

Sláintecare

Healthy Communities Health Literacy Report

**School of Health and Human
Performance, Dublin City University¹
Insight Centre for Data Analytics,
Dublin City University²**

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Maeve Murray^{1,2}, Craig Smith¹, Stephen Behan^{1,2}, Hannah Goss¹



Éire Shláintiúil
Rialtas Áitiúil
Healthy Ireland
Local Government



Dublin City Council
Comhairle Cathrach Bhaile Átha Cliath



Rialtas na hÉireann
Government of Ireland



Comhairle Contae Mhaigh Eo
Mayo County Council

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Executive Summary

Understanding health literacy: Health literacy is the ability to access, understand, appraise, and apply health-related information to make informed health decisions and maintain good health throughout life. It plays a critical role in enabling individuals to navigate the healthcare system, engage with healthcare providers, manage their health, and prevent diseases. Despite the importance of health literacy, our report finds that a significant proportion of the Irish population faces challenges in this area, which can lead to poorer health outcomes and increased healthcare costs.

Key findings:

- **Prevalence of Low Health Literacy:** Around 40% of adults in Ireland have limited health literacy. This limitation impacts their ability to effectively manage personal health and interact with healthcare services.
- **Consequences of Low Health Literacy:** Individuals with lower health literacy levels are less likely to engage in preventive healthcare measures and are more likely to require emergency medical interventions, resulting in higher healthcare expenditures and poorer health outcomes.

Key findings (based on research found in Ireland for this report):

- **Contextual Understanding of Health Literacy:** A broader focus across different domains should be established in Ireland to promote understanding and interest in the concept.
- **Emphasis on Education and Continued Development:** At a community level, actions are needed to promote and develop health literacy across the lifecycle. Prevention of low levels of health literacy is advocated for through some established settings, but sustainable approaches are needed. This includes expanding a focus towards youth in different settings.
- **Working in Partnership with Communities in Developing Shared Solutions:** Building health literacy responsive health systems that understand and reflect community needs and distinct characteristics is crucial.

Impact of health literacy interventions:

Our research strongly supports the implementation of health literacy actions and interventions, which can lead to significant benefits.

- **Enhanced Personal Health Management:** Improving health literacy helps individuals better understand health information and guidelines. This can support healthier lifestyle choices and can improve ability to manage chronic conditions.
- **Organisational Health Literacy:** Internationally, there is a shift in focus to building the health literacy responsiveness of health organisations. A systems approach to health literacy is needed to create enabling environments that optimise equitable access to and engagement with health information and services.
- **Reduced Healthcare Costs:** By promoting preventive care and improving the management of ongoing health conditions, higher health literacy can decrease the reliance on emergency care services and reduce overall healthcare costs.
- **Community Empowerment:** Effective health literacy programmes empower communities, particularly in underserved or vulnerable areas, by equipping individuals with the knowledge and skills needed to improve their health and wellbeing.

Recommendations based on report findings:

- **Co-Develop Targeted Health Literacy Actions:** Co-Design, implement and monitor programmes tailored to address the specific health literacy needs of diverse community groups.
- **Integrate Health Literacy into Existing Policies, Programmes and Practices:** Encourage individuals and organisations to communicate clearly and effectively, ensuring that all individuals can understand their health and their choices.
- **Support and Expand Community Health Initiatives:** Increase investment in community-based initiatives that focus on elevating health literacy, particularly in the communities of greatest need.
- **Measuring Health Literacy:** A shared understanding of the concept will enable national and locally relevant strategies for surveillance, evaluation and impact assessment to be developed, ideally with a long term focus. This ongoing monitoring will meet evolving health literacy strengths, needs and challenges.

Conclusion

Improving health literacy across Ireland is not merely a healthcare concern, but a social imperative that can lead to better health outcomes, more effective utilisation of the healthcare service, and a healthier nation overall. By adopting these recommendations, stakeholders across various sectors can contribute to building a more health-literate society.

Glossary

Action research	Used to bring about improvement or practical change. A group of people who know about a problem work together to develop an idea about how it might be resolved. They then go and test this idea. The people who take part in the testing provide feedback on their experiences. They may also identify further actions that need to be researched and tested. This cycle of developing solutions and testing them is repeated until the problem has been solved.
Carer	A relative, friend or partner who provides, intends to provide, or used to provide a substantial amount of care to another person on a regular basis, but not necessarily through living with them.
Case study	A study reporting observation on a specific area.
Co-design	This is the active and meaningful engagement and participation of relevant stakeholders (e.g. people with lived experiences, community members, health workers and other professionals, managers, policy makers) throughout the process of designing healthcare services and health promotion activities, drawing on their experiences and in-practice wisdom.
Community	A specific group of people, often living in a defined geographical area, who share a common culture, values and norms, are arranged in a social structure according to relationships which the community has developed over a period of time. Members of a community gain their personal and social identity by sharing common beliefs, values and norms which have been developed by the community in the past and may be modified in the future. They exhibit some awareness of their identity as a group and share common needs and a commitment to meeting them.
Confidentiality	During a research project, the researchers must put data protection measures in place, to ensure that all of the information collected about the participants is kept confidential. This means that the researchers must get the participants' written permission to take part.
Convenience sample	A group of individuals being studied because they are conveniently accessible in some way. This could make them particularly unrepresentative, as they are not a random sample of the whole population.
Data	The information collected through research. It can include written information, numbers, sounds and pictures. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, e.g. in reports, graphs or diagrams.
Determinants of health	The range of personal, social, economic and environmental factors that determine the healthy life expectancy of individuals and populations.
Eligibility criteria	A set of requirements or characteristics that people must have in order to join a research study. These include inclusion criteria and exclusion criteria. For example, a study might only accept participants who live in a particular community.
Ethics	Moral principles that guide researchers. Research ethics are a set of principles that are designed to govern behaviour to protect the safety, dignity, rights and wellbeing of the people taking part.
Focus groups	Small, roundtable discussion groups responsible for looking at and talking about specific topics or problems.

Health	A state of complete physical, social and mental wellbeing, and not merely the absence of disease or infirmity.
Health advocacy	A combination of individual and social actions designed to gain political commitment, policy support, social acceptance and systems support for a particular health goal or programme.
Health behaviour	Any activity undertaken by an individual for the purpose of promoting, protecting, maintaining or regaining health, whether or not such behaviour is objectively effective towards that end.
Health communication	The use of communication strategies (e.g. interpersonal, digital and other media) to inform and influence decisions and actions to improve health.
Health development	The process of continuous, progressive improvement of the <i>health status</i> of individuals and groups in a population.
Health education	Any combination of learning experiences designed to help individuals and communities improve their health by increasing knowledge, influencing motivation and improving health literacy.
Health equity	The absence of unfair, avoidable or remediable differences in health status among population groups defined socially, economically, demographically or geographically.
Health literacy	<p>Entails people's 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 lifecourse.</p> <p>Health literacy represents the personal knowledge and competencies that accumulate through daily activities, social interactions and across generations. Personal knowledge and competencies are mediated by the organisational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and wellbeing for themselves and those around them.</p>
Health literacy responsiveness	The extent to which health workers, services, systems, organisations and policy-makers (across government sectors and through cross-sectoral public policies) recognise and accommodate diverse traditions and health literacy strengths, needs and preferences to create enabling environments that optimise equitable access to and engagement with health information and services, and support for the health and wellbeing of individuals, families, groups and communities.
Health outcome	A change in the health status of an individual, group or population that is attributable to a planned intervention or series of interventions, regardless of whether such an intervention was intended to change health status.
Health policy	Refers to decisions, plans, and actions that are undertaken to achieve specific health care goals within a society.
Health promotion	The process of enabling people to increase control over, and to improve their health.
Infrastructure for health promotion	Those human and material resources, organisational and administrative structures, policies, regulations and incentives that facilitate an organised health promotion response to public health issues and challenges.
Lay summary	A lay summary is a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included.

Lifecourse	A culturally defined sequence of stages that people typically pass through as they progress from birth to death. Health across the lifespan reflects a complex interplay of biological, behavioural, psychological, and social protective and risk factors that contribute to health outcomes across the span of a person's life.
Methodology	The approach of how the research study will and should proceed.
Participant	Someone who takes part in a study.
Primary health care	An overall approach to the organisation of health systems which encompasses the three aspects of: multisectoral policy and action to address the broader determinants of health; empowering individuals, families and communities; and meeting people's essential health needs throughout their lives.
Public health	Organised activity of society to promote, protect, improve, and – when necessary – restore the health of individuals, specified groups, or the entire population. It is a combination of sciences, skills and values that function through collective societal activities and involve programmes, services and institutions aimed at protecting and improving the health of all people.
Published research	Research that has been peer reviewed and published in a research journal.
Research	<p>Involves finding out new knowledge and finding out whether something works, it is about studying facts, reasons, and purpose, asking the right questions and looking for the answers (the outcomes).</p> <p>“the attempt to derive generalisable or transferable new knowledge to answer or refine relevant questions with scientifically sound methods” – UK Research Governance Policy Framework.</p>
Researcher(s)	The people who conduct research. They may do research for a living, and be based in a university, hospital or other institution, and/or they may be a service user or carer.
Research methods	Research methods are the ways researchers collect and analyse information. Research methods include interviews, questionnaires, diaries, clinical trials, experiments, analysing documents or statistics, and watching people's behaviour.
Service user	Someone who uses or has used health and/or social care services.
Service provider	Someone who uses or has used health and/or social care services.
Sláintecare Healthy Communities	A cross-government initiative to deliver increased health and wellbeing services to 19 community areas across Ireland.
Umbrella review	A review of reviews where there is synthesised evidence from other published reviews.
Wellbeing	A positive state experienced by individuals and societies. Similar to health, it is a resource for daily life and is determined by social, economic and environmental conditions.

Abbreviations

CBPR	Community Based Participatory Research
DDDA	Double Diamond Design Approach
DEIS	Delivering Equality of Opportunities in Schools
ECOSOC	Economic and Social Council for United Nations
ETB	Education Training Board
EU	European Union
HLS-EU	European Health Literacy Survey
ICA	Irish Countrywomen's Association
NALA	National Adult Literacy Agency
NCD	Noncommunicable Diseases
PICQ	Psychosis Information and Confidence Questionnaire
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
REALM	Rapid Estimate of Adult Literacy in Medicine
RTA	Reflexive Thematic Analysis
WHO	World Health Organisation

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Section 1:

Introduction

1.1 Background

Internationally, there has been growing interest in the concept of health literacy across multiple health domains. Enhancing health literacy is crucial, not only for individual wellbeing, but also for bolstering public health and ensuring the long-term sustainability of healthcare systems (Liu *et al.*, 2020). Health literacy is concerned with the capacities of people to meet the complex demands of health in a modern society (Kickbusch, 2008). The World Health Organisation (WHO) has recognised health literacy as a critical, modifiable risk factor for health (WHO, Shanghai Declaration: 2016). Health literacy is central to preventing and controlling noncommunicable diseases (NCDs). Health literacy supports people, communities, and organisations in addressing NCDs and their determinants, taking meaningful action to reduce risk factors, and support health and wellbeing for all. Addressing the issue of low health literacy has the potential to increase health, health equity and health system effectiveness through building citizens' capacities for health (Rowlands *et al.*, 2018). In line with this, in 2022, the WHO published "Health literacy development for the prevention and control of noncommunicable diseases" which aimed to support countries and partners build health literacy responsive environments and interventions across countries, sectors and stakeholders (WHO, 2022).

The Sláintecare Healthy Communities Programme, which was launched in 2021 by Sláintecare Healthy Ireland in the Department of Health, working with the Health Service Executive and local authorities and community agencies, focuses specifically on promoting health and wellbeing at the community level. This involves initiatives aimed at preventive healthcare, health promotion, and addressing the social determinants of health. Local Authorities have employed Local Development Officers and have been

provided funding to improve public realm and fund locally identified projects to improve health and wellbeing. The Department of Health are working across Government with the Sláintecare Oversight Group to coordinate interventions and policy responses. This involves initiatives aimed at preventive healthcare, health promotion, and addressing the social determinants of health. As a result, health literacy is a key area of focus for the Sláintecare Healthy Communities Programme.

The Health Literacy Research Report, one of the first documents to bring health literacy into the national health discourse in Ireland, was published in 2002 by the National Adult Literacy Agency (NALA, 2002). The report presented actions for research, budget, local networks, accessibility and training. Despite these recommendations, results from the 2012 European Health Literacy Survey found 4 in 10 Irish adults to have limited health literacy in the last EU Health Literacy Survey (Sørensen *et al.*, 2015). Notably, this survey has not been repeated since 2011, but remains the most comprehensive evaluation of health literacy levels. Whilst there have been some inroads to addressing health literacy in Ireland, and internationally, in recent years, it is clear more can be done to have a meaningful and sustainable impact at an individual and systemic level in Ireland.

The aim of this report was to present national and international understandings of health literacy, as well as in depth explorations of the health literacy related strengths, issues and needs of two designated Sláintecare Healthy Community areas.

1.2 Project Methods

The key tasks of this project were to:

1. A review of the literature exploring existing strengths, barriers and needs to health literacy in Ireland.
2. Carry out an assessment of key stakeholder organisations and individuals involved in health literacy focussing in two case study areas: i) Finglas and Cabra, and ii) Mayo.
3. Work with Dublin City Council and Mayo County Council, and Sláintecare Healthy Communities, to support a meaningful consultation process with relevant stakeholders.

To meet the requirements of the project, studies was broken into specific work packages and parts as outlined below (see Figure 1.1 below). This work includes reviews of existing research and practice, but also the exploration of lived experiences of members of the public in two case study areas. Ethical Approval for work packages that required data collection was granted by Dublin City University (DCUREC/2023/156).

This report is developed through sections that explore areas outlined above. For the purpose of this report, and where appropriate, sections conclude with a summary evidence and a recommendations table to support reflections and considerations for the reader. Evidence and recommendations have also been mapped to the WHO Health Literacy Recommend action area (WHO, 2022) for each summary table in each section.

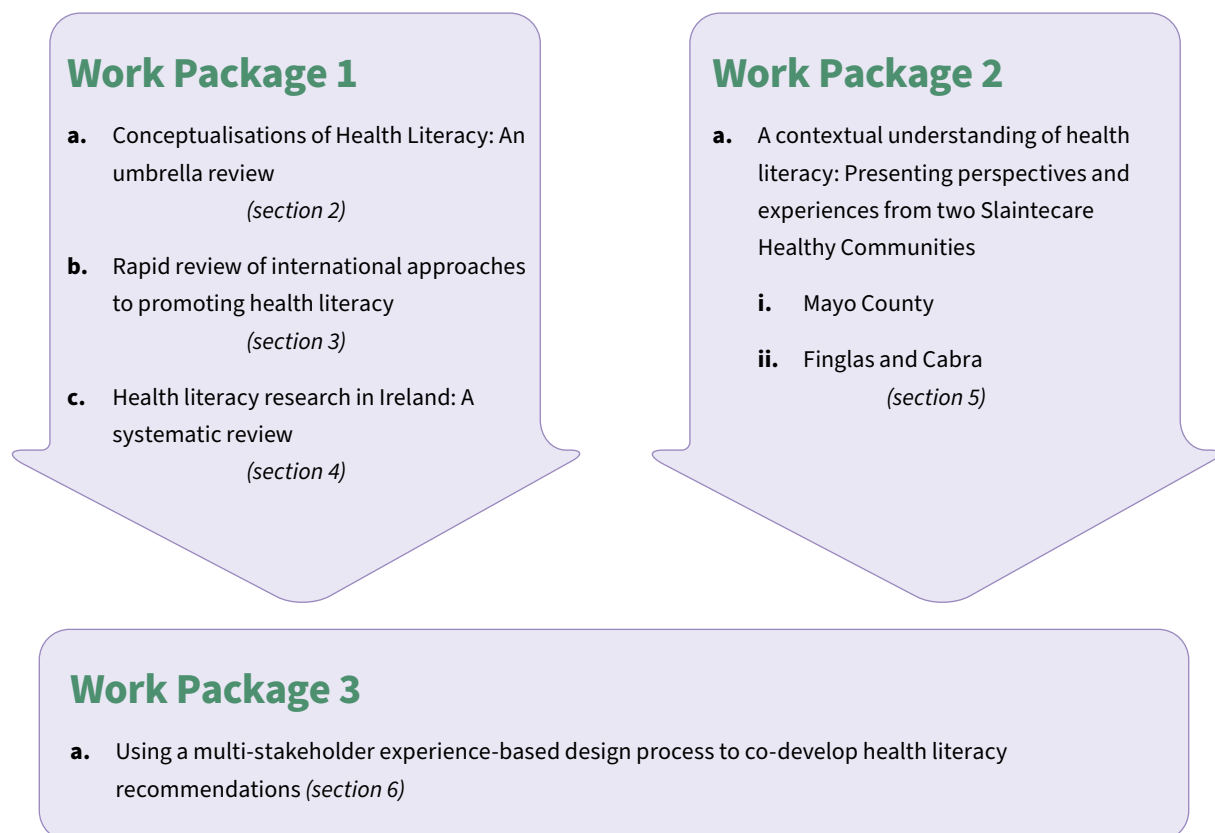


Figure 1. 1 Overview of Work Packages

What is Health Literacy?

