putting in a whole load of wind farms, which is fine and I'm in favour of wind farms and alternative energy, but our carbon footprint would go way down if we actually cycled in the places that we can cycle. So I think there's very little joined-up thinking in terms of health promotion. (P2FA)

### Sharing Information

Some participants were actively sharing health information with extended family/friends and some were actively trying to change the health practices of others:

So there's little bits here and there, even just me in the class here; I'm passing it along because there's 13 of us so I'm passing it on to them and their wives and their kids. So there's a whole bundle of people out there that's getting the information as well. Even the booklets that I get here I pass them on there and they're all reading them. Some things they might change, some they mightn't. You know that they are trying themselves as well because like a few of us started doing a few changes and you see them doing it as well; even like there's a few of my brothers and they've given up salt altogether. (P1FL)

I do especially say to immediate family. I did, I spoke to my niece about it, I spoke to my sister. I'm very much a kind of pass it on, I think that's important. The more people who know, you know ... Passing it on, kind of giving people, say my sister, both sisters actually and also my sister's partner because he had a stent put in; I suppose I rang him then just this week and said are you aware that you really should have a blood test on a regular basis; well he was but he hadn't, so that kind of thing. (P8FL)

Participants recognised that dietary changes would also have a positive impact on other family members such as children and grandchildren.

I've a young lad there, he's seven, he comes in [saying,] 'Granddad, I'm starving.' I say, 'go to the fridge there and get something for yourself.' And he'll pick the fruit and he'll eat it, whereas if it wasn't there he'd be looking for Tayto (crisps) or something like that. (P16ML)

But there isn't as much around for them [grandchildren], there's no biscuits around or anything like that. Yeah. And I thought first that we'd try it—I thought it wouldn't last—but now it's nearly normal, do you know, that we don't have it. (PP23FL)

#### 4. Discussion

The overall aim of this study was to explore developments in the use of health literacy skills for individuals in the context of managing risk factors for CVD. The findings are consistent with an approach that goes beyond the functional aspects of health literacy to capture broader social contexts [43]. The findings have generated important insights into factors that support developments for health literacy capacities and indicate that individuals with varying levels of health literacy can engage with self-management. Findings support the development of health literacy capacities across the functional, interactive and critical health literacy domains and engagement with health knowledge that goes beyond personal health management to the social determinants of health [5,42].

Although many participants had been managing risk factors and/or conditions for some time, they found that it was possible to re-engage with information that was presented in a very practical and relevant format and tailored to them. In terms of managing lifestyle factors associated with illnesses such as diabetes, CVD and stroke, having an understanding of the importance of good nutrition and diet is crucial, as well as the ability to apply that information [44]. Participants learnt how to read and interpret food labels and were able to apply this information to their everyday lives. This allows for a greater sense of control over self-care behaviours and participants, therefore, experienced changes in how they perceived control and self-efficacy in relation to managing their risk factors. These findings indicate that participants are becoming more empowered and support the conceptualisation of health literacy as an instrument in the empowerment process [45]. Other studies [46] have examined specifically the role of self-efficacy and health literacy in improving health outcomes

and also advocate the need for self-management programmes to promote the development of self-efficacy. Numerous studies have postulated the links between self-efficacy, health literacy and self-care behaviours [8,47,48]. Work by Lee et al. [48] suggests that studies focusing only on the functional aspects of health literacy may not reflect the relevance of self-efficacy. Therefore, interventions need to also focus on the communicative and critical aspects of health literacy [7,48,49]. A recently developed health literacy communication training for healthcare professionals has also emphasised the inclusion of skills to enhance both interactive (shared decision-making) and critical health (enabling self-management) skills of healthcare providers [50]. Participants in this study described health literacy experiences that incorporate aspects of both communicative/interactive health literacy (i.e., the ability to extract meaning from different sources of information and share the information) and critical health literacy experiences (i.e., the ability to critically analyse information and apply it to decision-making process). Findings in the current study indicate that participants also experienced enhanced self-efficacy in managing their health regardless of their level of health literacy at the start of programme (i.e., whether adequate or limited). This is an important finding as it may indicate that persons with limited health literacy can engage well on structured programmes and develop their health literacy at all levels as a result.

Similar to findings from the Skilled for Health study [51], there was evidence that participants were actively ‘cascading’ or sharing their newly acquired information with their family and wider community. Edwards, Wood, Davies and Edwards, [52] in their study used the term health literacy mediators to describe individuals who passed on their health literacy skills. This is linked to distributed health literacy though in this instance it is about supporting others to become more health literate (rather than being supported).

Findings in relation to anxiety provide further support of findings from time point 1 [22], which highlighted the impact of illness-related anxiety and fears on the ability to fully utilise health literacy capacities. In the current study, participants reported how their concerns had been alleviated and they were thus able to engage with and utilise health information more effectively. This concurs with work by Dunn, Margaritis and Anderson [13], which emphasised the role of the HCP in the provision of social

support and reduction of anxiety for patients with CVD. Further, they also point out that patients are then in a better position to be able to take on board and have a better understanding of their condition. Morgan et al. [53] also stress the need for self-management support to include the broader contexts of an individual's life so that management is not constrained within a narrow disease control approach [53]. Findings in this study support a view of participants, not as a patients but as active participants in their own health management, and more akin to being 'citizens in relation to the health promotion efforts in the community, the work place, the educational system, the political arena and the market place' [5] (p. 13).

Participants in this study participated in a community-based risk reduction programme, which provided them with the opportunity to make comparisons between typical healthcare encounters and those at the programme. There were many positives associated with how information was imparted; the group effect ('collective efficacy' as described by Bandura [54]), the accessibility and approachability of the staff; the time of staff; emotional support; social support; motivation etc. All of these factors would seem to be conducive to promoting effective self-management [53]. The programme also offered the opportunity to become more familiar with medication regimens and treatment plans including being aware of when and why changes to these were made. Overall, participants noted positive developments in their interactions with HCPs. These were attributed to having increased knowledge and understanding of one's condition as well as a sense of increased confidence regarding communication with the HCP.

All participants reported having acquired increased understanding of issues relevant to their self-care. Findings indicated that participants had a new level of engagement with the issues as they often were exposed to a new perspective or information presented in a new way.

One of the most important findings was in relation to participants' understanding of medications and side effects. It was noteworthy that participants continued to question the use of statins and continued to favour lifestyle approaches (where benefits seen). This understanding can be attributed to a combination of knowledge acquired both through the programme and through their own information-seeking.

An important finding in the current study is the engagement of participants with broader issues that can impact on health and the contextualisation of health issues. In terms of health literacy this is a shift towards critical health literacy whereby individuals start to address the demands and complexities of their social contexts [12]. These findings compare favourably to those reported by Rowlands et al. [16] where social determinants, social activity and the local community were viewed to influence the translation of knowledge into health behaviours. Participants were able to reflect on how physical and structural factors can directly affect one's health and wellbeing. Participants' responses also indicated that they are capable of locating responsibility (for health) beyond the individual level [55] and are making sense of knowledge within their own 'social space' [43] within their own family and community environments. This indicates that developments in health literacy have moved beyond the acquisition of knowledge to also use health literacy capacities as a resource for engaging in health at the community level [43, 55]. The community-based programme offers the potential to develop critical health literacy and lends support to community-based programmes for the management of chronic illness. The potential to develop critical health literacy capacities is important. Beginning with having an increased insight into the limits and opportunities of one's personal control, it is evident that there is potential to develop this further as an important element of self-management. Future research could build on the value of the qualitative longitudinal approach and incorporate more of a participative methodology whereby individuals could map and elucidate the facilitators and barriers in the empowerment process as health issues are managed. It would also be useful to examine this approach with individuals outside of access to a structured programme so that comparisons between organisation/system demands on health literacy could be made.

#### 4.1. Strengths

A strength of the current study is the qualitative perspective, which allows for a more in-depth examination of the development of health literacy capacities from the perspective of individual study participants. The longitudinal aspect of this study also allows us to identify the types of factors that can contribute to the positive development of health literacy for individuals over time. It is also possible to see that developments occurred regardless of initial health literacy levels. It is important that

these developments are explored outside of the clinical encounter so that aspects of social and community contexts, where health and illness management and health promotion activities frequently occur, are also addressed.

#### 4.2. Limitations

The relatively small sample and the attrition of study participants from phase 1 to phase 2 is an important study limitation. Attrition is a frequently reported issue in longitudinal studies, which in the case of this study resulted mainly from the illness experiences of participants and limited programme engagement in a small number of cases.

Only preliminary analysis was possible between interviews at time one and the completion of time 2 interviews due to time constraints and resource limitations. However, the keeping of memos and field notes following all interviews assisted in the overall analysis process. This study is focussed on a specific population sample who attended a risk reduction programme. It is possible that some of the positive effects in relation to the development of health literacy capacities evident at the completion of phase 2 are due in part to the effects of programme participation. The fact that participants had just completed the 12-week programme is likely to have influenced their perceptions regarding positive outcomes.

#### 5. Conclusions

Study findings demonstrate that, overall, participants have become more empowered in managing their health and self-care. Developments in terms of perceived confidence and self-efficacy were apparent, which in turn impacted on positive relations with HCPs. Crucially participants have also demonstrated an increased ability to critically reflect on social and environmental issues that can support or impede their health opportunities. These findings support the idea that health literacy should be regarded as context and content specific and that critical health literacy can be achieved in the absence of high functional health literacy skills [56,57]. Findings also demonstrated that individuals have the capacity to acquire new insights and perspectives in managing health issues, even where the illness is not new. This can mitigate against resignation regarding long-term treatment plans and the promotion of their own health in a more active manner.

## Appendix A. Interview Guide

How would you describe your experience of taking part in the programme (a structured CVD risk reduction and health promotion course)?

Can you tell me about how you have been getting information about your health/health issues in general since we last met?

How has your understanding changed in relation to your own health situation/relation to health issues in general?

Have you learnt anything that makes it easier to make judgements on what information is useful and what is not? How have you done this?

Tell me about how you have used any information from the course? What has helped/hindered this process?

Can you tell me about your understanding of health and well-being issues in general?

If it were possible to make any changes in your own neighbourhood, what might you do to make it more health promoting for yourself/your community?

Can you tell me what changes you see or feel in yourself as a result of participating in the programme?

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**Author Contributions:** V.B.M. conceived the study design, collected and analysed the data, and wrote the paper. M.M.B. and J.S. also contributed to study design, data analysis, and review of the paper.

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## Appendix 3: Paper III

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### **Facilitators and barriers to the development of health literacy capacities over time for self-management**

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#### ABSTRACT

##### Background

Health literacy (HL) is a dynamic construct that is content and context specific. An understanding of the facilitators and barriers involved in the development of HL over time can provide important insights for health care providers (HCPs) in supporting patients with chronic illness.

##### Methods

This study used a longitudinal qualitative study design involving repeat interviews at three separate time points over a twelve-month period. A purposive sample of twenty-six participants attending a structured CVD risk reduction programme took part in the study, seventeen of whom completed all three interviews. The HLS-EU measure was used to determine HL levels at beginning and end of the twelve-month period. Employing a qualitative thematic analysis and longitudinal specific question frameworks, a trajectory approach was applied to explore individual cases longitudinally.

### Findings

Facilitators and barriers to HL capacity development were identified. Participants demonstrated increased perceptions of having control and being empowered over time. However, this was also found to be impacted by external life events. Study participants were also found to be embedding health knowledge, motivation and behaviours over time within the everyday contexts of their lives. The relationship with the HCP permeated all aspects of HL capacity development including aspects of treatment decision-making. Participants identified the need for psychological supports and the increased importance of looking after their mental health.

### Conclusion

Positive developments in HL capacities are important for the self-management of illness. Longitudinal findings underscore the importance of the HCP in supporting the development of HL capacities over time. These findings lend support to the need to integrate HL into medical and other HCP curricula to raise awareness of the concept of HL.

Keywords: Longitudinal; self-management; health literacy; Health care provider.

Plain language summary: Using a longitudinal qualitative study design, this study proposes that health literacy capacities develop over time and that the health care provider (HCP) plays a central role in this process. Findings from this study support the need to embed health literacy training into medical and other applied HCP curricula in order to raise awareness of the concept of health literacy

## **Facilitators and barriers to the development of health literacy capacities over time for self-management**

### **INTRODUCTION**

Health Literacy (HL) is content and context specific and concerns the capacities of people to meet the complex demands of health in modern society (Nutbeam, 2015; Sørensen et al., 2015). It is closely linked to the main tenets of health promotion whereby it is viewed as a personal and population asset for achieving greater autonomy and control over health decision-making (Nutbeam, 2015; Nutbeam,

McGill, & Premkumar, 2017). Health literacy is an important factor in the maintenance and improvement of health (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004) and is also considered to be a crucial component in the self-management of illness (Coulter & Ellins, 2007; Diane Levin-Zamir & Yitzhak Peterburg, 2001; Lloyd, Ammary, Epstein, Johnson, & Rhee, 2006; Sorensen et al., 2015).

Limited HL is an invisible barrier to healthcare delivery and a barrier to effective patient care (Magnani et al. 2018; Seurer & Vogt, 2013)). Research has consistently found that individuals with low HL experience poorer health outcomes across a wide range of areas and poorer use of health services. A systematic review by Berkman et al., (2011) identified this association for use of preventive services, self-management of illness such as adherence to medication, and increased admission to hospital and longer hospital stays. The Health Literacy Pathway model developed by Edwards, Wood, Davies and Edwards (2012) describes developments in HL for individuals but is overly focused on responding to ill-health rather than acknowledging social determinants of health and the role of health promotion (Guzys et al. 2015). An individual's HL is dependent on the relationship between individual capacities, the healthcare system and broader society and barriers to use of HL capacities include socioeconomic circumstances, social support as well as the nature of the healthcare setting (Jordan, Buchbinder & Osborne, 2010). People who have developed higher levels of HL will have skills and capabilities that enable them to engage in a range of health enhancing actions (IUHPE, 2018). Edwards et al. (2012) identified further barriers in the use of HL skills in terms of personal, emotional and health professional barriers.

Research has indicated that improving self-efficacy levels in patients can result in increased confidence in making health behaviour changes which is fundamental to self-management (Bodenheimer, 2002). Models describing self-management behaviours highlight the three patient attributes of knowledge, self-efficacy and beliefs, that combined, are important for effective self-management (Bodenheimer, 2002; Lawn & Schoo, 2010; Wingham, Harding, Britten & Dalal, 2014). These also correspond to the mediating factors identified by Paasche-Orlow and Wolf (2007) in their model of possible causal pathways between HL and health outcomes. A review on the impact of HL on self-management skills suggest a link between HL and self-management skills but calls for an increased emphasis on intervention studies to examine this further (Mackey, Doody, Werner & Fullen, 2016).

Self-management strategies can result in improved health outcomes for those with chronic diseases (Ruiz, Brady, Glasgow, Birkel & Spafford, 2014) and HL has been identified as a potential facilitator or barrier to improved health outcomes (Mackey et al., 2016). Low HL is associated with poorer self management skills (Nutbeam, 2008; Naik, Street, Castillo, & Abraham, 2011; Mbaezue, Mayberry, Gazmararian, Quarshie, Ivonye & Heisler, 2010). Health literacy is crucial to enable people to manage their health. Much of the self-management of chronic diseases is performed by individual patients outside of the medical or healthcare setting. Often this care is quite complex. Medication adherence frequently requires understanding complex scheduling and dosing details, as well as information

relating to dietary choices and timing and appropriate vigilance about symptoms and side-effects (Magnani et al, 2018, Boren, 2009).

Nutbeam's (2000) model of HL, involving functional, interactive and critical levels, can be applied to self-management (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015). HL is conceptualised in this model as involving skills at various levels, which have an ascending order of complexity and can gradually lead to greater personal autonomy and empowerment (Smith, Nutbeam, & McCaffery, 2013). A number of studies have indicated that interactive and critical HL are stronger predictors for successful self-management than functional HL (Heijmans et al., 2015; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013; van der Heide, Heijmans, Schuit, Uiters, & Rademakers, 2015) suggesting that more complex skills are involved.

Although there has been a recent proliferation in research studies in HL (Nutbeam, Levin-Zamir, & Rowlands, 2018), increased insight is needed into how the development of these complex skills can be facilitated. A qualitative longitudinal study design allows for an increased understanding of HL challenges experienced in the management of health and illness over a period of time and of the strategies individuals might use to address such challenges. This is an important consideration for health care providers, especially in relation to self-management programmes, in order to highlight specific areas where more supports may be necessary to facilitate the shift from functional to critical HL capacity development. Increasing rates of chronic illness worldwide will place increasing demands on health systems (Busse, Blümel., Scheller-Kreinsen, & Zentner, 2010). One way to ameliorate the effects of this is to engage patients in more effective self-management. (Heneghan et al 2009). Health Literacy is central to this approach (WHO, 2016). However, having an understanding of how HL developments can be supported is crucial. This is the focus of this study which offers the potential of identifying important levers and vulnerable points in the development of HL where more intensive supports may be needed. The study seeks to expand the understanding of how HL development can be supported through addressing the following research questions: Does HL develop over time in the context of prevention and health promotion interventions and what are the main barriers and facilitators to HL development?

This study employs a qualitative methodology incorporating the HLS-EU conceptual model to explore individuals' experiences. This is a recently developed comprehensive model of HL that emphasizes the capacities necessary to be considered health literate and to make decisions about health: access, understanding, appraisal and application, which can be linked to functional, interactive and critical levels of HL (Sørensen, et al. (2012).

## METHODS

### Study design

A longitudinal qualitative design (Table 1) was deemed most appropriate for this study, as the main aim was to generate rich data and an in-depth understanding of individuals' perspectives and experiences of HL capacities and how and why these might change over time (Corden & Millar, 2007). The number and frequency of serial interviews that compose a longitudinal study is dependent on how a given research problem is posed and so will vary from study to study. In terms of deciding on how much time should pass before successive interviews are conducted, the answer is the amount of time sufficient to examine relevant change from one point to another (Hermanowicz, 2013; Saldana, 2003). In this study the longitudinal element covered 12 months, which is an appropriate timeframe in longitudinal qualitative research (LQR) (Holland, Thomson & Henderson, 2006). The timeframe was also deemed apt to discern changes in HL capacities and dovetailed with the timeline of the risk reduction programme that participants were attending. Findings directly relevant to time points 1 (T1) and two (T2) have previously been published (McKenna, Sixsmith, & Barry, 2017, 2018). This paper presents the overall longitudinal findings for 17 participants from time 1 (T1) to time 3 (T3) and explores their development of HL capacities over a 12 month period. The aim of this study is to understand individuals' experiences over time in using HL capacities, including facilitators and barriers, to manage their health and illness. Specifically this study adopts a trajectory approach to describe how experiences change over time (Grossoehme & Lipstein, 2016).

Table 1: Overview of timeline, sample and methods for overall longitudinal qualitative study

<i>Time points</i>	Sample	Methods
T1: (Baseline: Beginning of programme)	26 Participants	HLS-EU <sup>1</sup> survey and interview completed
T2 (End of programme@ 12 weeks)	19 Participants	Interview completed
T3 (One year follow up @ 12 months)	17 Participants	HLS-EU survey and interview completed

<sup>1</sup> (HLS-EU Consortium, 2011)

## Participants

The sample frame for this study were individuals attending a community-based structured cardiovascular risk reduction programme. Purposeful sampling was used in order to identify individuals with a range of risk factors for cardiovascular disease, as well as those with established disease in order to obtain their views and experiences (Creswell, 2013). The programme was used as a 'vehicle' to engage individuals as they managed their health and illness over a 12-month period. Twenty-six individuals were interviewed at T1, nineteen at T2 and seventeen were interviewed at T3 due to attrition of seven participants over the duration of the study.

Initial recruitment took place in conjunction with the programme nurse, who identified individuals who were cognitively able to participate and had an understanding of the English language. Recruitment for T1 took place between February and December 2014 and the sample were followed up over a 12 month period with final T3 interviews taking place in January 2015.