It is generally accepted that the term health literacy was first used in the 1970s, and by 2006, researchers recognised that there was a huge variation in definitions, understandings and applications of the concept globally (Baker, 2006). As with any broad and emerging field, arriving at a consensus on the definition of the term health literacy is challenging. The definition proposed by Sørensen *et al.*, (2012) is perhaps the most broadly accepted internationally:

“Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the lifecourse” (Sorenson et al., 2012, p3)

In practice however, it’s arguably not the most widely used definition. The lack of clarity surrounding what the concept actually is, has the potential to undermine and stall the operationalisation of health literacy. Defining the concept has historically been a significant focus of the research field, with numerous papers, definitions and systematic reviews presented (see Section 2). Advocates for the concept have been critical of some widely used definitions that are based on the assertion that individual capacity to comprehend and apply health-related information for beneficial health outcomes. Suggesting that in fact, recent empirical research does not provide evidence of these claims (Liu et al., 2020). This suggests that the issue of shared clarity regarding what health literacy represents, has been compounded in recent years as the understanding of the concept has developed from an individual perspective, to a growing focus on systems level health literacy. That is, historically, health literacy has been positioned as an individual capability, but more frequently, health literacy is now being viewed as a collective responsibility.

With this in mind, for meaningful operationalisation of health literacy in policy and practice, there needs to be an understanding of what health literacy is at its core. Throughout academic literature, policy and practice there

are many domains commonly associated with health literacy. Nutbeam (2000) categorised these different skills as functional, communicative/interactive, and critical health literacy levels, and more recently, Nutbeam describes health literacy efforts as still ‘work in progress’ (p.g 903, 2018).

A 2022 Lancet editorial attributed the lack in meaningful progress to limitations to a blinkered view of individualistic health literacy, which fails to recognise that the health of communities is often dictated by social and environmental factors outside the control of individuals, and as numerous health interventions continue to overlook certain segments of the population (Lancet, 2022). A contemporary, transparent, and transferable understanding of health literacy is needed. Understanding what health literacy is, is crucial to develop effective, meaningful and sustainable ways in improving health literacy from an individual to a systems level. A shared understanding encourages a cross-sector, coordinated approach to promotion, implementation and development of health literacy. Amongst other things, this will allow us to develop relevant and appropriate strategies for monitoring health literacy, determine correlates of health literacy, implement interventions to improve health literacy, and crucially share and develop best practice in these areas. As a result, work is needed to transparently outline the contemporary understanding of health literacy, with a view to actionable change.

Section 2:

Conceptualisations of health literacy: An umbrella review

2.1 Introduction

In Ireland, health literacy has been developed sporadically, with limited strategic direction, in a range of sectors, perhaps as a result of the lack of an agreed position or consensus around the construct. Internationally however, there have been numerous studies, including several systematic reviews, that have sought to define and conceptualise health literacy.

The aim of this research is to conduct an umbrella review of international approaches to operationalising health literacy, as well as to identify established definitions and health literacy dimensions to inform the development of health literacy promotion in Ireland.

The aim of this umbrella review was to answer the following research questions:

1. How is health literacy currently defined and operationalised internationally?
2. What are the key dimensions of health literacy?

2.2 Methods

This umbrella review was registered a priori with PROSPERO (ID: CRD42024535025) and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) umbrella review methodological guidelines (Aromataris *et al.*, 2015).

Given the existence of multiple studies which have previously aimed to define, conceptualise, or review definitions and conceptualisations of health literacy, instead of reviewing primary papers, an umbrella review

(Aromataris *et al.*, 2015), also known as a systematic review of reviews (Smith *et al.*, 2011), was conducted. This review aimed to answer two research questions 1) How is health literacy defined internationally within the literature? 2) What are the key dimensions of health literacy according to the literature? Umbrella reviews, which integrate the findings of previously conducted reviews on the same or similar topic, are a relatively new form of evidence synthesis. The comparison and contrasting of findings of review studies allows for the evaluation of the consistency of research findings, the compilation of greater volumes of evidence and the discovery of insights adding value beyond restating previous findings (Hasanpoor *et al.*, 2019). This type of review is particularly useful when multiple reviews already exist on a topic (as is the case within this topic area), yet there is still a lack of a consensus around a specific issue. Implementing an umbrella review in this instance, allows for the comparison and contrasting of health literacy definitions and conceptualisation in order to develop a greater understanding of the concept and to identify the most common health literacy dimensions. Although the systematic review by Sørensen *et al.*, (2012) reviewed definitions and conceptual models of health literacy and identified specific dimensions of health literacy, it is 12 years since this research was published with numerous systematic reviews being conducted since. Given health literacy is such a fast-growing and ever evolving concept, this review will aim to provide a comprehensive and contemporary understanding of the concept that can inform the development of future health interventions and policies.

2.1.1 Search Strategy

Three electronic databases were searched—PubMed, Web of Science and Scopus—to identify relevant evidence. ‘English’ and ‘peer reviewed’ filters were marked on all searches. The search strategy was developed using Boolean operators (AND/OR), incorporating the relevant terms (Appendix 1 <https://bit.ly/ReportAppendices>). Specifically, 17 keywords (definition, model, concept, dimension, framework, conceptual framework, theory, analysis, qualitative, quantitative, competence, skill, “public health”, communication, information, functional, critical) were combined (using the Boolean operator and) with the search terms “health literacy”. The search was limited to publications after 2012 (post the seminal publication of Sorenson *et al.*, 2012). The search strategy and choice of databases were also informed by Sørensen *et al.*, (2012). Decisions regarding the search strategy were also made in consideration of feasibility given the wider project’s timeline. The search itself was conducted between July and August 2023. All records were exported to Covidence managing software for screening and all duplicates were removed. Two reviewers independently assessed the eligibility of the studies. Following title and abstract screening, full-text copies of potentially relevant studies were obtained and screened for full-text inclusion. In the case of disagreement, a third author was contacted for discussion until consensus was reached.

2.1.2 Study Selection Criteria

The final review only included systematic review studies that (i) assigned primary focus to the definition of health literacy in the main body of the article, (ii) were published in an academic journal, (iii) were written in English language and (vi) were published after 2012. We formulated no restrictions for the target population of the review.

2.1.3 Analysis and Synthesis of Results

The methods adopted to analyse and synthesise the findings of this review were built on the work of Sørensen *et al.*, (2012) and followed a similar process to that of Bröder *et al.*, (2019). Specifically, all studies included within the review were qualitatively assessed and synthesised using a deductive content analysis (see Figure 2.1). Firstly, eligible studies were screened for common definitions and conceptualisations of health literacy. Following this, a deductive analysis of the dimensions of each definition and/or conceptualisation of health literacy identified within this study was carried out using the six clusters of health literacy and the individual dimensions previously identified by Sørensen *et al.*, (2012). These broader clusters of health literacy developed by Sørensen *et al.*, (2012) included (1) competence, skills, abilities; (2) actions; (3) information and resources; (4) objective; (5) context; and (6) time, with each individual cluster containing a range of individual dimensions relating to health literacy (see Appendix 1 <https://bit.ly/ReportAppendices>). Therefore, the dimensions of health literacy, which were included within the definitions and/or conceptualisation identified within the studies reviewed as part of this study, were mapped to the clusters and individual dimensions previously developed by Sørensen *et al.*, (2012). Additional dimensions, which were not previously identified by Sørensen *et al.*, (2012), but were contained within the definitions and/or conceptualisations of health literacy reviewed within this study, were added to the relevant wider cluster yielded by Sørensen *et al.*, (2012). Similar dimensions (or synonyms of dimensions) were then grouped together within the cluster. See Figure 2.1 for a breakdown of this process. In the case of disagreement of whether a new dimension was, a third author was contacted for discussion regarding which clusters a specific dimension until consensus was reached.

The aim of the deductive content analysis was to develop a comprehensive map of health literacy dimensions, each aligning to a specific cluster previously identified by Sørensen *et al.*, (2012). For a full breakdown of each cluster and the accompanying dimensions for each included study, please see Appendix 1(<https://bit.ly/ReportAppendices>).

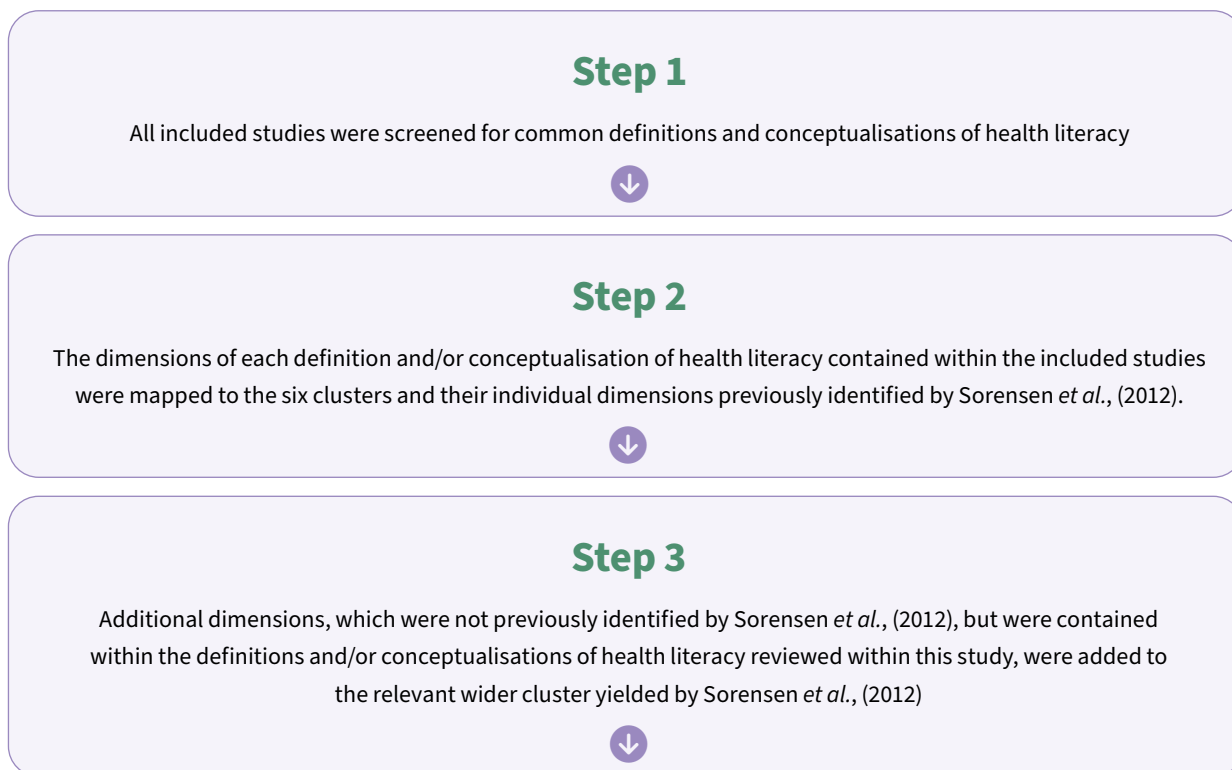


Figure 2. 1 The process of the deductive content analysis

2.2 Results

Figure 2.2 details the search and screening process. The literature search yielded 1291 publications; after removing 507 duplicates, 784 publications were subsequently screened. Of these publications, 757 were excluded based on title and abstract because they did not fulfil one or more of the inclusion criteria. The remaining 27 publications were retrieved for full-text review. A total of 18 failed to meet the inclusion criteria, leaving nine remaining studies. The main reasons for excluding full texts were that health literacy was not defined within the publication and the study outcomes irrelevant to the research question.

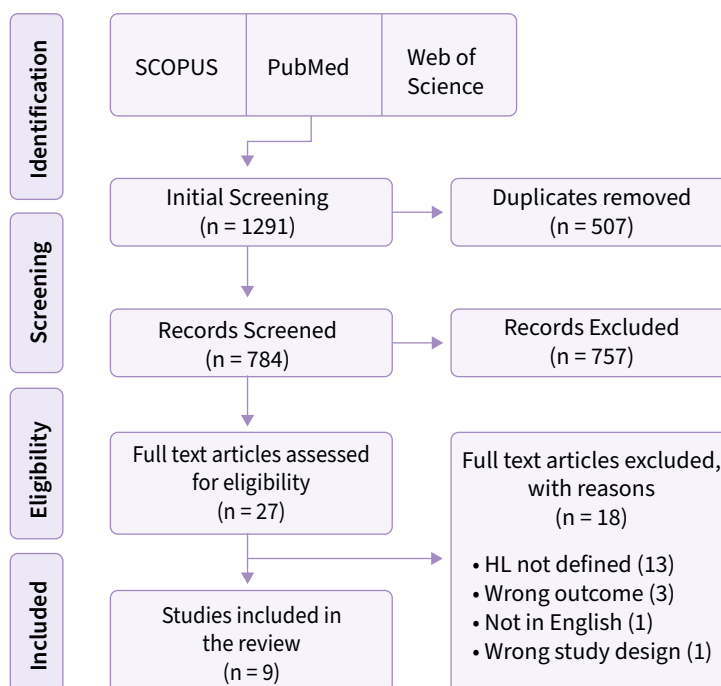


Figure 2. 2 PRISMA flowchart for literature review process

Across the included studies, all included details (often in table format) of primary definitions of health literacy. Some common definitions that appeared within numerous reviews are highlighted in Table 2.1.

Author	Definition
WHO (1998)	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
American Medical Association (1999)	'The constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the healthcare environment
Nutbeam (2000)	The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health
Ratzan and Parker (2000)	Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions
Institute of Medicine (2004)	The individuals' capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions
Kickbush <i>et al.</i> , (2006)	The ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the healthcare system, the marketplace and the political arena
Zarcadoolas, Pleasant & Greer (2006)	"The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life
Australian Bureau of Statistics (2008)	The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy
Sørensen <i>et al.</i> , (2012)	Health literacy entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the lifecourse
PICQ	Psychosis Information and Confidence Questionnaire
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International Prospective Register of Systematic Reviews
REALM	Rapid Estimate of Adult Literacy in Medicine
RTA	Reflexive Thematic Analysis
WHO	World Health Organisation

Table 2. 1 Commonly used definitions of health literacy

2.2 Dimensions of Health Literacy

This review, which builds on the work of Sørensen *et al.*, (2012), further highlights the multidimensional, and critically, continually evolving, understanding of health literacy. Although Sørensen *et al.*, (2012) identified a huge array of dimensions previously, this review demonstrated the developing nature of the concept of health literacy, with many additional dimensions identified in relation to the concept in the last decade. Based on this review, it appears that health literacy encompasses, among others, one's skills, competencies, knowledge, and motivation to carry out a wide range of actions throughout the lifecourse in order to promote and maintain health within the healthcare setting and in everyday life. The following sections detail the cluster of dimensions that were identified across the included studies.