### Profile of Study Participants

All of the participants (n=17) had completed a 12 week CVD risk reduction programme and were referred through various pathways including general practice and hospital departments such as cardiology, stroke, and endocrinology. Participant characteristics, including HL levels recorded at T1 and T3 are summarised in Table 2.

Table 2: Profile of study participants

<b>Participants (n)</b>		17
<b>Gender (n, %)</b>		
Male		7(41%)
Female		10 (59%)
<b>Age (mean, range)</b>		<b>59 (36-76)</b>
<b>Education: highest level attained to date (n, %)</b>		
Primary School (PS) level (Low)		2 (12%)
Incomplete PS (Low)		1 (6%)
Secondary-intermediate level (Low)		7 (41%)
Completed secondary(Medium)		2 (12%)
Diploma/certificate(Medium)		2 (12%)
Primary degree (High)		1 (6%)
Postgraduate/ higher degree (High)		2 (12%)
<b>Social class (n, %)<sup>2</sup></b>		
I (High)		1 (6%)
II (High)		5 (29%)
III (Medium)		0
IV (Medium)		1 (6%)
V (Low)		2 (12%)
VI (Low)		2 (12%)
VII(Low)		6(35%)
<b>General HL level from HLS-EU measure at T3 (n, %)</b>		

Limited	5 (29%)
Adequate	12 (71%)
<b><i>Health service access (n/%)</i></b>	
Private health insurance	8 (47%)
Medical card only <sup>3</sup>	4 (23%)
Private AND medical card	3 (18%)
Neither	2(12%)

<sup>2</sup>(Central Statistic Office, 2012)

<sup>3</sup> A medical card allows access to GP services, community health services, dental services, prescription medicines and hospital care free of charge under the General Medical Services Scheme for sub-groups of the population based on income levels/specific medical conditions(Department of Public Expenditure and Reform, 2016; Health Service Executive, 2017).

## Data collection procedures

### Interviews

Semi-structured interview guides were used to explore the development of HL and to identify changes in knowledge, attitudes and experiences over time. The development of the interview guide was informed by Sørensen's conceptual model of HL (Sørensen et al., 2012) in order to explore all the capacities associated with HL. Interview questions across time points 1-3 focussed on the areas of accessing, understanding, appraising and applying health information and transcript data were initially categorised within these areas. In addition, questions were also included to explore further issues that had been identified in T1 and T2 of the research (for example, concerns about upcoming treatment decisions). The interview schedule was piloted prior to commencement of data collection with a small number of individuals attending the structured programme. All interviews took place at the community-based programme building and were conducted by the first author (VMcK). Retention issues and attrition of participants is common in qualitative longitudinal studies (Hermanowicz, 2013; Murray et al., 2009). In this study attrition was attributed to a combination of issues including a limited

engagement with the risk-reduction programme and illness factors that prevented programme completion.

#### Data analysis

All interviews were audio recorded digitally, transcribed verbatim and analysed using thematic analysis (Braun & Clarke, 2006) which was facilitated through the use of N-Vivo version 10 qualitative software. Qualitative validation criteria were applied in this study in line with established guidelines (Creswell & Miller, 2000; Guba, 1981; Maxwell, 1992) as set out in Table 3 below.

Table 3: Validation Criteria

Validation criteria	Description
Credibility:	Participants' perspectives were reported as accurately as possible and the participants' own voices were used. Review and refinement of themes through a consensus process was undertaken among the three authors.
Triangulation:	Convergence was sought among multiple sources of information (interview transcripts, memos, relevant theory, and researchers' analysis) to verify interview data and to develop themes. A level of member checking was achieved where key issues and themes arising at T 1 were reviewed with the participants at the start of T 2 and T3 interviews.
Transferability:	Detailed accounts of the data and the context of data collection are provided.
Descriptive validity:	Multiple reading of the transcripts took place and recordings were listened to in line with the methodology of thematic analysis (Braun & Clarke, 2006).
Interpretive validity:	The study participants' voices were relied on as much as possible for interpretation of meaning alongside the meaning attributed by the researcher.
Theoretical validity	The findings were clearly set out within relevant theory in the field of HL.
Researcher reflexivity:	Preliminary analysis between time points allowed the researchers to reflect on personal assumptions related to HL and social contexts.

The study used a hybrid approach of inductive and deductive coding and theme development, employing a thematic analysis methodology as advocated by Braun and Clarke (2006). Longitudinal analysis included summarising and comparing the data both cross-sectionally and longitudinally

(Thomson & Holland, 2003). A matrix format (Grossoehme & Lipstein, 2016; Miles, Huberman, & Saldana, 2014) using Xcel (2013) was employed to facilitate the ordering and summarising of data for each participant across T1-T3. Trajectory analysis, which focuses on changes over time for an individual or small group of individuals, was used to meet the aim of the current study (Grossoehme & Lipstein, 2016). Sample matrices and an overview of the process are available in Appendix 1.

Aspects of Saldana's framework (Lewis, 2007; Saldaña, 2003; Saldaña, 2002) (Appendix 2) were used in order to ensure that the analysis captured the process of development and changes rather than presenting cross-sectional findings only (Calman, Brunton, & Molassiotis, 2013; Saldana, 2003). By linking back to the previous data set, it was also possible to determine what changes or developments had occurred in terms of HL capacities. Preliminary analysis took place between interviews at T1 and T2 and T2 and T3 to allow reflexivity on the part of the researcher (Carduff, Murray, & Kendall, 2015) as well as to focus on process and changes rather than on snapshots (Calman, Brunton & Molassiotis, 2013). This preliminary analysis allowed the researcher to identify key issues that could then be returned to for further exploration in subsequent interviews.

In this study data saturation was reached in terms of inductive thematic saturation (analysis focus) and data saturation (data collection focus) as outlined in models of saturation put forward by Saunders et al. (2017). In addition phases 3-5 of Braun and Clarke's (2006) methodology for thematic analysis (searching for, reviewing, defining and naming of themes) were applied, involving a process of checking for theme saturation to ensure that all data fit the themes and no new themes are identified.

#### Ethical considerations

The study was independently reviewed and approved by the Research Ethics Committee, National University of Ireland, Galway in May 2013. All participants were provided with written and oral details of study participation and provided with written informed consent to participate in the study. Emphasis was placed on the voluntary nature of study participation, with the removal of all identifiers and assurance that all information would be anonymised. Due to the nature of longitudinal research, consent should be viewed as a process rather than an initial act (France, Bendelow & Williams, 2000) In this study consent was requested from each individual at each time point. The Participant Information Sheet specifically set out that all participation was voluntary and that participants were free to opt out of the study at any point.

## RESULTS

Building on findings from T2 the overall longitudinal findings indicate that developments occurred across the different levels of HL (functional, interactive and critical). However, there was individual variations in these developments contingent on personal experiences and contexts.

Table 4: Themes together with sub-themes and categories

Theme	Sub-theme	Categories
Gaining control and becoming empowered	Psychological impacts of external events  Self-efficacy	Dealing with stress  Dealing with pain  Past negative healthcare experiences/delayed diagnosis  Ability and confidence to make lifestyle changes
	Looking after self	Need for psychological supports  Fears and anxieties  Dealing with grief
Embedding knowledge, health practices and motivation	Accessing and using information	Awareness of limitations  Knowledge on diet and exercise
	Environment	Urban/rural  Facilitator/Barrier to health promotion practices
	Food literacy (what shapes food choices)	Marketing  Food labels  Family/social aspects
Dynamics of relationship and Support of HCPS	Communication, rapport, trust and approachability	Positive/negative outcomes  Non paternalistic
Treatment decision-making	Managing and challenging side-effects  Decisions about treatment	Fears and misconceptions  Logistical and practical considerations

Four themes were identified from this longitudinal analysis and together with sub-themes and categories are presented in Table 5 below. Barriers and facilitators in the development of HL capacity were evident within all four themes and are described below. Quotation labels are numbered by participant (P) and also denote gender (M: Male; F: Female) and HL level at T3 (A: Adequate; L: Limited).

## **Gaining control and becoming empowered**

Analysis of data across T1 to T3 indicated that, overall, participants gained a greater sense of control over their health and illness over the 12 month time period which facilitated the development of HL capacities. However, the potential for gaining increased confidence and control could be impacted by the experience of adverse circumstances in terms of illness or other demands placed on the individual. External life events (such as taking on the care of older relatives) impacted psychologically on their ability to effectively use and develop their HL capacities and in this regard acted as a barrier.

### *Self-efficacy*

Many participants experienced positive growth in confidence associated with changes in health practices that were sustained over time. Being able to see real change, such as improved weight, contributed to self-efficacy and the understanding of personal ability to exert control over one's life circumstances and health issues

*I thought I never could [lose weight], I thought there was nothing I could do about it and yet there was. I think I'm more confident now in knowing that I can do things too, that if I wanted to change something I can. (P23L)*

### *Psychological impacts of external events*

Changes in life and health circumstances of the individuals themselves or of close family members impacted on their perceived control and confidence either positively or negatively. For some, external life events acted as barriers to their ability to engage with health issues.

*I don't feel I have any control at the moment. Sometimes I don't leave my mum's house until late in the night, I'm too tired. I suppose I'm emotionally drained, , so it's difficult. So that impacts on my life a lot. (P8L)*

Over the 12 month period, participants moved from focussing mainly on physical aspects of their health to identifying the importance of looking after their own mental health and linking its relevance to sustaining physical health and managing lifestyle plans. One participant identified the practical and emotional strains of caring for older family members, combined with upset over a daughter's recent emigration and linked these events to her engagement in comfort eating:

*I eat when I'm emotionally not in a good place. I'm always thinking "Oh God I shouldn't be doing this". ..and I'm mad with myself that I put on weight since October – that I didn't kind of pre-empt having all this additional kind of stress would cause me to eat more. (P8L)*

#### *Looking after self*

Over the 12 month period, developments were apparent in participants' abilities to reflect back on and re-evaluate events, including the role of stress and the impact of grief. One participant reflected on how ongoing stress had negatively affected him and the adverse effect it has on his blood pressure. He reflects on how this was intensified due to living on his own and being unemployed. However, his more recent engagement with employment has had a positive impact on his mental health:

*Because now I know, I suppose I went so far down and so deep that I didn't know what way to fight back. And now I'm gone to the stage that – I will never go back there again. (P13A)*

Having coped with illness in one self and others, participants start to see the importance of looking after themselves:

*Well in looking after myself, concentrating on what I want to do, and doing the exercises for me. Thinking about myself more, not worrying about my children or grandchildren, they're going to be fine. This is my time. (P15LA)*

#### *Need for psychological supports*

Together with an increased awareness of the significance of mental health, participants also spoke about the importance of, and need for, psychological supports at certain times during illness management. However, it was also acknowledged that this could be difficult to access in terms of costs and knowing how or where to access services. Participants recognised the importance of being able to talk through psychological aspects such as coping and fears and anxiety around health problems. There is now a realisation that mental health matters have to be addressed, and mental health looked after, in order to have the ability to take care of the physical aspects of health.

One participant described how she had felt when the support of the programme ended and reflected how GP appointments do not allow time for talking through emotional concerns:

*I think it was something I'd been holding in for, since I was diagnosed nearly. And it was good to actually have a heart to heart talk with somebody because doctors don't have any time really. I think I've had excellent care, I'm blessed with medical care. But the talking bit is missing (P21L)*

Coping with a new illness requires making adjustments, facing limitations and dealing with new challenges. New illness requires re-engagement with new information and new ways of using HL capacities but this can be obstructed by fears and anxieties. Empowerment and increased control

experienced over time could be diminished by the onset of a new illness due to the fears and anxieties when coping with a new situation.

One participant who had experienced serious illness since T2 reflects on the mental challenges after hospital discharge and adjusting to new limitations:

*I could see all the negative things really, and if I got a twinge, or as I said, if you coughed twice, you were thinking “oh God is this coming back again?” (P5L)*

### **Embedding knowledge, health practices and motivation**

It is clear that study participants have continued to embed health practices up to nine months after programme completion. Many of these practices centre on diet and exercise and there is an increased awareness of the importance of the combined effect of the two practices together in order to obtain the greatest benefits. Participants were also surprised at how manageable it was to make dietary changes seeing that it really required very small changes over a period of time and this impacted on self-efficacy and motivation. This engagement with health practices and knowledge facilitated the development of HL capacities over time including developments in motivation.

#### *Accessing and using information*

Participants continued to develop knowledge about health and illness issues over the duration of the study. In some instances apprehensiveness at T1 about concerns had been replaced with confidence in being able to access and understand new levels of knowledge over the 12 month period.

*Do you know because I knew more and I read more about it, I just flew through everything belonging to it, you know that kind of way. (PIA)*

In the case of a new onset of illness, participants had to navigate a different illness context using HL capacities. Participants indicated a confident approach to gaining information and assistance as needed. One participant had drawn on a number of different resources to access information for her oxygen treatment plan:

*If I saw anything now in a paper or a magazine, straight away I would read it and keep it. Even like about the oxygen because I knew nothing really about oxygen, or lacking in oxygen but I found the company that supplies the oxygen now, they would be very good. (P5L)*

However, some participants still struggled to fully access information and to understand all aspects of their condition:

*I'm still not clear on the type of cardiomyopathy I have and even the night I went to [out of hours doctor service], the doctor said 'so is it the genetic, something?' and I didn't know. I still don't know that. I haven't got a clear answer from [Dr] really or maybe he has and I haven't taken it in, because one thing I've learned is that when you're sick you cannot think. Or my memory went completely and my taking in of information was terrible. (P21L)*

#### *Environment*

Participants have sustained an awareness of the broader determinants of health, evident in the importance placed on the living environment, which can impact on health practices and health outcomes. Participants continued to reflect on their environments in terms of local community, living space and availability of facilities to engage in health pursuits (walking, swimming, gym). The environment and access to facilities also impacted on motivation to engage in health practices. Rural environments are seen, on the one hand as peaceful and a positive environment for raising children that contribute to a natural healthy way of life but also present challenges in terms of transport and facilities to engage with health practices. The availability of local facilities in more urban areas makes healthy pursuits more feasible.

*The environment – I've mentioned to you before what would make a big difference is paths on roads, now they are doing a whole major roadworks approaching the village, and there is talk that there'll be a cycle lane and a path – so that would be quite nice. (P8L)*

However, the experience of anti-social behaviour in an urban neighbourhood can impact on the ability to get out and can also negatively impact on mental health.

*And there's the little thugs as well. And the guards are always up and down to them. ...and all the damage is done, they're breaking trees and everything up there – throw stones at windows and doors. I'm telling you, you're a prisoner in your own house at night, because you can't go out, because they're hanging around the area like (P10L)*

#### *Food literacy*

Sustaining practices around diet go beyond an understanding of what type of foods one should buy and eat. Participants are now also identifying the relevance of cultural, social and family practices and how these can impact on food choices and being able to maintain healthier practices. For example, in cutting out sweet foods and baked goods, there were concerns around not having anything in for visitors. There was also recognition that the marketing and proliferation of very cheap offers on biscuits, confectionary etc. can make it difficult to stick to healthy eating plans:

*We don't have it around as much, we don't have the chocolate or crisps. Oh yeah and every*

*one of them [grandchildren] came into the house, they used to say 'it's not fun here anymore', even my daughters, there was no, when there was no biscuits for the tea and things like that, they all kind of got used to it (P23L).*

Family practices can also impact on food practices. One participant describes the challenges of adhering to low-cholesterol diet when sharing meals with family:

*Well, left to my own devices now, so when I'm on my own I will do whatever I have to do in the morning, and then I might have a salad at lunch time. But if my wife or my daughter or my son are in the house, lunch time could be anything, do you know, everyone is coming in at different times, and next thing there is soup and sandwiches, or different things being eaten like, and you participate. Like other people in the house don't have cholesterol problems, so they can get away with eating different things, you know. So from that point of view like I have to kind of cater for myself and that (P16L).*

Being able to read and understand food labels also impacts on food buying choices. There is also an increased awareness on how advertising can use language that is confusing to the consumer:

*The advertising, because you get these, all these ninety percent fat free and you say 'that's fantastic' but it's an outrageous amount of fat in a small little container of yoghurt or whatever. (P4A)*

### **Dynamics of relationship and support of HCPs**

The impact of the relationship with the HCP on development and use of HL capacities is evident in this study. Positive interactions facilitated engagement and development of HL capacities while more negative interactions could act as a barrier. These interactions are particularly important for accessing and appraising of health information. The HCP may facilitate or impede the process depending on the nature of the relationship and the quality of rapport, communication and support in that relationship. The General Medical Practitioner (GP) remains the main source and most trusted source of information for many and also plays an appraisal role where problems are discussed. However, negative experiences were also highlighted including concerns about missed and delayed diagnoses and difficulties in seeking referrals. Participants are generally reluctant to leave a GP and to seek out another practice. In some cases the overall perception of a good relationship with the GP supplants concerns about the service being provided.

#### *Communication, rapport, trust, approachability*

Positive HCP experiences centred on having a good rapport, clear communication and a non-paternalistic approach. One area of concern was difficulties in securing a referral.

One participant has identified a strategy of using the locum to get a referral as she feels her own GP is reluctant to make referrals:

*But sometimes I think he's not great at if you feel you want to be referred to someone – he doesn't do that so much. But what I've done –I discovered when the locum was in, so I went back to her. Immediately she wrote a referral letter. So that's my way. I'll deal with her. (P8L)*

Having a good rapport is of a paramount importance even where there are concerns that an illness was not diagnosed in a timely way:

*Like on the one hand – maybe the ovarian cancer thing I kind of think, why was it missed? on the other hand I have a good relationship with him, and I think that is important.. You know he kind of understands me after all these years (P8L)*

During the course of the study participants also engaged with HCPs on the structured programme. Participants reflected on the positive aspects of access to a multidisciplinary team, the approachability of staff as well as the encouragement and non-paternalistic approach offered. This was linked to enhancing motivation for the participants.

*I think between the whole lot, and the fact that we got the exercise, the dietician and the nurse and we got on so well with them. They seemed to be so interested in us that I felt that I didn't want to let them down either (P23L)*

### **Treatment decision-making**

Health literacy capacities are needed to engage with treatment decision-making and to make relevant decisions. Where access to relevant information or understanding is limited or conflicting information is provided, barriers to participation with treatment decision-making can occur.

#### *Managing and challenging side effects*

Participants were very knowledgeable about the side effects of medications they were taking and were engaged in seeking solutions to address the side effects. Different strategies were used for this which seemed to be impacted by the relationship and level of communication with the HCP. The majority sought advice from HCPs but some did not. Participants were proactive in raising issues regarding medication side effects with medical teams and requesting changes. As in previous interviews, some participants were concerned about the side effects associated with the use of medications to lower cholesterol. Some of these concerns were linked to media reports about cholesterol lowering drugs.

Conflicting advice regarding medication use is confusing and upsetting for patients. One participant had experienced severe dizziness on a certain drug. When he mentioned this to his HCP, it was agreed that this was a typical side effect from long term use and that another medication could be prescribed instead. However, another consultant told him to stay on the medication.

Sometimes fears about medication side effects were based on reading up on the side-effects rather than the actual experience of side effects. Being able to discuss concerns with Dr was found to be helpful.

*And I went back to say I want to get off of these because I don't like what I seen about the side effects. He said "look we'll try and cut down" because he said "if you go off them now straight away the pain might get worse (P10L).*

#### *Decisions about treatments*

For some participants fears about treatment and their understanding of what it entailed could impact on delays in seeking treatment. In some cases this was based on not having a clear understanding of what a treatment procedure actually involved. One participant had delayed taking up testing for sleep apnoea due to her concerns about what the treatment actually involved.