2.2.1 Competences, Skills and Abilities

The wide range of skills associated with health literacy was highlighted within reviews. Although many have stated vaguely that a health literate person requires personal skills or a constellation of skills (Malloy-Weir *et al.*, 2016; Huhta *et al.*, 2018; Kasagari *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022), others have posited that one requires more specific cognitive and social skills. Examples of such, which are contained within the review, include the ability to comprehend (Bröder *et al.*, 2017; Liu *et al.*, 2020; Truman *et al.*, 2020) and communicate (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022) appropriately, as well as someone's level of knowledge (Bröder *et al.*, 2017; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022). Furthermore, the review underscored the psychological influence on health literacy. Although the importance of motivation was comprehensively reiterated (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasagari *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*,

2022), the specific influence of an individual's self-efficacy (Kasgari *et al.*, 2020; Liu *et al.*, 2020), attitudes (Bröder *et al.*, 2017; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Urstad *et al.*, 2022) and beliefs (Huhta *et al.*, 2018; Urstad *et al.*, 2022) on health literacy was also stated.

2.2.2 Action, Agency

This cluster included the widest variety of dimensions, with many being added to the work of Sørensen *et al.*, (2012) from this review. The ability to find, understand, critically appraise, and apply health information was clearly linked with the health literacy of a person, with each of these actions (or synonyms of these actions) occurring across all but one (Muscat *et al.*, 2022) of the review papers included within this umbrella review. The significance of emotional regulation was also included as a key dimension, including the ability to emotionally self-regulate to the demands of an experience and to cope with health situations or conditions (Bröder *et al.*, 2017; Kasgari *et al.*, 2018; Liu *et al.*, 2020). Although, there has been a move to ensure that health literacy encompasses more than just basic literacy skills, based on the findings of this review it appears that such skills are still deemed critical to one's health literacy (Malloy-Weir *et al.*, 2016; Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022).

2.2.3 Information

Although the vast majority of included reviews identified information as being a key dimension to health literacy, how this was phrased varied across the studies. Some opted to just include 'information' broadly within their definition or conceptualisation (Malloy-Weir *et al.*, 2016; Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022), whereas many stated the information should be relating to health and health services (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Urstad *et al.*, 2022) or health concepts (Malloy-Weir *et al.*, 2016; Huhta *et al.*, 2018; Liu *et al.*, 2020). Some studies were more specific, including

the importance of being able to deal with medical and healthcare terminology, instructions, and information relating to health systems (Huhta *et al.*, 2018; Kasgari *et al.*, 2020). Additionally, the format of information also varied, with some stating the importance of one not just being able to deal with health information in written and spoken form, but also emphasised the importance of dealing with digital, electronic, and online forms of information (Fleary *et al.*, 2018; Huhta *et al.*, 2018; Liu *et al.*, 2020).

2.2.4 Objectives and Purposes

Similarly, this cluster was also wide-reaching, emphasising the important, but broad, purported role of health literacy. The overarching purpose of health literacy, based on the included reviews, was to increase quality of life (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022) and to promote or maintain health (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022). Other key objectives, based on the findings of the review, which potentially contribute to the overarching purpose, included the ability to understand health issues, components of health and how to take action in order to address potential health complications and prevent disease (Bröder *et al.*, 2017; Huhta *et al.*, 2018; Kasgari *et al.*, 2020); the ability to make appropriate and informed healthcare choices, decisions and judgements (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022); to empower one to take more control over their health (Bröder *et al.*, 2017; Kasgari *et al.*, 2020; Liu *et al.*, 2020); and to have the capacity to function within the healthcare environment (Malloy-Weir *et al.*, 2016; Kasgari *et al.*, 2020; Liu *et al.*, 2020).

2.2.5 Context

Regarding the context, the healthcare environment appeared to occur most commonly within the review (Fleary *et al.*, 2018; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020). This includes, quite generally, health care systems (Liu *et al.*, 2020), settings (Fleary *et al.*, 2018; Liu *et al.*, 2020), and health situations (Huhta *et al.*, 2018). Furthermore, the review suggests that health literacy contexts include a ‘variety of settings’ (Malloy-Weir *et al.*, 2016; Huhta *et al.*, 2018; Liu *et al.*, 2020), such as everyday life contexts. For example, in the community, workplace, marketplace, online, during physical and psychosocial activities and within the political arena (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Huhta *et al.*, 2018; Kasgari *et al.*, 2020; Liu *et al.*, 2020; Truman *et al.*, 2020; Urstad *et al.*, 2022).

2.2.6 Time

The concept of health literacy, based on the review’s findings, is based across the lifecourse, with some definitions and conceptualisations stating that it evolves over the lifetime (Malloy-Weir *et al.*, 2016; Bröder *et al.*, 2017; Huhta *et al.*, 2018; Truman *et al.*, 2020).

Summary of evidence and recommendations for Section 2.

	Summary of evidence	Health literacy recommendations from authors	Alignment with WHO health literacy recommendation
2.1	This review emphasises the complex and multidimensional nature of the concept of health literacy.	When supporting health literacy, it is crucial to consider the range of health literacy dimensions (not just the basic functional health literacy skills) and how best to support these on an individual and population level.	Action area 1.1: Development and understanding of health literacy that is contextually appropriate
2.2	Health literacy is an ever-growing concept; many new health literacy-specific dimensions have been added to the concept since the last review in the seminal paper by Sørensen <i>et al.</i> , (2012).	It is crucial that we consider health literacy in the modern world. This is particularly important in the light of the ever-growing objectives and purposes of health literacy; the contexts in which health literacy skills are needed; and the type of information that requires health literacy skills.	Action area 1.1: Development and understanding of health literacy that is contextually appropriate
2.3	It is clear from the findings the immense number of competences, skills, and abilities, as well as the actions one may be required to acquire in order to navigate health-related situations across a range of contexts in everyday life.	Such a skillset, coupled with the various and ever-growing number of antecedents to being health literate, such as the foundational competencies (e.g., general literacy skills, individual characteristics) and demographic, psychosocial, and cultural factors, places a significant focus on the individual to develop their health literacy as an individual capability. It is essential that adequate support and services are put in place in order to allow one to develop the necessary capacities, which may relieve the pressure on the individual.	Action area 4: Target priority groups that are not receiving or easily accessing health information or health care
2.4	Health literacy is moving from a concept primarily concerned with providing people with the knowledge and skills to deal with medical information to a concept that needs to be considered across everyday life.	When supporting the development of the health literacy competencies, focus should be recentred around providing one with the abilities and knowhow to navigate and tackle everyday situations relating to health, as well as those specific to medical information.	Action area 5: Integrate health literacy at the national level through to local levels

Section 3:

International approaches to promoting health literacy

3.1 Introduction

The Ministerial Declaration of 2009 from the United Nations Economic and Social Council (ECOSOC) emphasised the significance of health literacy in achieving substantial health improvements (United Nations Economic and Social Council, 2009). It urged the creation of suitable action plans to advance health literacy. The role of health literacy in support Sustainable Development Goals has also been highlighted (Budhathoki *et al.*, 2017). The WHO, the European Commission, and Health 2020, amongst others, have also all recognised the importance of health literacy within policies, reports and practices (for a comprehensive review focussed on the evidence of existing policies in Europe, and their effectiveness for improving health literacy, please see Rowlands *et al.* (2018)). “Health literacy development for the prevention and control of noncommunicable diseases” also provides examples of international case studies (WHO 2022).

Given the increasing relevance and prominence of health literacy within global health policy, a growing number of countries have established health literacy plans, strategies and actions. The following section gives a very brief snapshot of some of these approaches within a select number of countries, with suggested references for further reading.

Australia

Health literacy was first included in Australia’s national health goals and targets in 1993. Since that time, the Australian government has made health literacy a priority and has recognised it as an imperative component when considering improved health care and overall health of the population of Australia. The country has a national

statement on health literacy (Australian Commission on Safety and Quality in Health Care, 2014). The National Strategic Framework for Chronic Conditions Australian Institute of Health and Welfare (2022) and the National Safety and Quality Health Service Standards (Australian Commission on Safety and Quality in Health Care, 2021) are two further national initiatives that acknowledge and integrate health literacy as an important component of the health system. There are also community initiatives such as health literacy training courses and health translations directory. Notably, “Develop Health Literacy” has been declared as one of five interrelated propositions for a futures-oriented curriculum with the topic of health and physical education in Australia (Australian Curriculum, n.d.). This element of the curriculum focuses on developing knowledge, understanding and skills related to the three dimensions of health literacy: functional dimension; interactive dimension; critical dimension.

Denmark

In 2009, the Danish Health Authority published a health literacy status report, which served as the basis for possible work with health literacy in a Danish municipal context. The report placed direction for future health literacy efforts in Denmark, but also recognised that Danish language translation of health literacy was, at the time, a barrier to wider implementation of the concept, ‘Sundhedskompetence’ is now a commonly used term. A 2013 study detailed initial efforts to promote and develop health literacy in Denmark, this included research, the application of health literacy in guidelines, and engagement of a wide variety of stakeholders across

health, policy, research, civil and social engagement, formal and informal education, media, business and industry (Sørensen *et al.*, 2020). Health literacy research is fairly prominent across the country, this has been focussed on assessment (Bo *et al.*, 2014) but also on educational interventions (Bruselius-Jensen *et al.*, 2017). A specific example of one such intervention is ‘Sundhedsdansk’, a free online learning platform which aims to support adult migrants learning Danish to learn more about the human body, health and diseases, and the Danish healthcare system (Nordic Welfare Centre, 2022). Other populations of focus have included pregnant women (‘MAMA ACT’), and ethnic minorities (‘LIVE’). The Danish Health Literacy Network was launched in 2016, and in 2019, in collaboration with the Danish Society of Public Health, the network published ‘Health literacy from a structural perspective: A path to equity in health?’ (Aaby Helle *et al.*, n.d.). The policy brief detailed eight recommendations to improve health literacy in the country, this includes for example, integrating health literacy in Danish health policies and strategies; developing health literacy throughout the lifecourse, integration of health literacy partnerships and co-creation process; and measuring and monitoring health literacy using local and national data. Specifically, this brief linked health literacy recommendations to the UN Global Goals for Sustainable Development, and will therefore influence health inequalities in the Danish population.

Finland

While there is currently no national policy on health literacy in Finland, perhaps one of the most significant Finnish advances in health literacy has been the incorporation of the concept into the school curriculum. In 2004, Health Education was introduced as a new, independent school subject, and in 2016 (Finnish National Board of Education, 2004), following a collaborative consultation process, a revised core curriculum was published, with health literacy as a core theoretical framework. The overall aim of the Health Education curriculum is to support the development of health literacy in a versatile manner, and specific five core components: theoretical knowledge, practical knowledge, individual critical thinking, self-awareness and citizenship are five core components of

health literacy, with specific grade appropriate objectives and assessment criteria detailed. Health Education teacher training in Finland has been built around different areas of expertise, with a clear focus on health literacy, to support the new Health Education curriculum (Paakkari & Paakkari, 2019). The impact of this curriculum is seen with higher proportions of adolescents in Finland reporting to have high health literacy (Paakkari *et al.*, 2020). Notably, the same survey (the HBSC study), also saw Finnish teens report the widest extremes in health literacy levels.

Germany

In 2020, in response to concerning results in national health literacy surveys, Germany introduced a national health literacy action plan that aimed to generate greater resonance in politics, associations, health professions and research, and to create a willingness to act among them (National Action Plan Health Literacy, 2018). It consists of 15 recommendations that focus on promoting health literacy in all areas of everyday life, creating a user friendly and health literate healthcare system, living a health literate life with chronic disease and developing health literacy research. Schaeffer *et al.* (2023) gives a detailed overview of the origin, development and structure of this national action plan. While this plan does focus on the healthcare system, in the same year of its launch (2020), the Alliance for Health Literacy in Schools was founded. It followed existing initiatives in Germany such as the National Action Plan for Health Literacy which had been in place since 2018 and follows the premise that schools are vital environments for strengthening health literacy. The Alliance for Health Literacy in Schools aims to develop quality standards for health literacy in the school setting and to anchor health literacy at the level of school organisation, teaching, school staff, and the wider school environment (TUM School of Medicine and Health Technical University of Munich, 2020).

Norway

Norway's approach to health literacy involves a combination of policy development, education, patient empowerment, and collaboration to improve the population's ability to understand and use health information effectively. Norway has a national strategy for health literacy, which was launched in 2019 (Norway National Strategy for Health Literacy, 2019). The aim of the strategy is to increase the health literacy of the population in Norway. It is targeted at health and social professionals, decision-makers, and managers as well as patient organisations and other relevant stakeholders. It pursues a cross-sectoral approach, in particular the involvement of the health and educational sector.

The Netherlands

The Netherlands are recognised as leaders in the European health literacy (in Dutch 'Gezondheidsvaardigheden') field. Set up in 2010, The Dutch Health Literacy Alliance represents a network of organisations, institutions, companies, and individuals. The Alliance has a website, organises network meetings and there are three active working groups devoted to research, education, as well as patient experiences and participation (Sørensen *et al.*, 2020). Other tools, methods and resources are available, mainly within a healthcare context (Heijmans *et al.*, 2015a; Heijmans *et al.*, 2015b).

Like many other participating countries, the publication of the HLS-EU findings in 2012 led to an increased focus on health literacy in The Netherlands. This included research into the translation of existing methods of measuring health literacy (for example, the Rapid Estimate of Adult Literacy in Medicine (REALM), the Health Literacy Questionnaire (HLQ)). Following the translation of these methods, research then explored the association between health literacy and health outcomes; provider choice and healthcare use; seeking and use of health information preferences for and participation in screening activities; shared decision making; and health self-management (Fransen *et al.*, 2014; van der Heide *et al.*, 2013; Fransen *et al.*, 2011). As a result of using these measures, cross country comparisons on national health literacy levels were able to be made.

In 2018, the Dutch Ministry of Health, Welfare and Sport in collaboration with the Netherlands organisation for health research and development invested in drafting a comprehensive research plan on health literacy with specific aim to improve research about health care services for people with low health literacy levels. Although the Dutch government has no official policy on health literacy, it is integrated within some existing documents.

United Kingdom

Scotland

In 2008, the Health Improvement Strategy division of the Scottish Government commissioned a Health Literacy Scoping Study which explored the concept of health literacy, its application to policy and practice in Scotland, and identified options for further development. In 2011, the Scottish Government appointed a policy lead for health literacy and a national clinical lead for health literacy and self-management, and in 2012, the National Health Literacy Action Group (NHLAG) was established to provide a national narrative, vision, direction and support to raise awareness and reduce the negative impact of poor health literacy. "Making it Easy a Health Literacy Action plan for Scotland" was published in 2014 (Scottish Government, 2014), with a 2017 update "Making it Easier", with progress against the implementation of this plan monitored by cross-sectoral stakeholders including Public Health Scotland, Health Care Improvement Scotland and NHS Education Scotland (Scottish Government, 2017). One key resource managed by NHS Scotland is "The Health Literacy Place". This online platform provides access to examples of existing good practice techniques and tools, generates and disseminates patient-based evidence of emerging effective health literacy innovations, shares resources and technologies, and provides references and articles that expand on the themes of Making it Easy. The resource also creates access to a community of practice, providing support and connection between those engaged with health literacy developments.

England

In 2015, Public Health England published a practice resource summary focussed on "Improving health literacy to reduce health inequalities" (Public Health England & UCL Institute of Health Equity, 2015), and in 2022 the National Institute for Health and Care Research (NIHR) provided a comprehensive overview of research funded by the NIHR

to date (National Institute for Health and Care Research, 2022). The National Health Service in England have a number of resources such as a content style guide (NHS, 2023), design principles (NHS, 2023b), the Health Education England Health Literacy Toolkit (Health Education England & NHS, n.d.). These outline guidance at an organisational level for improving the health literacy responsiveness of organisations. In 2023, in relation to the link between health and digital literacy, NHS England have also released on a five year partnership working with Libraries Connected and Arts Council England (NHS England, 2023).