*I had this imagination in my head of what I'd seen on the television, of you being inside in a room all wired up and they're all sitting outside watching. It turned out like to be completely different. (P5L)*

## **DISCUSSION**

This study set out to examine developments in HL over time and to identify the facilitators and barriers in that process. Study findings support the conceptualisation of HL as an asset (Martensson & Hensing, 2012; Nutbeam, 2008, 2015; Pleasant & Kuruvilla, 2008). Developments across the three levels of HL (functional, interactive, critical) were also apparent, simultaneous with a progression in personal empowerment as advocated by Nutbeam (2015). Such progression is also contingent on an individual's self-efficacy, which was also evident in the current study. The study findings also showed that developments in interactive HL were apparent in interactions with HCPs together with the appraisal and discussion of medication side-effects and treatment options. The identification of environmental facilitators and barriers to health promotion and healthy living, as well as a shift towards a greater focus on addressing psychological issues, is indicative of critical HL (Chinn, 2011).

This study was underpinned by the HLS model empirically validated by Sorensen et al. (2012) whereby HL is recognised as a process involving the consecutive competencies of accessing, understanding, appraising and applying health information, which also links HL to its antecedents and consequences (Sørensen et al., 2012). According to the model, application of the competencies provide individuals with the abilities to take control over their health by overcoming personal, social, structural and environmental barriers to health. In this study participants were identifying barriers and moving towards addressing them such as the need for better walking facilities and the need to mind their mental health. Study findings also support the contention that HL is a dynamic construct and that the skills and competencies of HL develop over the life course as contextual demands change over time (Levin-Zamir, Leung, Dodson, & Rowlands, 2017; Sørensen et al., 2012). Findings from this study support many aspects of Sorensen's HL model. The core aspects of knowledge, motivation and competences are

central to the development of HL capacities over time. Our findings show that self-efficacy plays an important role in the use of HL capacities. In the main, participants experienced increased confidence and self-efficacy in being able to manage their health. The focus of the cardiovascular risk reduction programme contributed to an increased ability to access appropriate information as well as having a better understanding of that information. This is also linked to improvements in appraisal, as participants could question information and could discuss it with HCPS. The study findings have also highlighted the importance of both psychological and situational contexts that can impact on HL capacities and this also supports the Sorensen framework. While the model sets out empowerment as a possible outcome of HL, our findings suggest that empowerment as a process is also very important. Another important finding, which is not addressed in the Sorensen model, is the role of the HCPs in the process of developing HL capacities.

Our study findings show that the HCP played a central role in both access and appraisal of information and could facilitate or impede gaining new knowledge (such as through the referral process). The relationship with, and perceived support from, the HCP were also important and interactions with HCPs permeate all aspects of HI capacity development from accessing information through to support for use of health information. An important finding is the participants' reported willingness to remain with a GP even where there were concerns over the level of care and services provided. This is an important issue as GPs are generally the first point of access to HC service and play a key role in building patients' HL (Lausen et al., 2018). HL capacity developments may be impeded where an individual is reliant on a local health service provider they do not have confidence in or with whom they are not wholly comfortable.

At T1 many participants perceived having limited control/power across situations, which shifted towards having an increased sense of control as time went on. Although overall increases in confidence can be equated with self-efficacy and positive HL developments, developments can be stalled by the onset of illness, changed life circumstances and/or poor communication experiences with HCPS. The broader context of the everyday life experiences of participants impacted on their abilities to positively use HL capacities and to sustain motivation and health practices over time. There is a greater need for HCP to have increased insight into what is happening in people's lives and to be aware of particular vulnerable periods where additional supports may be required.

In particular HCPs, in the primary care setting, could be more sensitive to recognising when psychological supports might be needed and how they could be made available. HCPs are also well positioned to support patients to develop greater self-efficacy around their health related activities as this contributes to enhancing motivation and empowerment. This is particularly relevant for patients with low HL(Lausen et al., 2018).

Overall, participants strived to manage their health and illness, particularly in relation to sustaining health practices, and identified the need to also manage psychological and emotional issues to be

successful. This complements Lorig and Holman's (2003) definition of self-management, which includes the three components of medical, role and emotional management. Findings also compare favourably with challenges to self-management put forward by Vallis (2009) which comprise barriers that are individually-based (low skills, motivation, self-confidence, emotional distress); relationship-based (e.g., lack of social support) and environmentally-based (e.g., negative stimuli for healthy behaviour in society).

Interactive and critical HI are acknowledged to play an important role in the successful management of chronic illness (Heijmans et al., 2015). The broader definition of critical HL put forward by Sykes, Wills, Rowlands, & Popple, (2013) is relevant for the realities of daily management of health and illness highlighted in this study. This includes having the ability to appraise and analyse health information in a critical way and apply it to the context of their own lives (Sykes & Wills, 2018). This is evident in some of the issues raised in this study such as the questioning of food marketing practices and treatment and medication implications.

Participant experiences of interactions with the programme staff lend support to preferences for access to community-based, holistic and one-stop multidisciplinary service to assist in health and illness management. Promoting HL is a central strategy for improving self-management in health (Levin-Zamir & Y Peterburg, 2001). Building an explicit HL component into programmes that focus on reduction of risk factors for various chronic illness as well as the improvement of secondary prevention is recommended for the delivery and evaluation of such programmes (Magnani et al., 2018). This study highlighted individual variation in HL developments over time. It is crucial that HCPs are aware of the HL needs of service users in order to help foster positive developments in their HL. It would be particularly useful to focus on the development of critical HL competencies as advocated by Sykes and Wills, 2018.

### Strengths and limitations

A strength of the current study is the qualitative perspective, which allows for a more in-depth examination of the development of HL capacities from the perspective of individual study participants. The longitudinal qualitative study makes possible the identification of contextual and intervening conditions surrounding change (Saldaña, 2002). The longitudinal aspect of this study also allowed us to identify the types of factors that can contribute to the positive development of HL for individuals over time.

The relatively small sample and the attrition of study participants from T1 to time T3 is an important study limitation. It must be considered that those who left the study could have experienced additional barriers in terms of HL capacity development, that are not accounted for in the study findings. However,

from reviewing the data it is apparent that the experiences of the seventeen study participants are sufficiently diverse in terms of health, illness, socio-demographic profile and life experiences to provide a realistic account of experiences. This study is focussed on a specific population sample who attended a risk reduction programme. It is possible that some of the positive effects in relation to the development of HL capacities are due in part to the effects of programme participation. Ultimately, study participation relied on the voluntary participation of individuals and so it is possible that those individuals who were most engaged with health issues were more likely to take part.

## Conclusion

Positive developments in HL capacities are important for the self-management of health and illness. Longitudinal findings underscore the importance of the HCP in supporting the development of HL capacities over time. These findings lend support to the need to integrate HL into medical and other HCP curricula to raise awareness of the concept of HL and to enhance HCPs communication strategies for patients with different HL skills (Kaper et al., 2018; Lausen et al., 2018).

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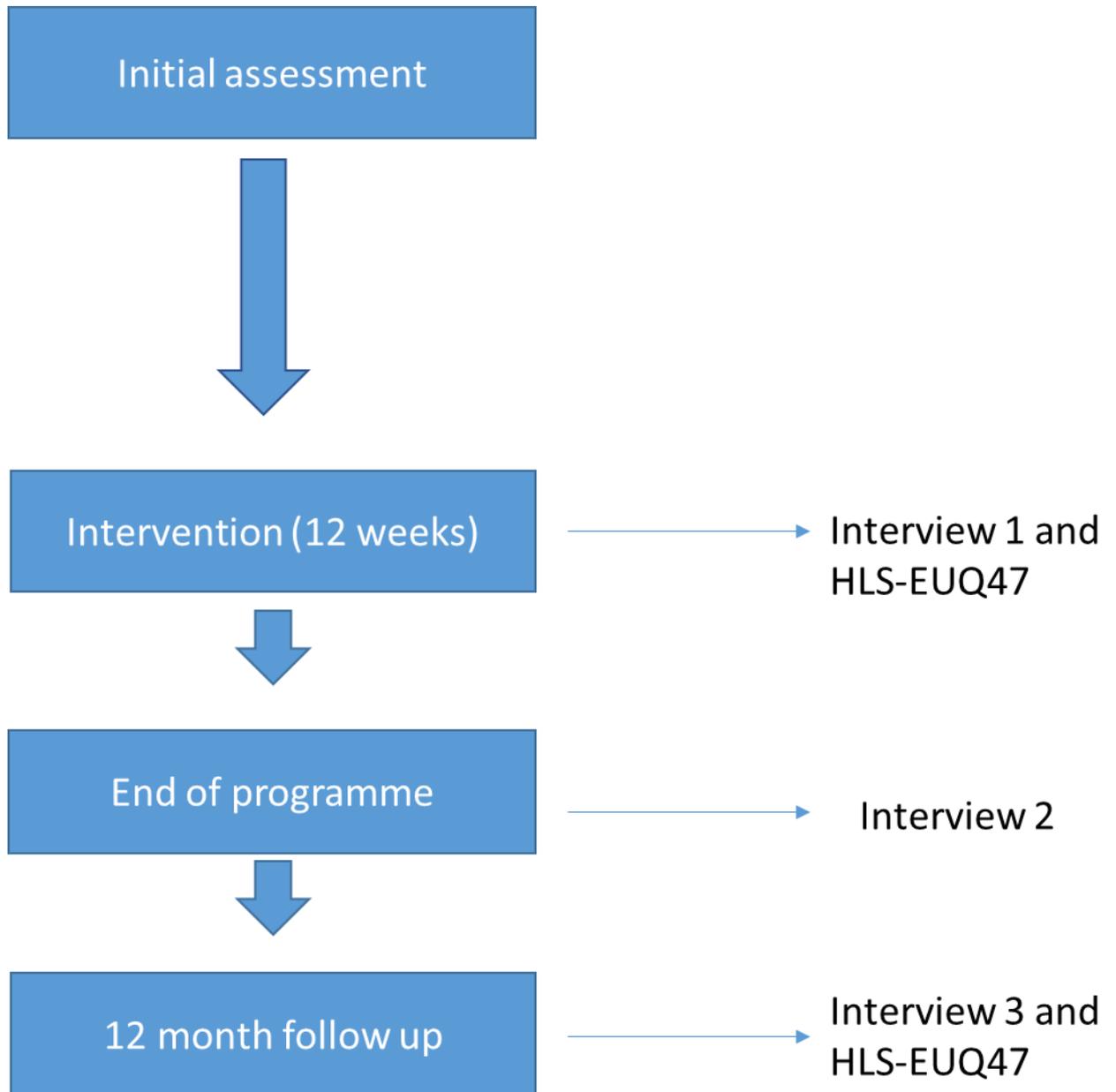
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Appendix 4: Overview of the risk reduction programme  
(Adapted from Gibson et al. 2014)



### Appendix 5: Attrition of study participants

Participant ID	Characteristics	Attrition time point	Comments
P6F	Female. Age:48  HL level: Limited	T2	Repeated attempts made to contact
PF9	Female. Age: 62 HL level: Adequate	T2	Did not continue with programme and did not wish to continue in study due to time constraints.
PF11	Female. Age.49 HL level: Limited	T2	Did not continue with programme and did not wish to continue in study due to time constraints.
PM14	Male. Age: 53  HL level: Adequate	T2	Did not continue with programme and did not wish to continue in study due to time constraints.
PF17	Female. Age: 75 HL level: Limited	T3	Repeated attempts made to contact.
PM18	Male. Age: 75 HL level: Limited	T3	Repeated attempts made to contact.
PF19	Female. Age: 67  HL level: Adequate	T2	Repeated attempts made to contact.
PM25	Male. Age: 60  HL level: Limited	T2	Did not continue due to illness.
PF26	Female. Age. HL level: Limited	T2	Did not continue due to illness.

## Appendix 6: Interview protocols

### Interview 1

Q1: Can you tell me about what has brought you to this programme?

Q2: Tell me about the kind of things that you do to keep yourself healthy?

Q3: How do you usually get information about *your* health or health issues in general?

Q4: How easy or difficult would you generally find it to understand any health information that you get?

Q5: Tell me about how you work out what information is useful for your own situation?

Q6: Tell me about the kind of things that you do with the health information you have obtained?

Q7: Can you think back to a visit, in the last 12 months or so, to your doctor (GP) or perhaps as an outpatient appointment at a hospital, how did you interact/communicate with your health care provider?

Q8: In general, tell me about whether you feel that you are in a position to easily make changes that you think could benefit your health.

Q9: Can you tell me a bit about your local community such as how involved you are in your local community?

Q10: What changes in yourself do you hope will result from this experience?  
(Programme participation)

## Interview 2

Q1: How would you describe your experience of taking part in the programme (a structured CVD risk reduction and health promotion course)?

Q2: Can you tell me about how you have been getting information about your health/health issues in general since we last met?

Q3: How has your understanding changed in relation to your own health situation/ relation to health issues in general?

Q4: Have you learnt anything that makes it easier to make judgements on what information is useful and what is not? How have you done this?

Q5: Tell me about how you have used any information from the course? What has helped/hindered this process?

Q6: Can you tell me about your understanding of health and well-being issues in general?

Q7: If it were possible to make any changes in your own neighbourhood, what might you do to make it more health promoting for yourself/your community?

Q8: Can you tell me what changes in yourself do you see or feel as a result of participating in the programme?

### Interview 3

Q1: Can you tell me about how you have been managing your health and wellbeing since you finished up the programme? (Over the past 12 months)

Q2: Can you tell me about how you have been getting information about your health and health issues in general in the previous 12 months?

Q3: How easy or difficult would you generally find it to understand any health information that you get?

Q4: Tell me about how you work out what information is useful for your own situation?

Q5: Tell me about the kind of things that you do with the health information you have obtained?

Q6: Can you tell me about any interactions with your health care provider (such as GP/hospital consultant/outpatient clinics) in the previous 12 months?

Q7: Can you tell me about any decision making you have been involved in with your health care provider (re treatment plans, medications, other procedures)

Q8: Thinking about your understanding of health and well-being issues in general-do you think that you have a good understanding of what impacts on your health/health in general?

Q9: Can you tell me about any changes in yourself since completing the course

Q10 In general, tell me about whether you feel that you are in a position to easily make changes that you think could benefit your health.

Q10: Tell me about how your community/neighbourhood is supportive of health

Q11: What kinds of changes in yourself do you see/feel in the past 12 months?

Appendix 7: HLS-EUQ47

**HLS-EU**

**Section A: Health Literacy Survey: Cure and Care**

**1. On a scale from very easy to very difficult, how easy would you say it is to...**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information about symptoms of illnesses that concern you	<input type="radio"/>				

**2. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information on treatments of illnesses that concern you	<input type="radio"/>				

**3. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find out what to do in case of a medical emergency	<input type="radio"/>				

**4. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find out where to get professional help when you are ill? (Instructions: such as doctor, pharmacist, psychologist)	<input type="radio"/>				

**5. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand what your doctor says to you?	<input type="radio"/>				

**6. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand the leaflets that come with your medicine?	<input type="radio"/>				

**7. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand what to do in a medical emergency?	<input type="radio"/>				

**8. On a scale from very easy to very difficult, how easy would you say it is to**

	Very easy	fairly easy	fairly difficult	very difficult	don't know
Understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?	<input type="radio"/>				

## HLS-EU

### 9. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge how information from your doctor applies to you?	<input type="radio"/>				

### 10. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge the advantages and disadvantages of different treatment options	<input type="radio"/>				

### 11. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge when you may need to get a second opinion from another doctor?	<input type="radio"/>				

### 12. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge if the information about illness in the media is reliable (Instructions: TV, Internet or other media).	<input type="radio"/>				

### 13. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Use information the doctor gives you to make decisions about your illness?	<input type="radio"/>				

### 14. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Follow the instructions on medication?	<input type="radio"/>				

### 15. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Call an ambulance in an emergency?	<input type="radio"/>				

### 16. On a scale from very easy to very difficult, how easy would you say it is to

	very easy	fairly easy	fairly difficult	very difficult	don't know
Follow instructions from your doctor or pharmacist?	<input type="radio"/>				

**Section B: Health Literacy Survey: Disease Prevention**

**17. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information about how to manage unhealthy behaviour such as smoking, low physical activity and drinking too much?	<input type="radio"/>				

**18. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information on how to manage mental health problems like stress or depression?	<input type="radio"/>				

**19. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information about vaccinations and health screenings that you should have? (Instructions: breast exam, blood sugar test, blood pressure).	<input type="radio"/>				

**20. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information on how to prevent or manage conditions like being overweight, high blood pressure or high cholesterol?	<input type="radio"/>				

**21. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand health warnings about behaviour such as smoking, low physical activity and drinking too much?	<input type="radio"/>				

**22. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand why you need vaccinations?	<input type="radio"/>				

## HLS-EU

### 23. On a scale from very easy to very difficult, how easy would you say it is to

very easy      fairly easy      fairly difficult      very difficult      don't know

Understand why you need health screenings?  
(Instructions: breast exam, blood sugar test, blood pressure)

### 24. On a scale from very easy to very difficult, how easy would you say it is to

very easy      fairly easy      fairly difficult      very difficult      don't know

Judge how reliable health warnings are, such a smoking, low physical activity and drinking too much?

### 25. On a scale from very easy to very difficult, how easy would you say it is to

very easy      fairly easy      fairly difficult      very difficult      don't know

Judge when you need to go to a doctor for a check-up?

### 26. On a scale from very easy to very difficult, how easy would you say it is to

very easy      fairly easy      fairly difficult      very difficult      don't know

Judge which vaccinations you may need?

### 27. On a scale from very easy to very difficult, how easy would you say it is to

very easy      fairly easy      fairly difficult      very difficult      don't know

Judge which health screenings you should have? (Instructions: breast exam, blood sugar test, blood pressure)

### 28. On a scale from very easy to very difficult, how easy would you say it is to?

very easy      fairly easy      fairly difficult      very difficult      don't know

Judge if the information on health risks in the media is reliable?  
(Instructions: TV, Internet or other media).

### 29. On a scale from very easy to very difficult, how easy would you say it is to?

very easy      fairly easy      fairly difficult      very difficult      don't know

Decide if you should have a flu vaccination?

### 30. On a scale from very easy to very difficult, how easy would you say it is to?

very easy      fairly easy      fairly difficult      very difficult      don't know

Decide how you can protect yourself from illness based on advice from family and friends?

### 31. On a scale from very easy to very difficult, how easy would you say it is to?

very easy      fairly easy      fairly difficult      very difficult      don't know

Decide how you can protect yourself from illness based on information in the media?  
(Instructions: Newspapers, leaflets, Internet or other media)

**Section C: Health Literacy Survey: Health Promotion**

**32. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information on healthy activities such as exercise, healthy food and nutrition?	<input type="radio"/>				

**33. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find out about activities that are good for your mental well-being? (Instructions: meditation, exercise, walking, pilates etc.)	<input type="radio"/>				

**34. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find information on how your neighbourhood could be more health-friendly? (Instructions: Reducing noise and pollution, creating green spaces, leisure facilities).	<input type="radio"/>				

**35. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find out about political changes that may affect health? (Instructions: legislation, new health screening programmes, changing of government, restructuring of health service)	<input type="radio"/>				

**36. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Find out about efforts to promote your health at work?	<input type="radio"/>				

**37. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand advice on health from family members or friends?	<input type="radio"/>				

## HLS-EU

**38. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand information on food packaging?	<input type="radio"/>				

**39. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand information in the media on how to get healthier? (Instructions:Internet, newspapers,magazines)	<input type="radio"/>				

**40. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Understand information on how to keep your mind healthy?	<input type="radio"/>				

**41. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge how where you live affects your health and well-being? (Instructions: Your community, your neighbourhood)	<input type="radio"/>				

**42. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge how your housing conditions help you to stay healthy ?	<input type="radio"/>				

**43. On a scale from very easy to very difficult, how easy would you say it is to**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Judge which everyday behaviour is related to your health? (Instructions:Drinking and eating habits, exercise etc.)	<input type="radio"/>				

**44. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Make decisions to improve your health?	<input type="radio"/>				

**45. On a scale from very easy to very difficult, how easy would you say it is to?**

	very easy	fairly easy	fairly difficult	very difficult	don't know
Join a sports club or exercise class if you want to?	<input type="radio"/>				

## HLS-EU

**46. On a scale from very easy to very difficult, how easy would you say it is to?**

very easy      fairly easy      fairly difficult      very difficult      don't know

Influence your living conditions that affect your health and wellbeing?  
(Instructions: Drinking and eating habits, exercise etc).