Northern Ireland

In Northern Ireland, health literacy was emphasised as a critical component of 'Making Life Better 2012-2023' (Department of Health, 2014). This public health framework aimed to create environments for individuals and communities in Northern Ireland that allowed them to take charge of their own health choices, enabling and supporting them to realise their full health and wellbeing potential, and thus reducing health disparities between various communities. Despite this ambitious aim, it was recognised that work being done within the health literacy field in Northern Ireland had not been consistently published or applied across sectors and healthcare settings. In 2019, a Regional Health Forum was established with the aim of addressing health inequalities through health literacy improvement on a regional basis.

Wales

The most recent Welsh national level report in relation to health literacy was published in 2024 (Marchant & Crick, 2024), with a 'focus on children and young people within the context of research, policy and strategy in Wales' (p.1). The authors highlighted that while health literacy had been identified as a long term priority back in 2010, limited progress had been made since. Specifically, in a national action plan outlined improving health literacy was one of seven key actions to make progress in achieving fairer outcomes for all. Yet despite changes in education, public health, social-care, wellbeing, economy and education in Wales in the last decade, explicit health literacy developments have not been made. However, the authors of this most recent report remain clear that improving health literacy aligns with these broader policy goals and can be a means to address health inequalities.

In 2022, the Senedd Cymru/Welsh Parliament recognised health literacy as an Area of Research Interest (ARI) to support the Sixth Senedd's strategy, emphasising its role in addressing health disparities. The policy discussion takes place against the backdrop of financial challenges, particularly exacerbated by the COVID-19 pandemic, impacting the health and social care system in Wales. While the Welsh Government has made short-term investments in priority areas, there appears to be less emphasis on initiatives supporting health literacy development. There are calls to re-energise health literacy as a national priority and development of health literacy assessment (particularly capitalising on opportunities for population data linkage of health, economic, education and administrative data in Wales) to build health literacy system capacity in Wales.

United States of America

Health literacy is well established and integrated within US policy. Since 2003, the US Department of Health and Human Services (HHS) has a health literacy workgroup that collaborates to ensure that improving health literacy remains a priority for the HHS. The workgroup strives to create understandable and actionable health information, support and facilitate engaged and activated health consumers and to refresh the health literacy science base on a regular basis (Santana *et al.*, 2021).

In 2010, a national action plan on health literacy was released by the US Department of Health and Human Services calling for increased research, development, implementation and evaluation of interventions to improve health literacy. The action plan is based on the two core principles that all people have the right to health information that helps them make informed decisions and that health services should be delivered in ways that are easy to understand and that improve health, longevity and quality of life. The plan also contains 7 goals aiming to improve health literacy and strategies for achieving them (Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). More recently, Lopez *et al.*, (2022) published an overview of the US health literacy landscape. They report identified three recommendations: i) the need for systematic and recurrent population-wide assessment of health literacy in the US: (ii) user-friendly technology to enhance the usability of the information shared: and (iii) recognising that improving health literacy requires more than just sharing information with patients and the public i.e. a systems approach U.S.

Summary of evidence and recommendations for Section 3.

	Summary of evidence	Health literacy recommendations from authors	Alignment with WHO health literacy recommendation
3.1	Studies have indicated low health literacy to be a problem in various countries internationally. This has often initiated in the development of national networks, further research and policy change.	The regular surveillance of health literacy on a national level is useful to guide future efforts. Furthermore, the initiation of a cross-sector national health literacy network in Ireland is needed.	Action area 5: Integrate health literacy at the national level through to local levels
3.2	Many countries internationally have recognised the link between health literacy and health inequalities.	Promoting health literacy can play a part in reducing health inequities.	Action area 4: Target priority groups that are not receiving or easily accessing health information or health care
3.3	Policy level intervention can include the development of new policies/ frameworks/ action plans, but also the integration of health literacy into existing policies.	Standalone and integrated policies should be considered in the development of health literacy at a policy level.	Action area 5: Integrate health literacy at the national level through to local levels
3.4	Health literacy is most commonly integrated into health care policies, but also within other fields, such as education.	A multisectoral approach is needed to shape health promoting environments to facilitate health literacy development.	Action area 5: Integrate health literacy at the national level through to local levels
3.5	The monitoring of implementation and progress against national policies/ frameworks/ action plans is varied and sporadic.	National and locally relevant strategies for surveillance, evaluation and impact assessment need to be developed, ideally with a long term focus. This ongoing monitoring will meet evolving health literacy strengths, needs and challenges.	Action area 1.2: Measure health literacy to identify and understand differences about who is being left behind

Section 4:

Health literacy research in Ireland: A systematic review

4.1 Introduction

As health literacy has grown in prominence internationally since the early 2000s, there has been sporadic development and implementation of initiatives, programmes, research projects, and policy documents focussing on health literacy on the Island of Ireland. Low health literacy levels have been reported in Irish adults (Gibney *et al.*, 2020), contributing to the general agreement that more needs to be done to support health literacy promotion in the region. To support future efforts, best practice should be led by high quality research evidence supporting the design, implementation, evaluation and dissemination of this work. While there is international research in these areas, future recommendations for best practice should also consider the specific cultural and contextual environment.

Ireland is recognised as one of the only countries in the European Union without universal healthcare coverage for all citizens, offering a ‘two-tiered system’ which contributes to, and exacerbates, rising health inequalities (Forster, Kentikelenis and Bambra, 2018). To note however, this section of the report will focus on research conducted on the island of Ireland, as although The Republic of Ireland and Northern Ireland represent two distinct political jurisdictions, health literacy development and health inequalities are common challenges across the Island. In Ireland, the standardised mortality rate for those in the least advantaged socio-economic group was twice as high as those in the most advantaged group based on analysis of data from 2018 (Duffy *et al.*, 2022). These inequalities translate into stark differences in life expectancy by socio-economic status. Life expectancy for males living in the most deprived areas of Ireland is five years shorter than those living in the least deprived areas. Indeed, proportional health rating for 65-74 year old men living in affluent areas was observed to be 34% higher

when compared to men of the same age range residing in deprived areas (Sláintecare Healthy Communities, 2022).

In the most recent Health Inequalities report for Northern Ireland, the male deprivation gap (7.3 years) showed no notable change since 2015-17, the female deprivation gap (5.1 years) widened slightly over the period. The report also indicated that preventable mortality was found to have increased in the most deprived areas, resulting in the inequality gap widening with the rate in the most deprived areas now treble that in the least deprived areas (Health Inequalities Annual Report 2023 (2023)). Across the island, many organisations and policies are in place aiming to reduce the health inequality gradient and the gap between the ‘most’ and ‘least’ deprived population groups, for example: the Healthy Ireland Framework, the Roadmap for Social Inclusion, Making Life Better Strategic Framework (2013-23) and Northern Ireland Health and Social Care Inequalities Monitoring System (Department of Health, 2014). Indeed, one key focus for Sláintecare Healthy Communities reform is to support health inequalities in Ireland. However, again adding to this complex environment, the responsibility for health, and subsequently health literacy, falls to and between multiple stakeholders across both jurisdictions.

Given these considerations, there is a need to capture the current understanding of health literacy in the Island of Ireland, to better inform policy makers, and other stakeholders. Specifically, identifying health literacy related peer-reviewed research conducted on the Island of Ireland should offer a clear, comprehensive, transparent and rigorous insight for researchers, practitioners and policy makers. This paper aims to explore the development of health literacy in the Island of Ireland, and over the past ten years, by systematically reviewing the peer-reviewed literature in this area.

4.2 Research Objectives

The overall aim of this review was to gain a contemporary understanding of health literacy through identifying and appraising existing research focused in an Irish context. A review of the existing strengths, barriers and needs to health literacy in Ireland through synthesising the existing research in an Irish context, will provide a better understanding of health literacy policy and practice to inform evidence-based recommendations. These findings will help target health literacy interventions where health inequalities have been observed. Reflection on this research will provide contextual consideration for future health literacy development strategies in respect to Sláintecare Healthy Communities reform.

4.3 Methods

4.3.1 Literature Selection and Search Strategy

For this review, we included English-language articles published in peer-reviewed journals or published books that reported on health literacy from an Irish context from 2013 to 2023. Seven electronic databases (Science Direct, MEDLINE, CINAHL Complete, Web of Science, Scopus, PsychoINFO and SPORTDiscus) were searched using Boolean operators (AND/OR), incorporating the relevant terms “health literacy” and “Ireland”. Given the specific requirement of the research to focus on health literacy on the Island of Ireland, the search terms were phrased to represent this. The search was respective of the research focus and, therefore, reflective of the timeframe from publication of the European Health Literacy survey in 2013 (Sørensen *et al.*, 2015). The search was conducted between October and November 2023, with follow up capture screening for publications in December 2023. All records were exported to the Rayyan systematic review platform for screening using Rayyan – Intelligent Systematic Review managing software (Ouzzani *et al.*, 2016) and all duplicates were removed.

Inclusion Criteria	Criterion	Exclusion Criteria
<p>Studies will be included if they report on a health literacy related area.</p> <p>Includes individual characteristics such as the ability to find, understand, appraise, remember, and apply information to promote and maintain good health and wellbeing. But also a systems approach to health literacy such as practice, policy, planning and regulations.</p> <p>Case studies, Protocol papers, Primary studies, Systematic Reviews, Meta analysis, Review articles</p>	Study Focus	<p>Article does not include a focus on health literacy, health behaviours, health promotion</p> <p>Systematic reviews that do not include primary research studies based on Island of Ireland.</p>
Any original health literacy related research or editorials published for the island of Ireland (Articles, report, government documents, book)	Type of Article	Duplicate publication, Full text articles were not available, Editorials, Book Chapters, Dissertations, Conference abstracts
Published articles based in the Island of Ireland	Geographical Area of Interest	Published outside of the Island of Ireland
Published since 01/01/2013, up until the 31/12/2023.	Time Period	Published from before 01/01/2013
All participant groups are included	Participant Group	Nil
Any	Setting (e.g. hospital, school, community)	Nil
Published in English	Language	Published in non English

Table 4. 1 Search Criteria

One reviewer (MM) screened titles and abstracts using the agreed criterion measures (Table 4.1). Following this, and to minimise reviewer bias, a second reviewer (HG) independently screened 20% sample of titles and abstracts. Using more than one researcher (Torgerson *et al.*, 2017) supported a quality review process in challenging eligibility criteria, errors and hidden assumptions in the search (Oliver *et al.*, 2017). Where consensus was not reached, a third reviewer (CS) screened and concluded. Following screening for title and abstract, full-text copies of potentially relevant studies were obtained and screened for full-text inclusion by one reviewer (MM). Where further agreement was required at this stage, a second reviewer (HG) confirmed the inclusion of the study through discussion and review of Table 4.1.

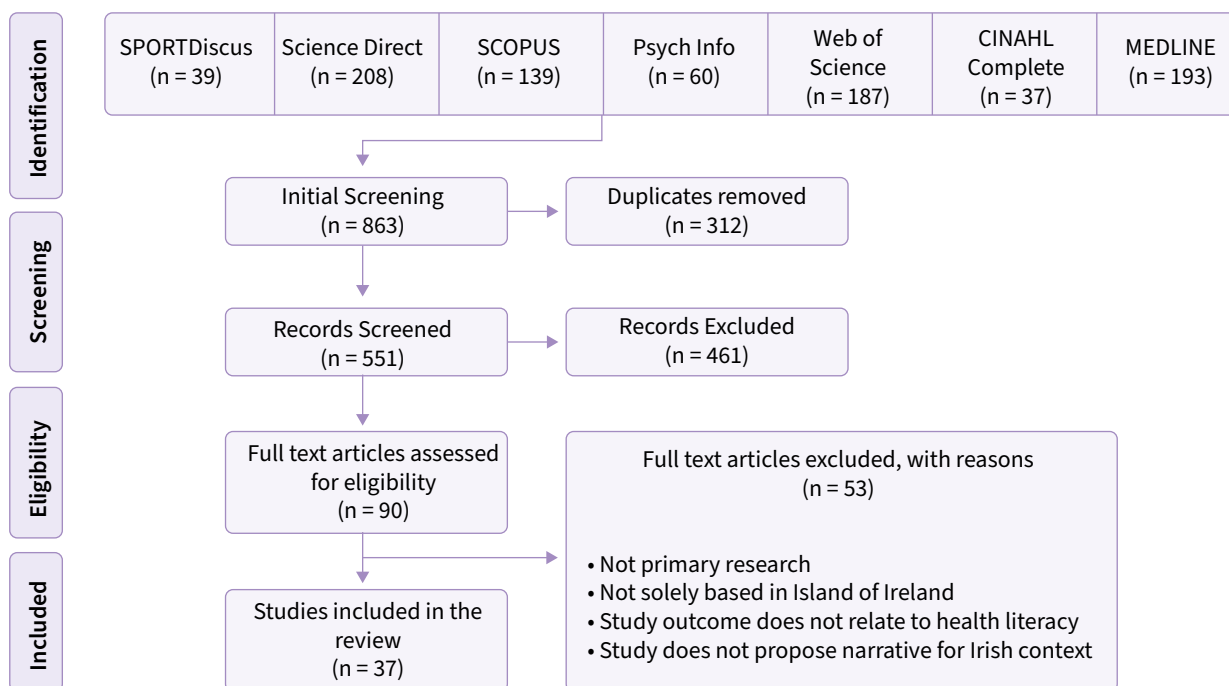


Figure 4. 1 PRISMA Flowchart for literature review process

4.3.2 Data Extraction and Reliability

Descriptive data for included studies were extracted and uploaded to an Excel document. Data extraction was completed by one researcher (MM) and confirmed by another (HG). For all studies, study characteristics (first author, year, geographical area in Ireland, sample size, study type, participant characteristics (sex, age), health literacy assessment/ measurement, socio economic measurement/ factor funding source (if applicable) and study results were imputed by a single author (MM). In addition, context (delivery type and setting) were coded. All extracted data were subsequently reviewed for accuracy

4.4 Results

To present literature findings from this systematic review of health literacy in Ireland, four areas were observed for reporting. These are labelled according to and related to study findings in Appendix 2 (<https://bit.ly/ReportAppendices>).

4.4.1 Population of Focus

Health literacy is one component mentioned in the various fields within health and education. These can be viewed as linked, due to the understanding that health literacy is both the process and the outcome of people's interactions with the culture and society in which they live (Keleher and Hagger, 2007). As a social determinant of health, limited health literacy is linked in a causal pathway to suboptimal or poor health. Low health literacy is thought to be a better predictor of health status than education, SES, employment, race or gender (Weiss, 2005). In Ireland, literature has reported on various aspect demographics in relation to health of populations with a view to understanding health literacy outcomes.

Population Recruitment

Study recruitment across the island demonstrated a range of population demographic indicators and study focus interests. Where studies reported location (as appropriate to the methodology), the majority listed cities within the island with other geographical areas included:

- Dublin (Clarke, Kearney, *et al.*, 2021; Doyle *et al.*, 2013; Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019; McGuirk & Frazer, 2021; McManus *et al.*, 2018; Smith *et al.*, 2022),
- Cork (Chambers *et al.*, 2015; Duggan *et al.*, 2014; Mathew & Kabir, 2022; Rutherford *et al.*, 2018)
- Belfast (Best *et al.*, 2016).
- Three studies (Browne *et al.*, 2017; Gilhooley *et al.*, 2019; McKenna *et al.*, 2018) were based in the West of Ireland, spanning across counties.
- Dublin was observed to be the most common location for reporting health literacy (18.9%).