**47. On a scale from very easy to very difficult, how easy would you say it is to?**

very easy      fairly easy      fairly difficult      very difficult      don't know

Take part in activities that improve health and wellbeing in your community?

## HLS-EU

### Section D: Demographic information

**1. Are you**

- Male  
 Female

**2. What age are you?**

**3. What is the highest level of education that you have completed to date?**

- Some primary (not complete)  
 Primary or equivalent  
 Intermediate/Junior/Group Certificate or equivalent  
 Leaving certificate or equivalent  
 Diploma/certificate  
 Primary degree  
 Postgraduate/higher degree  
 Refusal

Other (please specify)

**4. What is your current marital status?**

- Single (never married)       Separated  
 Cohabiting       Divorced  
 Married       Widowed

**5. Which of these descriptions BEST describes your usual situation in regard to work?**

- Employee (incl. Apprenticeship or Community Employment)
- Self-employed outside farming
- Farmer
- Student full-time
- On state training scheme
- Unemployed, actively looking for a job
- Long term sickness or disability
- Home duties/looking after the home or family
- Retired

Other (please specify)

**6. Are you**

- Referred individual
- Partner/family member/friend

**7. If you are referred did you bring a partner**

- Yes
- No
- N/A (Not Applicable to you)

**8. In general would you say that your health is?**

- Excellent
- Very good
- Good
- Fair
- Poor

**9. Is your daily activity limited by a long term illness, health problem or disability?**

- Yes
- No

**10. Are you covered by a medical card?**

- Yes
- No

## HLS-EU

**11. Do you have private health insurance that covers the cost of private medical treatment (e.g. VHI, LAYA)**

- Yes  
 No  
 Refusal

**12. Regarding smoking cigarettes, cigars or a pipe, which of the following applies to you?**

- You smoke at the present time  
 You used to smoke but have quit  
 You never smoked

**13. In the last 30 days, how many times did you drink any alcoholic beverages?**

- Daily  
 4-5 times a week  
 2-3 times a week  
 Once a week  
 2-3 times a month  
 Once  
 N/A  
 Don't know  
 Refusal

**14. How often during the last month did you exercise for 30 minutes or longer e.g. running, walking, cycling?**

- Almost everyday  
 A few times a week  
 A few times this month  
 Not at all  
 I haven't been able to exercise  
 Refusal

**15. Are you actively involved in your community, e.g. do you volunteer/take part in activities?**

- Almost everyday  
 A few times a week  
 A few times a month  
 A few times a year  
 Not at all  
 Refusal

## Appendix 8: General and specific health literacy scales

and their respective items; minimum number of valid answers necessary for index calculation; minima and maxima of scale metric. (Adapted from HLS-EU Consortium, 2012)

Scale	General	Health Care	Disease Prevention	Health Promotion	Find Information	Understand Information	Evaluate Information	Apply Information
Q1.1	✓	✓			✓			
Q1.2	✓	✓			✓			
Q1.3	✓	✓			✓			
Q1.4	✓	✓			✓			
Q1.5	✓	✓				✓		
Q1.6	✓	✓				✓		
Q1.7	✓	✓				✓		
Q1.8	✓	✓				✓		
Q1.9	✓	✓					✓	
Q1.10	✓	✓					✓	
Q1.11	✓	✓					✓	
Q1.12	✓	✓					✓	
Q1.13	✓	✓						✓
Q1.14	✓	✓						✓

Q1.15	✓	✓			✓
Q1.16	✓	✓			✓
Q1.17	✓		✓	✓	
Q1.18	✓		✓	✓	
Q1.19	✓		✓	✓	
Q1.20	✓		✓	✓	
Q1.21	✓		✓		✓
Q1.22	✓		✓		✓
Q1.23	✓		✓		✓
Q1.24	✓		✓		✓
Q1.25	✓		✓		✓
Q1.26	✓		✓		✓
Q1.27	✓		✓		✓
Q1.28	✓		✓		✓
Q1.29	✓		✓		✓
Q1.30	✓		✓		✓
Q1.31	✓		✓		✓
Q1.32	✓			✓	✓
Q1.33	✓			✓	✓
Q1.34	✓			✓	✓

Q1.35	✓			✓	✓			
Q1.36	✓			✓	✓			
Q1.37	✓			✓			✓	
Q1.38	✓			✓			✓	
Q1.39	✓			✓			✓	
Q1.40	✓			✓			✓	
Q1.41	✓			✓				✓
Q1.42	✓			✓				✓
Q1.43	✓			✓				✓
Q1.44	✓			✓				✓
Q1.45	✓			✓				✓
Q1.46	✓			✓				✓
Q1.47	✓			✓				✓

Minimum number of valid answers for scale calculation

Item Number	43	15	14	14	12	10	11	11
-------------	----	----	----	----	----	----	----	----

Convenient metric of scales

Minimum	0	0	0	0	0	0	0	0
Maximum	50	50	50	50	50	50	50	50

To allow meaningful and convenient calculations with indices and for comparisons between sub-indices, all eight scales were set to a metric between 0 and 50, using the following formula:

$$Index = (mean - 1) * \left(\frac{50}{3}\right)$$

Where:

*Index*..... is the specific scale calculated

*mean*..... is the mean of all participating items for each Individual

*1* ..... is the minimal possible value of the mean (leads to a minimum Value of the Index of 0)

*3* ..... is the range of the mean

*50*..... is the chosen maximum value of the desired scale

## Appendix 9: Participant information sheet



### Participant Information

Please take time to read the following information carefully and discuss it with others if you wish. Please contact me if anything is not clear or if you would like more information.

**Title of the Study:** An investigation of the development of health literacy over time for persons attending a structured cardiovascular disease prevention and health promotion programme.

**Researcher:** My name is Verna McKenna. I am a University Teacher at NUI, Galway and am undertaking a part time PhD in the discipline of Health Promotion.

**Invitation to Participate:** You are being invited to take part in this research study which is to form part of my PhD thesis in Health Promotion. As a participant on the CROÍ MyAction programme I would like to describe and explore your experiences of gaining access to, understanding and evaluating health information. I would also like to explore how you then use this health information in your own life over a 12 month period. All of these aspects of interacting with health information are referred to as 'health literacy'.

**What is the study about?** The aim is to explore how participating in the MyAction programme influences your ability to manage your own health and your overall

understanding of your own health and its promotion. You will also have the opportunity to reflect on how you interact and communicate with other health care professionals (such as your GP) and to consider ways to improve this communication.

How was I chosen?

All participants who are attending the MyAction programme are being invited to participate.

What will taking part involve?

In week one of the MyAction programme you will be asked to complete a survey on how you find and use health information. In week 2 or 3 of the programme you will be asked to take part in an interview to explore these issues in more detail. A second interview will take place at the end of the programme (usually 12 weeks after you start). Finally a third interview will be arranged for the 12 month mark when you take part in a final assessment with CROÍ.

All interviews will take place in the CROÍ building, Moyola Lane Newcastle and will be recorded with your permission. All participants who take part in the interview process will be offered a voucher which can be redeemed against fitness classes at CROÍ.

With your consent the researcher will also collate the following data from Croí: your BMI and mean waist circumference, blood pressure, cholesterol, Mediterranean diet score and physical activity scores.

**What are the possible benefits of taking part?** It gives participants the opportunity to identify and explore how they understand and use health information in their

everyday health decision making. In particular participants will have the opportunity to describe how the MyAction programme might help participants to understand and manage risk factors for coronary heart disease and diabetes. Participants will also have the opportunity to reflect on how they interact and communicate with other health care professionals (such as the GP) and to consider ways to improve this communication.

**What are the possible disadvantages?** There are no foreseeable risks attached to taking part in this study.

**Ethical Considerations:** It is important to point out that anonymity and confidentiality is assured. Data collected will be anonymised, stored securely and accessed only by the researcher. The data will be stored for 5 years and then destroyed.

No individual will be identifiable. The comments of those interviewed will be referred to as ‘participant 1, participant 2 etc.’ in the final report.

Individuals who wish to participate in the interviews will be asked to complete and sign a consent form (attached) prior to commencing participation in the study. All participation is on a completely voluntary basis and individuals are free to withdraw at any time.

**What will happen at the end of this study?** A copy of my PhD thesis will be sent to the CROÍ organisation and also will be available through the James Hardiman Library, National University of Ireland, Galway. A summary of the results will be sent to all participants who indicate on the questionnaire that they wish to receive such a summary.

**Whom do I contact for more information or if I have any concerns?** Please contact me if you have any questions at all, at [verna.mckenna@nuigalway.ie](mailto:verna.mckenna@nuigalway.ie) or by telephone@ 091-493604

Thank you for taking the time to read this information.



Study Phase:

Participant Identification Number:

CONSENT FORM

Title of Project:

Researcher:

Please initial box

1. I confirm that I have read the information sheet dated-----

for the above named study and have had the opportunity to ask questions.

2. I am satisfied that I understand the information provided and have had enough time to consider the information

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights been affected.