Of the published research identified in this review, 81.1% of studies have noted a specific population of focus in their reporting, which includes age range and/or mean age (see Appendix 2 <https://bit.ly/ReportAppendices>). Where studies have not reported age (16.2% of the included studies), narrative information can be inferred to relate to:

- adult or older age groups (McKenna *et al.*, 2023; Ní Chorcora & Swords, 2022; Quinn *et al.*, 2019; Rutherford *et al.*, 2018; Smeaton, 2023; Toibin *et al.*, 2017);
- adolescent age groups, forming 10.8% of the report findings (Best *et al.*, 2016; Goss *et al.*, 2021, 2022; Smith *et al.*, 2022);
- adolescent and adult samples were incorporated in 13.5% of studies (Byrne *et al.*, 2015; Chambers *et al.*, 2015; Gibney *et al.*, 2020; Jackson *et al.*, 2020; D. O'Keeffe *et al.*, 2016)

No study observed children younger than adolescent or teenage years (<13 years old) in their health literacy reporting. Numerous study reports focus on older adult participants, with many highlighting recruitment of 18 year old plus participants. This is reflected in the study aims for specific clinical populations relating to adult cases such as:

- obstetric (Duggan *et al.*, 2014);
- chronic illness (Browne *et al.*, 2017);
- chronic pain (Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019);
- cancer survivors (Clarke, Dunne, *et al.*, 2021) as well as cancer screening (Clarke, Kearney, *et al.*, 2021; Rutherford *et al.*, 2018); and cancer information seeking (Drummond *et al.*, 2019)

Study aims also related to adult populations specifically as:

- participants attending adult literacy classes (McKenna *et al.*, 2023);
- older adults (Gibney & Doyle, 2017; O'Riordan *et al.*, 2023);
- workforce population samples (Duffy *et al.*, 2021; Ní Chorcora & Swords, 2022; Quinn *et al.*, 2019; Sutton *et al.*, 2018); and
- third level students attending a higher education institution (Mathew & Kabir, 2022; McGuirk & Frazer, 2021; Smeaton, 2023) related to a range of ages in adulthood.

Sex

This report noted, 18.9% of studies included in this review omitted reporting on sex and other demographic information, although in many cases this information was not relevant as these studies related to a narrative detail of research undertaken, or a report of a study protocol description or methods for developing health literacy.

64.8% of studies noted sample demographics of both male and female participants. Indeed, in studies which reported on both male and female samples, over half (66.7%) of these samples were female dominant in recruitment and participation (>50% female). The review also highlighted:

- 10.8% of studies included female only studies (Duggan *et al.*, 2014; Gilhooley *et al.*, 2019; Quinn *et al.*, 2019; Rutherford *et al.*, 2018)
- 5.4% focussed on male only participants (Best *et al.*, 2016; Drummond *et al.*, 2019).

Sociodemographic Information

Of studies involving participants, information relating to sociodemographic and/ or socioeconomic characteristics were also reported when pertinent to the research objectives. Methods of reporting sociodemographic and/ or socioeconomic characteristics varied. Education was often reported in studies (54.0%). However, this itself was reported in various ways:

- highest education level achieved by the participant involved in the investigation (Clarke, Dunne, *et al.*, 2021; Coughlan *et al.*, 2013; Drummond *et al.*, 2019; Duggan *et al.*, 2014; Gibney *et al.*, 2020; Gibney & Doyle, 2017; Mackey, Blake, Squiers, *et al.*, 2019; McKenna *et al.*, 2017, 2018; McManus *et al.*, 2018; D. O’Keeffe *et al.*, 2016; S. O’Keeffe *et al.*, 2023),
- studies also used parents’ highest level of education achieved (Byrne *et al.*, 2015);
- participant literacy level (Gilhooley *et al.*, 2019),
- recruitment of participants from a specific tier of the education system e.g. university students (Doyle *et al.*, 2013; Mathew & Kabir, 2022; McGuirk & Frazer, 2021; Smeaton, 2023; Sullivan *et al.*, 2022) or school level (Best *et al.*, 2016; Byrne *et al.*, 2015; Goss *et al.*, 2021, 2022; Ní Chorcora & Swords, 2022; Smith *et al.*, 2022).

In research including school aged participants, studies were observed to include school deprivation level (13.5%). Four studies (Goss *et al.*, 2021, 2022; Smith *et al.*, 2022; Sullivan *et al.*, 2022) noted involving schools within Irish Department of Education’s ‘Delivering Equality of Opportunities in Schools’ (DEIS) action plan, therefore, identifying as a DEIS school where pupils attending would be within a particular social demographic. Similarly, a further study (Best *et al.*, 2016), reported recruitment consideration for secondary as opposed to grammar education level. Indeed, level of deprivation indicators were included in demographic information (Clarke, Kearney, *et al.*, 2021; Gibney & Doyle, 2017), with social class (Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019; McKenna *et al.*, 2017, 2018) and social status (Gibney *et al.*, 2020; Gibney & Doyle, 2017) also reported.

Employment

Employment was reported by 13.5% of studies involving participants. Reported employment data included:

- current employment level (employed/ unemployed) to retired or not working (Clarke, Dunne, *et al.*, 2021; Coughlan *et al.*, 2013; Mackey, Blake, Squiers, *et al.*, 2019),
- employment profession (D. O’Keeffe *et al.*, 2016; Sutton *et al.*, 2018)
- including studies which also captured data on participants’ general income (Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019).

Studies that reported on clinical participants generally included:

- a measure of healthcare or health service access within Ireland such as medical card status and/ or private health insurance as an indicator of socioeconomic status (Clarke, Dunne, *et al.*, 2021; Coughlan *et al.*, 2013; Drummond *et al.*, 2019; Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019; McKenna *et al.*, 2018).
- a measure of residential information including information on participants living arrangements (Clarke, Dunne, *et al.*, 2021; Clarke, Kearney, *et al.*, 2021; Gibney & Doyle, 2017; Gilhooley *et al.*, 2019) as well as residential area breakdown for rural/ urban population sample (Clarke, Dunne, *et al.*, 2021; Coughlan *et al.*, 2013).

4.4.2 Research Design

Sampling

There have been numerous approaches to research design and study type in the exploration of health literacy in the island of Ireland over the last decade. Where recruitment sampling information was utilised and reported, specific purposive sampling was used for 21.6% of the included studies within this review. Critical case sampling (selecting a small number of important cases) was used for Ireland's only indigenous ethnic minority group, recognised as the Travelling community (Gilhooley *et al.*, 2019). Where specific recruitment information was noted, but not specific sampling methods, targeted recruitment was utilised for 43.2% of studies. Indeed, purposeful targeted recruitment was reported for the majority of studies (64.9%) included in this review. For example, sampling of GAA coaches, although not specifically detailed through a strategy, was used by one study (Duffy *et al.*, 2021). Convenience sampling accounted for 5.4% of studies with convenience and snowball sampling utilised for one study (2.7%: Sutton *et al.*, 2018). A cluster based sampling method used by one study, allowed random sampling through geographic clusters in a two stage approach (Best *et al.*, 2016). Two further studies reported using random sampling methods for participants (Coughlan *et al.*, 2013; Gibney & Doyle, 2017), with analytical sampling also used as a subsample for reporting (Gibney *et al.*, 2020a; Gibney & Doyle, 2017).

Study Design

The majority of studies reported using a cross sectional design in their methodology (43.2%). Two studies reported on separate phases of a longitudinal study consisting of a 12 month period, providing timepoint reporting on health literacy at baseline and the development of health literacy capacities of individuals attending a structured cardiovascular risk reduction programme (12 weeks) in Ireland (McKenna *et al.*, 2017, 2018). Similarly, there were other examples of connected research outputs on health literacy published in the last ten years (Goss *et al.*, 2021, 2022a; Smith *et al.*, 2022). One study (Jackson *et al.*, 2020) presented information on health literacy from a larger project in a clinical population in Ireland, with a further study similarly using survey results from a larger project (Coughlan *et al.*, 2013). Two studies (Gibney *et al.*, 2020a; Gibney & Doyle, 2017) utilised larger study methodologies, in this case the European Health Literacy Survey 2013, to report on survey results only on health literacy in Ireland.

The publication of health literacy intervention studies (13.5%) were evident over the last ten years. Indeed, intervention studies explicitly reported their methodology (McManus *et al.*, 2018; O'Keeffe *et al.*, 2023; Sutton *et al.*, 2018) and presented findings in relation to their specified health literacy related outcomes (these varied between studies, and detail of this is provided in Monitoring and Evaluation). Other studies provided intervention study design details differently. The initial pilot study intervention methodology was reported on (Toibin *et al.*, 2017) or details on an intervention for a sample of sub-participants was described (Sullivan *et al.*, 2022). Regardless of the specific research aims of these intervention studies, all study populations, with the expectation of one community based Gaelic football player intervention (O'Keeffe *et al.*, 2023), were focused on clinical health literacy samples.

Quasi-experimental within-subjects study design was employed by research focusing on adolescent mental health literacy (Byrne *et al.*, 2015), with further adolescent population research utilising a convergent mixed methods design (Goss *et al.*, 2021). A formative evaluation study design was integrated for reporting on adolescent perceptions of a health literacy intervention (Smith *et al.*, 2022). An exploratory qualitative research approach was undertaken for one study reporting on experience of skin disease and relationships with healthcare providers for a specific community population in Ireland (Gilhooley *et al.*, 2019).

Recently, co-design approaches have received growing attention in the field of health literacy research. A qualitative participatory qualitative community-based participatory research study design was employed (McKenna *et al.*, 2023) to support a hospital based health literacy plan through co-creation. Similarly, (Goss *et al.*, 2022a; Smith *et al.*, 2022) described co-design processes with youth populations to support a health literacy intervention.

Where specific research study design approaches were not reported, and where study methods were not part of a larger project, different descriptive approaches were reported in 18.9% of the studies included within this review. Three research papers reported narrative and descriptive processes for health literacy educational outcomes for third level education or Higher Education Institution students (Doyle *et al.*, 2013; McHugh *et al.*, 2022; Smeaton, 2023). Two of these studies focussed on clinical student expertise (Doyle *et al.*, 2013; McHugh *et al.*, 2022) in supporting better health literacy in their practice.

Indeed, working with others in supporting health literacy needs was a dominant study focus for 16.2% of the studies published in Ireland in the last decade. This ranged from clinical practitioners working directly with patients (Quinn *et al.*, 2019; Sullivan *et al.*, 2022; Toibin *et al.*, 2017), or wider professional groups working with young people to better understand and support health literacy (Duffy *et al.*, 2021; Ní Chorcora & Swords, 2022; Sutton *et al.*, 2018).

The use of vignettes within qualitative research over the last ten years was also evident, with 13.5% of studies reported use or development of vignettes in their methods. These were mostly linked to development of health literacy outcomes in youth (Byrne *et al.*, 2015; Chambers *et al.*, 2015; Goss *et al.*, 2021, 2022b; Ní Chorcora & Swords, 2022), with three of these studies focussing specifically on mental health literacy (Byrne *et al.*, 2015; Chambers *et al.*, 2015; Ní Chorcora & Swords, 2022).

Study Timeframe

Study timeframes varied. Where studies reported the timeframes of data collection (21.6% of all studies included in this review), timeframes spanned from <1 month (Duggan *et al.*, 2014); <2 months (Browne *et al.*, 2017); <6 months (Goss *et al.*, 2022; Mathew & Kabir, 2022; Rutherford *et al.*, 2018; Smith *et al.*, 2022) and 13 months

(Jackson *et al.*, 2020). One intervention research study (Sutton *et al.*, 2018) detailed delivery of the intervention for 82 occasions over an 8 year period.

The timeframe between data collection and study publication also varied. The majority of research in the last ten years which reported data collection timeframes in study publications (32.4%), listed publication of research >2 years from data collected. Three of these studies were >5 years from data collection to publication due to the methodology including a national survey (SLÁN: Coughlan *et al.*, 2013; HLS-EU: Gibney *et al.*, 2020; Gibney & Doyle, 2017). A further two studies (McHugh *et al.*, 2022; Smeaton, 2023), although specific data collection or detail on timeframe was omitted in study design reporting, stated pilot methodology timeframes were undertaken two years prior to study publication.

This review also brought forth the time sequence of all the included studies related to health literacy (see Figure 4.2). Traction in the field of health literacy in Ireland has grown steadily in the last decade, with 15 studies published in the initial years (pre 2019). Increasing interest in the area of health literacy was observed with 22 studies published in the last 5 year period, 15 of these since the COVID-19 pandemic outbreak in 2020.

4.4.3 Domains of Focus

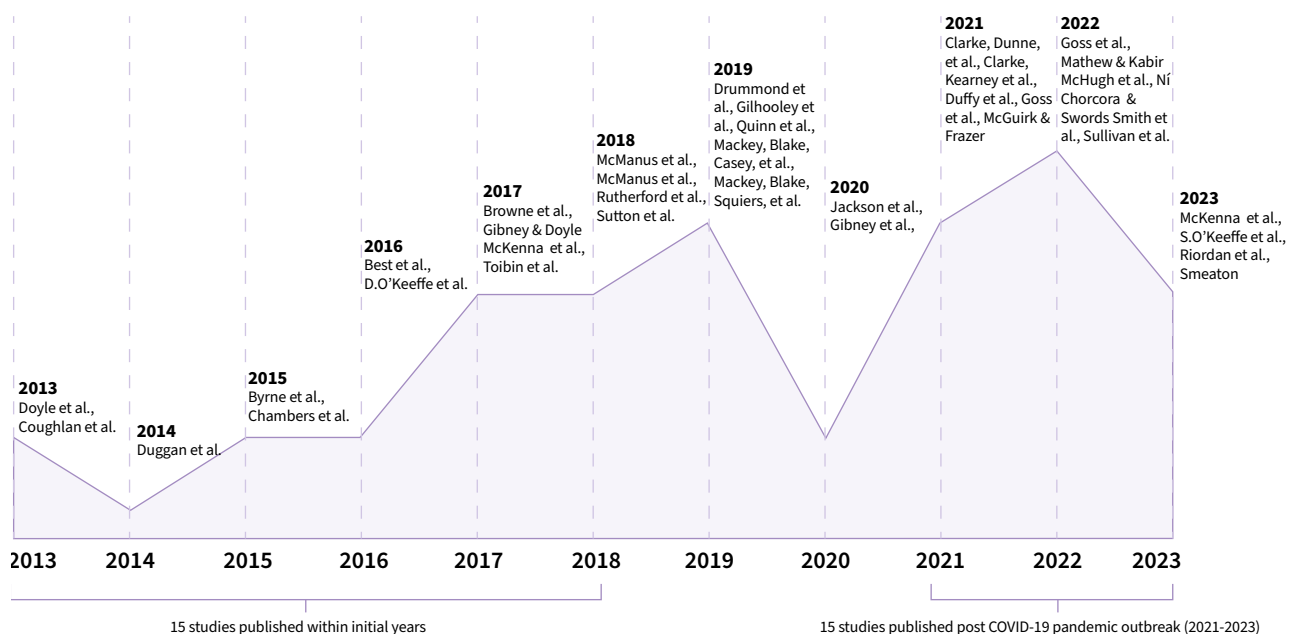


Figure 4.2 Timeline of Health Literacy Research in Ireland (2013 – 2023)

Health literacy is a component of various literacies mentioned in the field of health and education, including cultural, technological, media and scientific literacies. Health literacy is a multi-dimensional concept, and as such interest in health literacy across the island of Ireland has been through a multi level approach. Over the last ten years, different aspects of focus for health literacy research have been observed. One distinct health literacy theme observed was the prominence of mental health literacy research in Ireland.

Mental Health

Mental health literacy was a particular health literacy area which has seen increased focus in recent years, interlinked within the broader lens for clinical, community and education research discussed further in this report. Eight studies (Best *et al.*, 2016; Byrne *et al.*, 2015; Chambers *et al.*, 2015; Duffy *et al.*, 2021; McGuirk & Frazer, 2021; Ní Chorcora & Swords, 2022; D. O’Keeffe *et al.*, 2016; S. O’Keeffe *et al.*, 2023) reported on mental health literacy within their research.

The range of scope for research output reporting on mental health literacy linked to:

- mental health literacy in youth (Best *et al.*, 2016; Byrne *et al.*, 2015; Chambers *et al.*, 2015);
- mental health literacy in educational settings (McGuirk & Frazer, 2021; Ní Chorcora & Swords, 2022);
- mental health literacy in sport settings (Duffy *et al.*, 2021; S. O’Keeffe *et al.*, 2023).

One study focused specifically on an assessment of mental health literacy regarding a specific aspect of mental health for the general public (D. O’Keeffe *et al.*, 2016).

Domain Description

For the purposes of this report, there were three broad domain areas that health literacy research focused upon or in relation to over the last ten years on the island of Ireland (see Figure 4.3). All three domains of focus areas are reported in more detail below.

Clinical

There were 19 clinical population studies published in Ireland within the last ten years. Clinical focus was

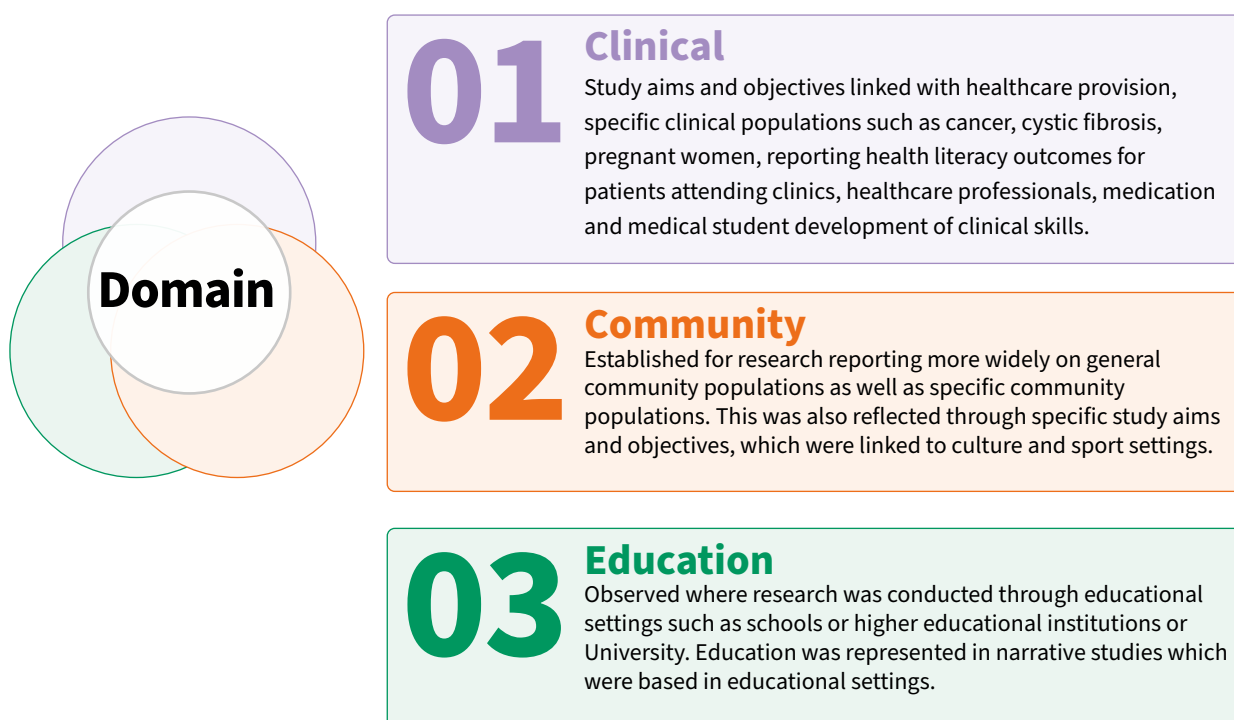


Figure 4.3 Three Domain Descriptions for Health Literacy Research in Ireland (2013 – 2023)

observed across:

- obstetric (Duggan *et al.*, 2014);
- chronic illness (Browne *et al.*, 2017)
- chronic pain: (Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019);
- cystic fibrosis (Jackson *et al.*, 2020);
- cancer (Clarke, Dunne, *et al.*, 2021; Clarke, Kearney, *et al.*, 2021; Rutherford *et al.*, 2018);
- populations and patients on dialysis (Riordan *et al.*, 2023).

Studies within a dominant clinical scope also presented characteristics in their sampling or location focus as community themes (McKenna *et al.*, 2017, 2018, 2023). Community themed elements included study design focus within community led adult health literacy classes (McKenna *et al.*, 2023) and a 12 week clinical risk reduction programme, undertaken in a community setting, referred to community based within the research methodology (McKenna *et al.*, 2017, 2018). An education theme could be observed as a secondary domain of focus, with the primary focus on clinical aims, methods and/ or outcomes. This was apparent within research where studies focused on clinical practitioners' development of clinical skills for improving health literacy during their medical training (Doyle *et al.*, 2013; Sullivan *et al.*, 2022).

Education

The educational system is also a dominant space for health literacy research on the Island of Ireland in the last decade, and subsequently there has been growing focus on adolescent and young adult populations. This includes research in:

- schools (Best *et al.*, 2016; Goss *et al.*, 2021, 2022; McGuirk & Frazer, 2021; Smith *et al.*, 2022), and
- universities (McGuirk & Frazer, 2021).

Specifically, the review included one study within a domain focus on oral health literacy in third level students (Mathew & Kabir, 2022), and complimentary to supporting health

literacy for adolescents in education, the review also highlighted studies that included teachers (Ní Chorcora & Swords, 2022) and schools (McHugh *et al.*, 2022).

Community

Community settings/ groups, supported themes of clinical and education health literacy research through recruitment focus, study aims and objectives and overview. Notably, two studies focussed on community sports coaches and health literacy (Duffy *et al.*, 2021; S. O'Keeffe *et al.*, 2023). Both studies reported on health literacy research in Gaelic games with study focus ranging from coaches (Duffy *et al.*, 2021) to players (S. O'Keeffe *et al.*, 2023). Similarly, community populations were the focus format for one study (Gilhooley *et al.*, 2019) which reported on the experience of skin disease and relationships with healthcare providers in Traveller women in Ireland. Indeed, similarly the interlinking themes of community and clinical research patterns were evident in this review.

Studies that used national survey data for reporting were conducted providing an Irish context for health literacy outcomes:

- Two studies utilised the European Health Literacy Survey (HLS-EU), distributed to communities throughout Ireland, to report on health literacy for a sub-sample of 389 participants (Gibney & Doyle, 2017) and 1005 participants (Gibney *et al.*, 2020) from a possible national sample of 1005.
- One study used similar market research in national community wide populations was used (D. O'Keeffe *et al.*, 2016), which reported on the relationship between mental health literacy regarding schizophrenia and psychiatric stigma in the Republic of Ireland.

4.4.4 Monitoring and Evaluation

Evaluation of Health Literacy

Research undertaken in health literacy over the last ten years on the Island of Ireland reported both qualitative (39.8%) and quantitative (48.6%) outcomes with a further five studies (13.5%) utilising mixed methods outcome reporting (Byrne *et al.*, 2015; McKenna *et al.*, 2017, 2018; Ní Chorcora & Swords, 2022; Sullivan *et al.*, 2022).

Evaluation of health literacy, when employing quantitative methods, reported the use of surveys (51.4%). Indeed, commonly adopted assessment tools included:

- Newest Vital Sign (Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019; McManus *et al.*, 2018; Rutherford *et al.*, 2018; Toibin *et al.*, 2017);
- European Health Literacy Survey (Jackson *et al.*, 2020; McKenna *et al.*, 2017, 2018); REALM (Drummond *et al.*, 2019; Duggan *et al.*, 2014);
- Mental Health Literacy Scale (McGuirk & Frazer, 2021; S. O’Keeffe *et al.*, 2023);
- Oral Health Literacy (Mathew & Kabir, 2022).

Research reporting specifically on mental health literacy also utilised mental health assessment measures including a self-report Psychosis Information and Confidence Questionnaire or PICQ (Sutton *et al.*, 2018) and a 22 item measure on depression literacy (Duffy *et al.*, 2021).

Research also highlighted a number of different strategies employed by healthcare providers to ‘identify’ low health literacy, often as part of recruitment and sampling strategies, but also a lens for interpreting findings. This was observed in one study (Quinn *et al.*, 2019) where radiotherapist interpretation of health literacy was utilised in the strategies undertaken to identify patients’ health literacy levels. This was reported as qualitative descriptors through visual/ verbal/ non-verbal cues used such as language used by patients, the content of questions they asked, patient body language, demeanour and their ability to carry out instructions. Further to this, patient low education level, lower socioeconomic and non-professional group, and overuse of drugs and/ or alcohol were considered characteristics of low literacy considered by radiotherapists. Difficulties identified by radiotherapists in recognising patients with low health literacy were due to

the limited time they had with patients, along with patients not speaking or volunteering information. Similarly, radiotherapists’ lack of awareness of the prevalence of low health literacy was also reported along with their consideration of health literacy of elderly patients, and patients with limited English.

Qualitative study reporting utilising interviews supported 13.5% of research outcomes in the last ten years. The use of interviews varied along with other qualitative methods:

- semi structured individual interviews (Browne *et al.*, 2017; O’Riordan *et al.*, 2023; Quinn *et al.*, 2019) to
- focus group interviews (Gilhooley *et al.*, 2019; Goss *et al.*, 2021; Smith *et al.*, 2022).
- vignette responses were noted by two studies (Chambers *et al.*, 2015; D. O’Keeffe *et al.*, 2016) with
- survey questions through a qualitative evaluation used for one study (Coughlan *et al.*, 2013).

One common method of reporting health literacy on the Island of Ireland was not observed in this report.

Health Literacy Level

Health literacy outcomes were reported in a variety of means within the included studies. Where an indication of health literacy for a population could be measured, five studies were able to report an >50% outcome for limited or inadequate measure of health literacy in their findings (Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019; Mathew & Kabir, 2022; McKenna *et al.*, 2017, 2018). Further to this, poor levels of psychosis mental health literacy for professionals working with youth was also recorded (Sutton *et al.*, 2018). Clinical settings/ populations demonstrated a range of inadequate or limited health literacy represented in research data over the last decade presented in Figure 4.4. The relationship of sex and health literacy was included in findings for three studies (Jackson *et al.*, 2020; Mackey, Blake, Casey, *et al.*, 2019; McGuirk & Frazer, 2021) with a significantly ($p < 0.001$) higher level of adequate health literacy being observed in female participants compared to male (Mackey, Blake, Casey, *et al.*, 2019; McGuirk & Frazer, 2021).

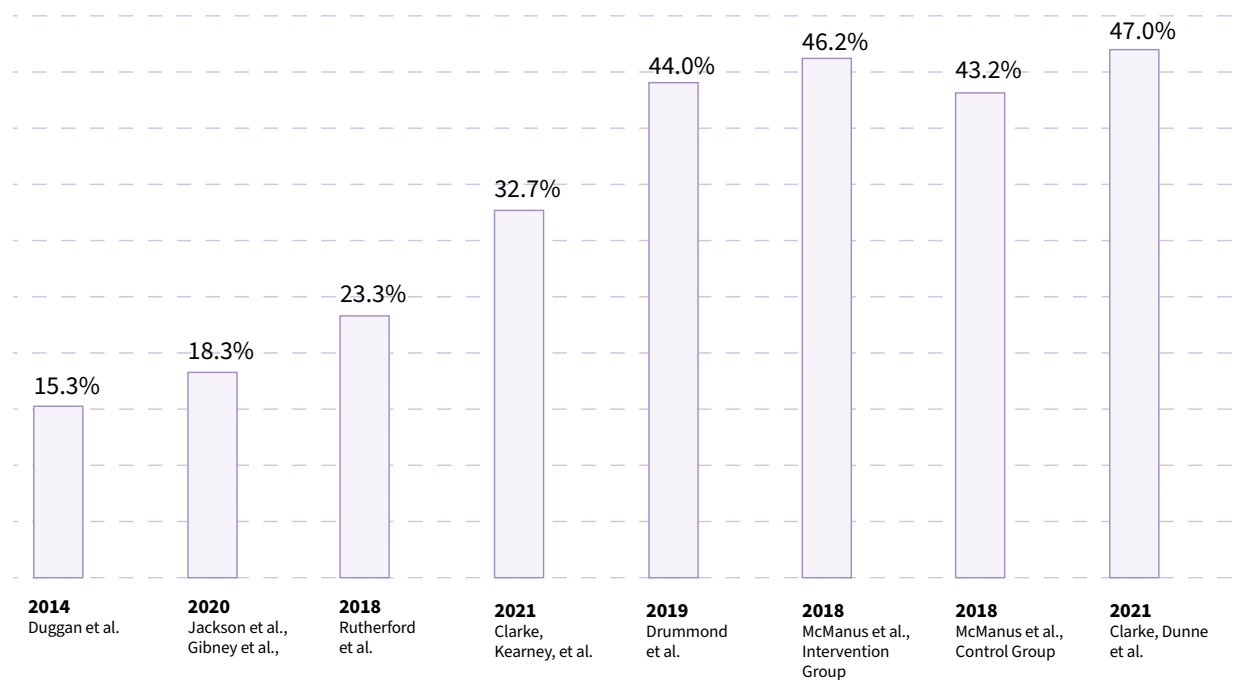


Figure 4. 4 Clinical observation of inadequate or limited health literacy in Ireland (2013 – 2023)

Education and Level of Health Literacy

Education, classified by highest level of completion, was reported as having a significant association ($p < .001$) on health literacy as reported by a proportion of studies (Clarke, Dunne, *et al.*, 2021; Duggan *et al.*, 2014; Mackey, Blake, Casey, *et al.*, 2019; Mackey, Blake, Squiers, *et al.*, 2019). Within study comparisons regarding type of education was also measured as one study (Mathew & Kabir, 2022) found non-medical students had higher inadequate oral health literacy (7.4%) compared to medical students (4.9%: $p = 0.081$). Similarly, age and health literacy was observed to have an association, with five studies reporting results that detailed the reduction of health literacy with age (Gibney *et al.*, 2020; Mackey, Blake, Squiers, *et al.*, 2019; Mathew & Kabir, 2022), with a further two studies citing a significant effect ($p < .05$: Duggan *et al.*, 2014); ($p < .0001$: Clarke, Dunne, *et al.*, 2021).

Employment and Level of Health Literacy

Employment and health literacy outcomes were reported detailing the differences in sample population. Specifically, one study reported inadequate health literacy according to participant employment status (Mackey, Blake, Casey, *et al.*, 2019). Indeed, inadequate health literacy for those employed (41%); inadequate health literacy for unemployed persons (10%); inadequate health literacy for those unable to work (27%) and inadequate health literacy for retired individuals (23%) were reported within sample differences.

Household income was also a reported evaluation measure for health literacy, with inadequate health literacy reported as 65% for monthly household incomes of $<€1350$ (Mackey, Blake, Casey, *et al.*, 2019) and adequate health literacy associated with household income $>€2950$ per month (Mackey, Blake, Squiers, *et al.*, 2019). Furthermore, medical card holders (54%) were observed in one study (Clarke, Dunne, *et al.*, 2021) to have higher levels of inadequate health literacy ($p < .001$).

Health Literacy Knowledge and Understanding

Health literacy outcomes were also found to be observed and reported in a number of other formats in Ireland. Health knowledge and understanding was evaluated across studies.

- O’Riordan *et al.*, (2023) reported limited participant understanding, along with participants’ poor health literacy and participant suffering, reflected limited patient empowerment.
- McKenna *et al.*, (2017) reported on other psychological factors that impact the application of health literacy capabilities. This included perceptions of control, such as being confident and proactive as opposed to not having control, and also dealing with family history in cardiovascular disease. Emotional reactions, including anxiety and coping, were also reported (McKenna *et al.*, 2017).