4. I agree to take part in the above study

\_\_\_\_\_

Name of Participant

Date

Signature

\_\_\_\_\_

Name of Person taking consent

(If different from researcher)

Date

Signature

\_\_\_\_\_

Researcher

Date

Signature

## Appendix 10: Sample of data ordering for participant 1

THEME	Time 1	Time 2	Time 3
Accessing	<p>Actively seeks information [Active information seeking]  <i>I just print in migraines; I'm not very good at computers or stuff so I just print in whatever comes up and I just keep reading.</i>                      Uses internet gets sister to 'not a computer person'</p> <p>Uses books. Might look up conditions</p>	<p>Being able to access needed info (through the programme)</p> <p>Proactive in using books to find out information and encouraging family to do so                      Prog-one point of access for all information-consolidation of information</p>	<p>New situation-difficulties in trying to find out info. about treatment options for someone with a drinking problem and mental health difficulties</p>
	<p>Goes to Dr</p> <p>Ask people (at home) about conditions</p> <p>Has looked up diabetes on internet but 'not very good on computer'                      Felt left on own to find out more about diabetes (following pregnancy)                      Picking up bits here and there and hoping to find out more on programme                      Wants to confirm that Ges DB is gone and to avoid getting again (suggest limited info provided)</p>	<p>Can always contact the prog in the future also  <i>I thought it just kind of steered you on the right course of knowing stuff that you didn't know anything about.</i>  <i>And stuff that you didn't know anything about that you got more information about them and all that</i></p>	<p>Realisation that in order to take care of yourself and those around you have to have information</p> <p>Confident now to source books on health topics and does so for family members also</p>

*But just you want to find out what to do to avoid it and there's not that much [cannot find the level of info she wants re diabetes]  
I just keep looking up; if I'm on the internet looking for it I just type in diabetes and whatever question I have and it comes up*

Understanding

Difficulties acknowledged ('sometimes you haven't a clue'.)  
Difficulty understanding medical language; new lang. double Dutch  
Wants to understand more about diabetes (family history) and heart disease  
Read in books, asks others to aid understanding  
Pharmacist very good re understanding of taking meds and med interactions  
Wants to know more-father died at 56 due to diabetes complications-feels could have known more about it at the time  
Father had diabetes but did not know a lot about proper management

*Explain how heart attacks actually happen, what actually happens to the body, little things you can do to avoid  
You know all about heart attacks and all that but you don't know how it happens, you don't know what it is,  
what it affects, stroke, diabetes and high blood pressure [change in understanding]  
Changes in levels of knowledge and understanding  
Multiple method used to convey information, an integrated approach  
Confident to ask anything that was not understood  
Understanding of concepts is enabled/improved through use of analogies  
Food choices and nutrition  
Integrated team approach  
New learning also re BP meds and diff side effects; links BP and risk of stroke*

Reads info and will ask Dr then to explain it more. Feel she needs to hear it from someone to understand -easier than just reading about it.  
Examples of better understanding good/bad cholesterol and T1/2 Diabetes  
Importance of having knowledge to know what is happening.  
New understanding of possibilities of prevention and promotion  
Refers to as '*going before it*' [meaning prevention]

*Keeping fit I think, keeping fit and healthy eating and just knowing and going before it. we'll say do you know like when you gain weight you have more chance of heart attack,*

*diabetes, they're saying cancers now, so basically you know try to lose weight.*

Terms Drs in hosp use can be difficult to u/s.  
Have to go looking up the diff words

Changes in understanding med use and self-management  
Now have a fuller understanding of health issues. Better u/s of 'whole lot together' (eating/exercise)

It's like trying to learn a new language



Appraising	Will bring info. to HCP to discuss	Being able to relate to health information is important	Increased awareness re healthy food led to increased appraisal of food items. Challenge of trying to appraise conflicting information e.g. use of low
	Asking the doctor about Just picking up bits here and there and hoping to find out more Will look up what she feels is wrong with here but when checks with Dr-it is not same thing Have requested and received hospital notes but has not been able to go through	Asking questions of prog staff  Using books and internet Being able to talk it through with person who breaks it down for you Written info complemented with verbal information	fat (with artificial sweeteners) vs full fat  Different practitioners offer differ information  Appraising info relating sweeteners to illness



Applying	Difficulties: Hard to find out what to do to avoid getting diabetes  No follow on info from Dr It's good to know because then when you know it you can do something about it you know there's help there Sometimes you can read too much into the thing because sometimes all the symptoms are kind of the same.	Feels now has info that she and family can use re diabetes/heart disease prevention. Being able to relate to health information is important  Sharing info with wider family circle  Dietary changes for self and family	Uses information all the time. Uses exercise. Applies food knowledge.
----------	--	---	--

	Want to know more about DB and CVD to take care of self and family.	Applying to everyday life	
Psy factors	<p>The appraisal process can cause worry Control-wants to know and understand the condition and to know what she can do about it. Wants to find it out herself</p> <p>More motivated with a group Control- she feels that she is better of finding out info and then just doing it. Not in control when don't have info that is needed</p>	<p>Improved motivation and attitude to exercise. Motivated to engage in preventive health behaviours such as exercise</p> <p>increased awareness re identification of mental blocks to exercising Has experienced mental health and positive moods associated with exercise</p> <p>Recognises barriers to motivation Changes in how she deals with stress</p> <p>Greater u/s of the negative effects of stress and its role as major RF Increased positive mood <i>Yeah I think I was just starting to do it first and I was like oh, but then as soon as I started; it's very addictive once you start it. I walk seven kilometres now daily and it's great.</i></p>	<i>Physically I've lost weight, my confidence grew because I think I lost weight, I got more happier</i>
Structural factors	<p>Rural-harder to sick with stuff and to be more active Have to drive everywhere</p> <p>Less choice re shopping</p>	<p>More walkways would make application of exercise easier for walk/bikes/buggies Comparison with other areas U/S importance off safe environments to make walking etc. possible</p>	New baby means can be more difficult to exercise on regular basis.

Little community participation/activity in area where she lives

City v rural

More effort needed to find out what is available re health related classes etc. in own areas

Questioning how can existing facilities be used? Facilities that are not currently in use.

New areas-making comparison re environments; Higher visibility of people exercising.

Reflected back on previous birth experience and compares it to more recent

Communication  
HCP

Don't really talk to DR about diabetes concerns. Just went for check-ups (despite worries)

There was no follow on thing-how to avoid getting diabetes

Will ask Drs questions-will spend ages asking Qs and DR is good at giving info then

Uses Dr to appraise info she has looked up on internet, books

So, GP used to appraise other medical info if I haven't a clue what he's on about, I'll sit there and listen and just nod. And then I'll ask a few questions but then if it's still not sinking in that's when I have to kind of find out more about it. So, the next time I go back I'll know what he's on about and maybe

Would be confident to take new info to GP

I'd know more about.

She describes knowing to ask more qs.  
Reflected on increased confidence to ask questions

He's explaining it the best he can, it's just that I'm prop not picking it up [onus on patient not Dr to check u/s).

Asking QS to get the whole story and then will try to find out more by self.

## Appendix 11: Code definition and coding samples

Node Properties

**General**

Name: Relationship with health care provider

Description: Participant describes how s/he interacts with health care providers

Nickname:

Hierarchical name: Nodes\Final paper1 themes\Relationship with health care provider

Aggregate coding from child nodes

Color: None

Created On: 05/10/2016 09:48 By: VMCK

Modified On: 28/01/2015 10:21 By: VMCK

OK Cancel

[<Internals\Baseline Interviews\PP15JG>](#) - 5 2 references coded [1.99% Coverage]

Reference 1 - 1.30% Coverage

Oh it's easy to talk to them, yea. And I've a good GP like, and he'll refer me in, and I'll meet up with the doctor and ask all the questions you want

Reference 5 - 1.74% Coverage

Well we do talk but sometimes I do feel that maybe it's kind of like, you know, what would you know, this is my area. Not that that's ever said but it's the impression maybe given. And a lot of the time maybe I don't; I'm not a confrontational person so I wouldn't, I wouldn't like to kind of rock the boat. And it's funny because I'm not afraid to speak out but I just know sometimes when you're dealing, maybe somebody with a reputation for being a bit short, not with me but with others.

The image shows a 'Node Properties' dialog box with a 'General' tab. The fields are as follows:

Name	Side effects of medication use
Description	Participant refers to experinces of side effects and how they death with these
Nickname	
Hierarchical name	Nodes\\Round1Categories\\Side effects of medication use
<input type="checkbox"/> Aggregate coding from child nodes	Color: None
Created On: 30/11/2016 09:41	By: VMCK
Modified On: 20/11/2019 13:32	By: VMCK

Buttons: OK, Cancel

Reference 3 - 0.89% Coverage

Oh yeah, I took one there a while back and Jesus I was tired for two days after it. I said these are not for me. I thought I'll go to bed and wake up refreshed, no way. I was still groggy all day and the next day. I said this is, no more of them for me like.

<Internals\Baseline Interviews\PR10EC> - 5 5 references coded [8.92% Coverage]

Reference 1 - 0.46% Coverage

They wanted me to, my doctor and in hospital they wanted me to go statins and I wouldn't.

Reference 2 - 0.58% Coverage

Because I'm afraid that, you know, you take a tablet to cure what's wrong with you but it affects something else

Reference 3 - 1.25% Coverage

I'd be afraid like, I mean all my blood tests that I get taken they're fine, they're perfect and if I were to go taking statins well who knows what'd happen. I might get liver failure or kidney failure or something, just to curing cholesterol.

The screenshot shows a 'Node Properties' dialog box with the following fields and values:

- Name:** Perceptions of control
- Description:** Participant describes feeling of control and confidence in relation to managing health. Impacts of this on level of how proactive re access/understand/appraise/using health inforamtion
- Nickname:** (empty)
- Hierarchical name:** Nodes\Round1Categories\Perceptions of control
- Aggregate coding from child nodes:**
- Color:** None
- Created On:** 30/11/2016 10:15
- By:** VMCK
- Modified On:** 30/11/2016 10:21
- By:** VMCK

Buttons: OK, Cancel

Reference 2 - 1.22% Coverage

I mean I'm fortunate enough that if I want eat healthily and, chicken and fish, I can afford it which is a good thing. If I wasn't able to afford it I might be, you know, saying I have to eat such a thing but I'm fortunate that I can control.

[<Internals\Baseline Interviews\PRO1SK>](#) - 5 3 references coded [2.85% Coverage]

Reference 1 - 0.81% Coverage

It's good to know because then when you know it you can do something about it, you know there's help there and all that.

Reference 2 - 0.63% Coverage

Yeah, I like to know what's up whether I do something about it or not at least I know myself.

## Appendix 12: Ethics approval letter



30<sup>th</sup> June 2013

Dear Ms McKenna

Ref: 13/May/16 An investigation of the development of health literacy over time for persons attending a structured cardiovascular disease prevention and health promotion programme

I write to you regarding the above proposal which was submitted for Ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted **APPROVAL**.

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 30<sup>th</sup> January 2014. Please see section 7 of the REC's Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours Sincerely

Allyn Fives

Chair, Research Ethics Committee