Empowerment or ownership of knowledge and understanding was also a finding in this review in relation to specific intervention approaches undertaken for health literacy in Ireland. Indeed, in one qualitative study, data contained positive statements from patients in the intervention group regarding trust and empowerment to participate in the effect of healthcare communication intervention (Toibin *et al.*, 2017). Health literacy improved significantly ($p < .01$), and most elements of participation increased slightly in both the groups (control and intervention) establishing the empowerment of the clinical population involved (Toibin *et al.*, 2017). Further to this, healthcare providers’ perceived effect of low health literacy (for individuals accessing healthcare), observed paternalistic attitude of patients (wanting the doctor to make treatment decisions); family interference and decreased patient autonomy; patient’s ability to manage self-care and side-effects (Quinn *et al.*, 2019).

Challenges presented by low levels of Health Literacy

A significant association between having limited health literacy and finding medical booklets and leaflets difficult

to understand, was a further outcome noted in relation to health knowledge and understanding (McManus *et al.*, 2018). Indeed, a significant difference ($p < 0.05$) was found between intervention and control groups in requiring help to read information and fill in forms from doctors, nurses or the hospital. 51.35% of participants in the control group, not exposed to the Universal Medication Schedule to rationalise understanding, found prescription vial instructions difficult ‘at least sometimes’. Outcomes reported after Phase 2 of a longitudinal study (McKenna *et al.*, 2018) for community clinical groups (previously reported at baseline (McKenna *et al.*, 2017)) demonstrated changes in this functional health literacy. This was attributed to re-engagement with health information and an increased understanding of risk and protective factors within this intervention. Furthermore, there were changes in interactive health literacy as changes in interactions with healthcare providers. Participants were noted to be more at ease in communicating with the healthcare providers as there was reinforcement/ reassurances through health programme feedback and interaction with the healthcare provider on the health concern, leading to increased knowledge and, therefore, participant confidence. Changes in critical health literacy through enhanced psychological insights and understanding the broader determinants of health changes in critical health literacy was also apparent (McKenna *et al.*, 2018).

Health literacy knowledge was shown to improve during an intervention for mental health literacy in Gaelic footballers (S. O’Keeffe *et al.*, 2023) as there were significant differences observed between intervention (who received a novel mental health literacy educational intervention program) and control groups at timepoint 2 ($p < .001$); timepoint 3 ($p < .001$) and timepoint 4 ($p < .001$) across a one month period. Indeed, mental health literacy was observed to be significant by interaction effect ($p < .001$) between groups where the educational intervention program improved the recognition of mental health issues and help-seeking resources for Gaelic footballers.

Similarly, attitudes towards seeking professional help to support mental health literacy were further observed to have a significant group by interaction effect ($p < .001$). Interventions in health knowledge and understanding, sourcing information, and looking for information are

common within the studies included in this review. Health information sourcing was also a component observed in health literacy research, with studies reporting on participants' identification of where their health knowledge is formed (Browne *et al.*, 2017; Gilhooley *et al.*, 2019; McKenna *et al.*, 2017; McManus *et al.*, 2018; O'Keeffe *et al.*, 2016).

Indeed, using health literacy capacities for self-management of health and illness was found to allow health information seeking through: keeping motivated; active and passive information seeking; appraising information and making sense of information (McKenna *et al.*, 2017).

- Healthcare providers were also reported as health information sources and support (Browne *et al.*, 2017; Gilhooley *et al.*, 2019; McKenna *et al.*, 2017).
- General practitioners (GPs) were cited as the main source of health information for patients (Browne *et al.*, 2017). Consequently, GPs were also highlighted (59.8%) as a support for individuals to gain health support (D. O'Keeffe *et al.*, 2016).

In youth, it was found that 65.8% of adolescents would cite a mental health professional as the support for individuals who require healthcare intervention when mental health issues were recognised in a peer (Byrne *et al.*, 2015). However, findings regarding help and support from other support professionals indicated that 95.6% teachers believed they did not have adequate training to support children with mental difficulties (Ní Chorcora & Swords, 2022).

The relationship with the healthcare provider, including the qualities of the provider (listening, good rapport, trust and feeling cared for), and the support for accessing and appraising information with the healthcare provider, was found to be important (McKenna *et al.*, 2017). Trust and communication were also found to be key considerations for healthcare providers in research focus with traveller populations (Gilhooley *et al.*, 2019). When relationships with healthcare providers deteriorated, as a result of bilateral poor health literacy in travellers (insufficient information received on management skin disease along

with lower literacy levels), disillusionment with the medical profession ensued. This was compounded by literacy challenges and barriers (Gilhooley *et al.*, 2019; McManus *et al.*, 2018). For example, participants reported their literacy levels were not assessed or considered before information was provided, resulting in some participants receiving incomprehensible information (Gilhooley *et al.*, 2019). Over half of participants in a further study of ward patients across eight hospitals, reported challenges in understanding medical booklets or leaflets as well as difficulty filling out medical forms (McManus *et al.*, 2018). Indeed, 45.7% of participants in a national community based study expressed motivation for a health literate health care system (Coughlan *et al.*, 2013).

Health Literacy Advocacy

Looking for information and health support was also identified in a number of studies in relation to health literacy:

- Mental health literacy was reported upon, 54.5% of participants reported seeking help if in same situation (D. O'Keeffe *et al.*, 2016) with other participants suggesting specific online strategies including search strategies and pathways for help-seeking (informal and formal online help-seeking: Best *et al.*, 2016).
- Men's cancer seeking behaviour was observed (Drummond *et al.*, 2019), reporting that 50.4% actively looked for cancer information and nearly all of those that did, reported it easy to find. However, significant differences exist for more men who actively look for cancer information and who found it easy, than those who have never looked and found it easy ($p < 0.001$). Similarly, significantly more men who actively look for cancer information, and who found it easy were able to compare information from different sources ($p < 0.001$) (Drummond *et al.*, 2019). Finally, there was no significant difference found between men who actively look for cancer information and those who do not in numerical literacy ($p = 0.281$), or disease risk understanding ($p = 0.498$).

Supporting health literacy of individuals for the future was a key theme throughout the literature suggesting action for health literacy service providers in Ireland:

- student feedback on patient information leaflets cited the importance of tailoring information for health literacy, including readability, and the utility of psychological theory for healthcare professionals (Doyle *et al.*, 2013);
- actions taken to improve the quality of existing written patient information and ensure changes are maintained, as well as implementing a process for user testing for new materials with service users (McKenna *et al.*, 2023);
- improvements in verbal communication with service-users using explicit, evidence based, and evidence informed health literacy communication techniques (McKenna *et al.*, 2023).

Limited health literacy awareness by healthcare professionals, as well as limited screening for health literacy in patients (Quinn *et al.*, 2019) in healthcare environments has been reported in Ireland. Research identified that experiential learning during clinical placements left students feeling more prepared for clinical practice (Sullivan *et al.*, 2022). Indeed, participants felt learning in this way offered a good foundation and graded exposure, as well as changing perspectives and addressing fears for practitioners to build confidence, and develop a paediatric mind-set.

The impact of others in supporting both one's own health literacy, and supporting the development of others, was evident over the last ten years. Where studies reported on healthcare or educational professionals, the impact of others in supporting health literacy was evident:

- Gaelic games coaches working with youth were found to have increased mental health literacy, which was significantly related to promotion in health via breadth of their role in supporting the young person (Duffy *et al.*, 2021). Importantly, mental health literacy in coaches was found to be directly associated with role efficacy and role breadth in early intervention for supporting young people's mental health.

- Irish Primary school teachers were able to correctly recognise a cluster of symptoms in a child as either anxiety or depression and distinguish between a child with an internalising disorder and a child experiencing situational distress (Ní Chorcora & Swords, 2022). Over half (54.5%) of teachers reported help giving responses for interaction with a child experiencing depression.

However, it is noted that teachers' confidence in their ability to help was the strongest predictor of their likelihood to help ($p < .05$). For young people, the impact of others on health literacy can be seen where study outcomes report perceived mental health to be more important than physical health for overall wellbeing (Goss *et al.*, 2021). Indeed, one study's responses were reflective of young people who are empathetic and view mental health from the perspective less as a marginal issue but a shared humanity (Chambers *et al.*, 2015).

Intervention through health literacy education, with a focus on youth, was also evident in study findings within recent years (Goss *et al.*, 2022; McHugh *et al.*, 2022; Smeaton, 2023; Smith *et al.*, 2022). Health literacy education has been promoted through different health topics such as food choice, mental health and wellbeing, physical activity and sedentary behaviour, sleep and substance misuse (Goss *et al.*, 2022), influence of social media, real life learning and lifestyle behaviours (Smith *et al.*, 2022) as well as behaviour change content (Smeaton, 2023) in health literacy development research. The preferred delivery of health literacy interventions was also valued if it was 'hands on' (McHugh *et al.*, 2022) and interactive (Smith *et al.*, 2022) when supporting health literacy in a younger demographic. Different pedagogical approaches also including 'healthy competition', problem solving and variety and choice (Smith *et al.*, 2022) were further reported as preferred engagement strategies for young people engaging in health literacy.

4.5 Conclusion

By examining the background and context, early policy, research, programmes, and the challenges for implementation, this review aims to contribute to the understanding of health literacy promotion in the region. Specifically, this section referred to the peer-reviewed research conducted on the Island of Ireland in the last decade. Critically, this systematic review only included peer reviewed publications. As such, there may be programmes and initiatives in relation to health literacy having previously, or currently, taking place across the island of Ireland that do not meet this criteria, and were therefore not included in this review. From this included work, several themes were identified in the existing literature, and critically, five key outcomes from this systematic review are offered (see Figure 4.5).

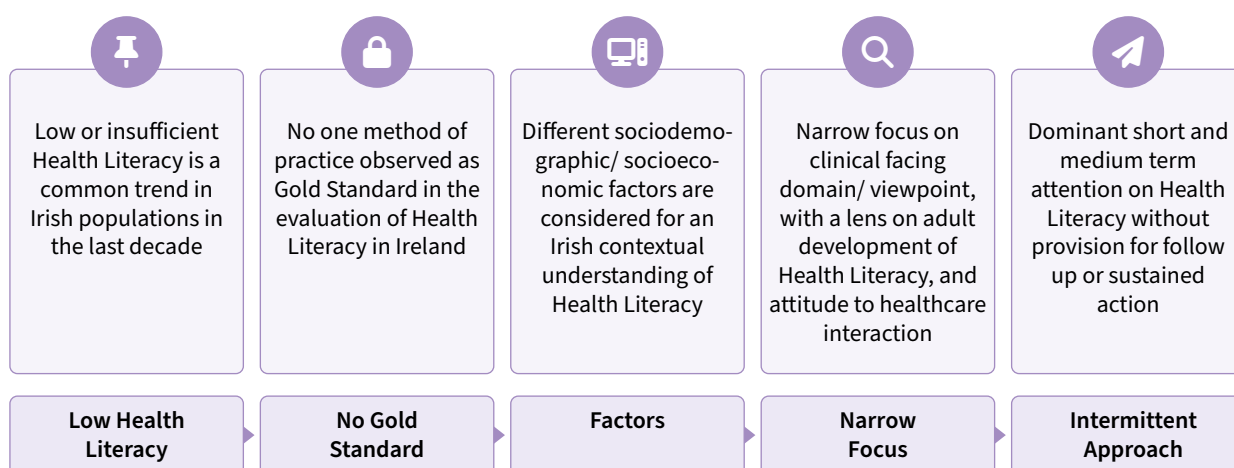


Figure 4. 5 Five Key Outcomes of a Systematic Review of Research in Ireland (2013 – 2023)

This section also offers valuable insights and recommendations for future efforts to enhance health literacy and improve the health and wellbeing of individuals in Ireland and Northern Ireland.

- Worryingly low levels of health literacy in Ireland have been reported throughout the last decade. However, this review has observed various evaluation methods undertaken to assess health literacy, pertaining to an observation that no gold standard of health literacy measurement has been agreed for an Irish context. A common approach, therefore, to understanding health literacy in Ireland has not been established. Steps towards identifying a health literacy measure for Ireland would support future research and intervention approaches.
- Notably, this review found a reliance on recruitment of adult populations for health literacy based research in the region. Spanning across different settings and focal points for research aims, adult health literacy has been a dominant Irish trend in developing knowledge and understanding in this area. This poses challenges for policymakers, educators and healthcare providers in supporting adolescent and youth, where prevention of low levels of health literacy can be targeted. Subsequently there are calls for more research to be developed in this area.

- Where health literacy levels have been reported, they have also linked to sociodemographic and socioeconomic descriptors. A relationship, therefore, with differing factors impacting on considerations for health literacy can be observed. However, the location of research over the last ten years has been towards specific city and suburb areas and may not be reflective of a varying demographic profile in Ireland. Some common descriptors are present in studies published to date, although there is an apparent emphasis on clinical populations as the prevalent focus area for research. This has meant that studies have linked with some specific directions towards healthcare practice and provision in Ireland. It is encouraging that emerging research in community and education fields has been observed through this systematic review. This emerging trend aligns to the broader focus of health literacy research developing since 2013. Development of sustainable research outputs in these areas, and across these sectors, can help support a broader focus on health literacy policy and practice in youth and adult populations across different settings.
- Short and medium term focus in health literacy investigation has also been evident, with a dominance in short term, cross sectional and narrative research observed in Ireland in the last decade. The reliance on a limited timeframe of research poses challenges in the creation of specific recommendations based on identified strengths, barriers, and needs in an Irish context. Indeed, sustained, and continuous observation of health literacy practices has not been viewed across Irish studies in the last ten years. A move towards a sustained research informed approach, across the lifecourse in Ireland, will support targeted and meaningful health literacy development.

Summary of evidence and recommendations for Section 4.

	Summary of evidence	Health literacy recommendations from authors	Alignment with WHO health literacy recommendation
4.1	In the (few) studies that have been carried out, it has been shown that health literacy levels across the island of Ireland are low or insufficient.	Further research needs to be carried out to comprehensively assess the levels of health literacy in Ireland.	Action area 1.2: Measure health literacy to identify and understand differences about who is being left behind
4.2	There is a lack of Irish-specific health literacy measurement tools.	In order to accurately assess the levels of health literacy across Ireland and subsequently identify the areas of concern, valid tools are required. Research is necessary to develop, trial and roll out a nationwide health literacy assessment to identify the health literacy strengths and weaknesses.	Action area 1.2: Measure health literacy to identify and understand differences about who is being left behind
4.3	Much of the research to date has focused on health literacy in adult populations and health literacy in clinical domains.	It has been well established that health literacy concerns much more than just adult and clinical populations, therefore, future research should consider health literacy across the lifecourse, starting with children and young people, and should also focus on the role and importance of health literacy skills in everyday life situations.	Action area 4: Target priority groups that are not receiving or easily accessing health information or health care
4.4	Thus far, research has focused on short- and medium-term research studies, with a lack of sustained longer-term approaches to investigate health literacy in Ireland.	It is important that future health literacy research is carried out over a longer term to identify the health literacy trends across the lifecourse, as well as the impact of potential health literacy policies and programs.	Action area 1.5: Overcome barriers to health literacy development and responsiveness

Section 5:

A contextual understanding of health literacy: Presenting perspectives and experiences from two Sláintecare Healthy Communities

5.1 Introduction

Whilst the previous section gives an overview of health literacy research published on the Island of Ireland over the last decade, there of course will be meaningful health literacy practice beyond published research to date. The WHO recommended that “projects and programmes should directly engage with people and communities for the purpose of health literacy development” (page 2, 2022). Responsive health literacy development requires thoughtful involvement of diverse local communities, and programmes and actions that ‘leave people behind’ can exacerbate health inequalities. As a result, this project sought to undertake meaningful engagement with community members.

A contextual understanding of health literacy on the Island of Ireland is required to support practical implications for policy makers and stakeholders to inform change. Indeed, a focus beyond the published literature is required to provide contextual insights into health literacy for Irish communities. Health literacy has been positioned as a relational concept, which emphasises individuals’ interactions with complex health and social systems (McKenna *et al.*, 2017). Established themes in health have demonstrated the need for participant voice in the development of a sustained and informed approach. Specifically, through Community Based Participatory Research (CBPR), partnering, or co-producing, research with a community organisation or group will develop, deliver and manage a research project (Health Service Executive Research and Development, 2021).

In 2021, Sláintecare Healthy Ireland in the Department of Health, working with the HSE and local authorities and community agencies, launched the Sláintecare Healthy Communities Programme to provide increased health and wellbeing services in 19 community areas across Ireland. An evidenced based process identified local areas in which health and wellbeing risk factors are particularly concentrated. Subsequently, particular initiatives are targeted for delivery to help promote and improve the overall health and wellbeing of people in those communities. The process to identify the Sláintecare Programme communities, was initiated by the Health Intelligence Unit in the HSE utilising the Health Atlas application (Health Service Executive Research and Development, 2024). The Health Atlas provides detailed profiles by small area and electoral district level. Applying the Pobal HP Deprivation index (Hasse and Pratschke, 2017) at these levels, identified areas with highest deprivation scores. The Pobal HP Deprivation Index (Hasse and Pratschke, 2017), is the core index for the Republic of Ireland and covers the small areas of the 2006, 2011, 2016 and 2022 Censuses. It is based on the combination of three dimensions of relative affluence and deprivation: Demographic Profile, Social Class Composition, Labour Market Situation. Subsequently, Sláintecare Healthy Community areas were identified for enhanced access to the full enhanced health and wellbeing programme. As part of the initial stages of the Sláintecare Healthy Communities Programme, health literacy was identified as an area of need by local development officers in their respective communities, leading to the current research collaboration.

The Slaintecare reform programme, therefore, can be seen to drive the reduction of health inequalities in Ireland. Slaintecare Healthy Communities is focussed on defined geographic areas of high deprivation, where interventions can be tailored according to the contextual factors within these areas with strong community engagement. This enables the provision of specific and integrated interventions that will have greater impact than general population focussed interventions.



This study aimed to explore the health literacy strengths, needs and issues encountered in Finglas and Cabra, representing an urban demographic Slaintecare Healthy Community area, and Mayo, recognised as a rural Slaintecare Healthy Community area.

Finglas and Cabra Slaintecare area was selected by the Department of Health based on evidence of health inequalities (HP Pobal Deprivation -12.7 to -20.3).

Finglas and Cabra is one of four Dublin City Programme Slaintecare areas and is formed from a cluster of electoral divisions including Finglas North A, Finglas North B, Finglas South, A, Finglas South C, Finglas South D, Cabra West A and Cabra West B,.

Specific to this Slaintecare area, urban demographic information associated includes population change increase. This was observed through a higher than state average of single parent families, with Finglas North A reported as one of 7 unemployment blackspots in Dublin City, with unemployment rates approximately twice the Dublin county rate.



West Mayo (Mayo) was identified as a Slaintecare Healthy Community, recording HP Pobal Deprivation as - 1.4 to - 18.3. The Mayo Slaintecare Healthy Community area covers the Erris Peninsula, from Lacken down to Newport and all the way to Achill.

The rural landscape of West Mayo provides reference to the area's situation in respect to the economic and social context of the wider county and rest of Ireland. An example of rural isolation can be represented in time with an average bus journey from Belmullet (the largest settlement in the Erris area to Castlebar the County town of Mayo taking up to 1 hour and 40 minutes journey time. Mayo has an ageing population, with observation of depopulation noted in the parish towns, islands and villages.



5.2 Methods

5.2.1 Study Design

Purposive sampling, with the aim of generating insight and in-depth understanding was undertaken (Patton, 2002). Sampling was initiated through Slaintecare and community networks within the rural (Mayo) and urban (Finglas/ Cabra) areas to recruit participants with lived experience of the health literacy strengths, needs and issues encountered in the Slaintecare Healthy Communities focus areas. Service providers and service users, along with general community participants were approached formally and informally for study participation. This included direct email to stakeholders within areas (where publicly email addresses were available), along with collaborative effort for recruitment through existing networks held by the Slaintecare Health Communities Local Development Officers and the research team.

Semi-structured interviews were employed, through a mix of focus group and individual interview as appropriate to participant availability and preference. In reflection of best practice, one researcher (MM) conducted all interviews irrespective of the large geographical landscape involved in this study. Time intensive, semi-structured face to face data collection was undertaken during location engagement with participants in January 2024 for the rural community area. This formed a blend of focus groups, and individual interviews, in a range of community areas in the Mayo Sláintecare area. This was followed with individual interviews undertaken online for participants recruited/ available after this timeframe up until February 2024. Similarly, focus group and individual face to face interviews were undertaken in the Finglas and Cabra Sláintecare area, where access and arrangement was supported for participants in community facilities. Where time restrictions and participant availability was impacted, online interviews were conducted. Data collection was undertaken across a four month timeframe (November 2023 to February 2024) for the urban area.

5.2.2 Participants

Thirteen focus groups and 15 individual interviews took place, with 75% of these conducted in person. Of the 13 focus groups, group size ranged according to availability and recruitment for the study, with the average group size of 7 participants in each of these (mode). In total, 105 individuals were recruited for interview ($n = 75$ female and $n = 30$ male). Participants included those involved in community initiative involvement and service users such as Men's Sheds and Sister Sheds, Adult Literacy Classes, Community Health Groups, Exercise Groups, Retirement Groups, Drug and Alcohol taskforce, Suicide Prevention and Youth Groups.

Interview questions were framed around current research in health literacy and were developed by an experienced research team. The semi-structured interview guide was then reviewed with Sláintecare Health Community Local Development Officers for each area, refined, and then agreed prior to interviews taking place. Participants provided written consent for participation, and were reminded of the ethical procedures employed regarding confidentiality arrangements. Interviews averaged 40

minutes in length, with recording undertaken by password secure devices. Recordings were transcribed verbatim by two research team members. Member checking was completed by the first author (MM) for comparison.

5.2.3 Data Analysis

Transcriptions were uploaded to NVivo (QSR International Pty Ltd., 2018, Version 12). Data was analysed using Braun and Clarke's six phase approach to Reflexive Thematic Analysis (RTA). After initial familiarisation with the data, first level coding was undertaken independently by the lead researcher (MM) for the first six transcriptions. Codes were generated and then discussed with research team members separately, who acted as 'critical friends' and supported a rigorous analysis of the subsequent coding. The initial themes were then reviewed, developed and structured. Throughout this process, the themes were refined, defined and renamed until they were deemed appropriate.

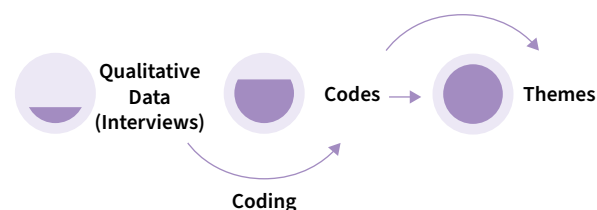


Figure 5.1 Process of comparing segments of text within and between codes to generate themes

The reporting phase was completed after the codes and themes developed (Figure 5.1). The findings predominantly reflect the first author's analysis of the data (MM) and were challenged by the co-authors, leading to rich, thorough and reflexive analysis. Initial analysis has allowed us to undertake a systematic approach to identifying and reporting salient features of the data. Further analysis and synthesis of the data over time provided more in depth formatting of the central organising concepts which are presented in the following sections.

5.3 Results

Five themes were identified, which are illustrated in Figure 5.2. These themes detailed participants’ strengths, needs and challenges in health literacy in their communities.

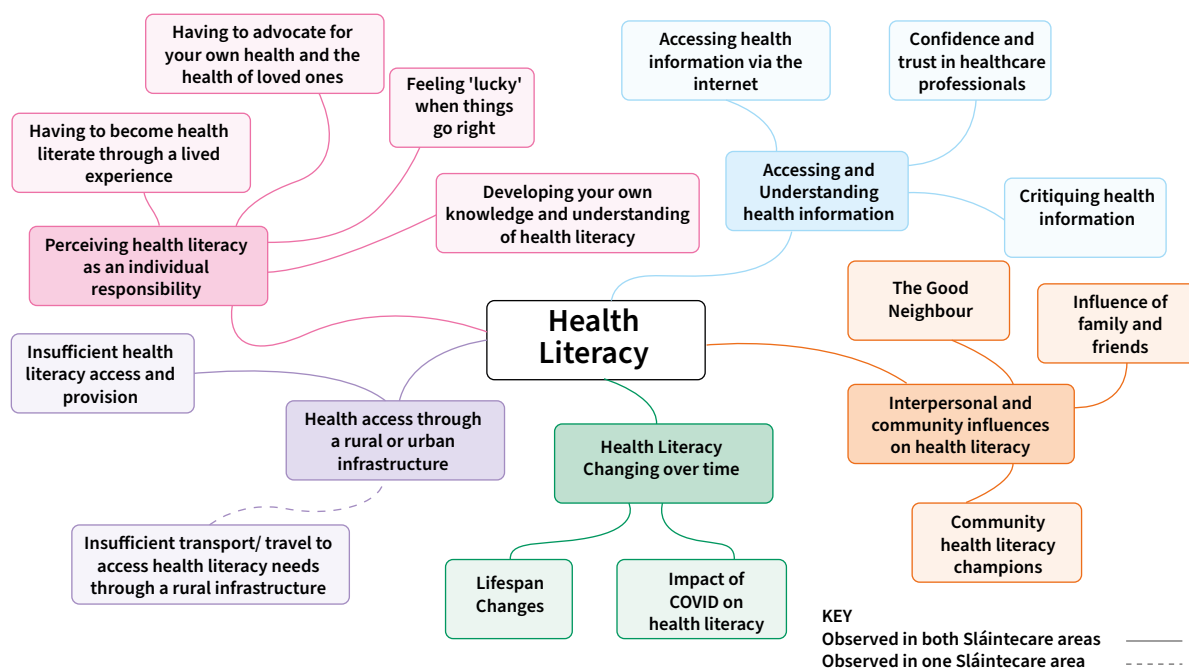


Figure 5.2 Thematic Map of Health Literacy Themes and Sub Themes

5.3.1 Accessing and understanding health information

Accessing health information via the internet

Health information was accessed in various ways by participants. One recurring method was the use of the internet for exploring health information, for example “I check the HSE website sometimes” (Individual 22: Mayo). Across both locations participants highlighted the ease of searching for information they wanted, Mayo community members repeatedly spoke of “Dr Google”. The ease of accessibility and immediate contact with information was important for many, “somebody can press a button on their laptop and go “Oh, right. That’s all the health stuff” (Focus Group 1: Finglas and Cabra). Participants also suggested innovative ways of using the internet to support their health:

...and chat GPT now. You can say “make me a healthy menu for the week for six people. One of my boys doesn’t eat this, one doesn’t eat this. This is how much money I have” and it’ll create a menu for the week (Focus Group 19: Mayo)

Critiquing health information

Understanding information provided through internet sources was a challenge for some. A participant spoke of the potential downsides of the sheer amount of readily available health information:

Because we can all diagnose ourselves...now to me, maybe not to the doctor’s delight. You know, there’s things like that that have improved. Probably the majority of you have smartphones. If you don’t know a word, you’re looking it up straight

away, and you have an answer for everything. So times have changed, but there are still plenty in the community that maybe not be on this level. (Focus Group 14: Mayo)

This was stressed by another participant, who, in speaking about how she accessed health information on social media reflected “although TikTok can have misleading information... it’s hard to decipher which is real, and which is not” (Focus Group 27: Finglas and Cabra). Other participants also spoke of being wary of the information they obtained online “I do double check it” (Individual 28: Finglas and Cabra) and “Some of the stuff you mightn’t want to take too much heed of... (Individual 7: Finglas and Cabra).

In some cases however, the availability of health information on the internet allowed individuals to feel more informed in making judgements, for example, around medication “if you were put on something [prescribed medication] and you weren’t quite sure what it was. Sometimes I would Google it just to see... And the side effects” (Focus Group 14: Mayo).

Confidence and trust in healthcare professionals

Healthcare professionals were frequently mentioned as trusted sources for health information. Community members in both areas indicated having confidence and trust in their healthcare professionals when accessing and understanding health information and healthcare. Examples ranged from accessing information from a local GP in the community:

Their [community participants in activator poles programme] relationship with their GP, I suppose, is key to them trusting their GP.. And they had that trust this [GP], this was the advice, and that’s the advice I’m going to follow and or if they were going to Galway or going to Castlebar to the hospital. That was the advice we’re going to follow. (Individual 25: Mayo)

to other medical professionals such as physiotherapists, pharmacists and other specialists in hospital settings:

If you ask questions in the pharmacy, they’re [the pharmacists are] really good. If I wasn’t [sure] what [medication] I was taking or I’m not sure about this or that, they would know. (Focus Group 16: Mayo)

Despite this, other participants called for further support “I’d like to know like better ways of dealing with it [a chronic condition], managing it. I think just more transparency around medical histories in general. That would be amazing” (Individual 28: Finglas and Cabra).

Trust and confidence was observed in other community healthcare professionals working outside of a medical setting. For example, one focus group discussed the value and importance of a specific physical activity programme, and how it was less about the activity itself, but about the informative way it was delivered:

And she [the physical activity programme leader] really focused on letting us know that it was all about being able to maintain the strength and balance, and the range of motion that we have. And then she talked a lot about the stretches as the way to keep us moving, to be able to keep moving so that we cannot seize up. And she did a lot. (Focus Group 16: Mayo)

5.3.2 Health literacy changing over time

Lifespan changes

Participants reflected on health literacy as changing over time through observations made in their own lives and the lives of others in their community settings. Generational differences were highlighted in both community locations as individuals reflected on health literacy changing, also voicing differences across age groups. In Finglas and Cabra, this was reflected in healthy food choices and the change over time towards the increased availability of convenience foods “I suppose in our generation there wasn’t as much junk food” (Individual 4: Finglas and Cabra) with others reflecting “I just think it’s harder now. It’s definitely harder for younger people” (Individual 10: Finglas and Cabra) regarding food choices. Despite these difficulties, other participants in a focus group in Finglas and Cabra spoke of an increase in knowledge in young people, and cited specific health eating programmes, initiatives and incentives in schools.

In Mayo, there was more of a general comparison to age ranges and differences in a person’s outlook, time and

health choices. This was spoken of in relation to change in lifestyles, for example “people 20 years ago didn’t have the time to walk, because they were so busy farming and doing turf, doing different things” (Focus Group 14: Mayo), but again, there was a perception of a change in attitude in younger people “Even the grandchildren, they’re kind of more [health] conscious. Yes. Yeah, we’re [the family] talking about “is this healthy, is that healthy?” (Focus Group 13: Mayo).

Impact of COVID-19 on health literacy

The impact of the COVID-19 pandemic contributing to health literacy changing over time in both community settings was observed in both areas. This was discussed through both a positive and negative lens by community participants in Finglas and Cabra, with some participants speaking of how it altered their food choices “it kind of brought you back to basics when you couldn’t go to restaurants, which I didn’t realise how often I went, which was quite a lot. So I started having to cook and cook at home” (Individual 8: Finglas and Cabra).

Others spoke of community food projects they enjoyed, it was “basically a large Whatsapp group. And then every week you get food delivered, and then you’d make it and send a picture in” (Individual 28: Finglas and Cabra). The negative impact of COVID-19 on functional health literacy was observed by participants in reflection of the development of unhealthy behaviours and the impact this had “when COVID started, kind of...my weight went up” (Individual 6: Finglas and Cabra).

The specific influence of social distancing “still, after COVID” (Focus Group 14: Mayo) was observed in relation to increasing rural isolation and less social interaction for individuals in Mayo “since COVID people definitely aren’t as social in the country, they’re not dropping in and out like they used to” (Focus Group 13: Mayo).

With other participants hopeful for this to improve “it’d be great to get back to that because I know, both mentally and physically, of all the things that were going on, it’s for the benefit of the community” (Focus Group 14: Mayo).

In one case, participants spoke openly and honestly about how the isolation of the pandemic was linked to substance misuse:

...getting dependent on alcohol and drugs. So, like, isolation, can be the very start of it...That’s what COVID did to a lot of people...There were a lot of people that weren’t [addicted] beforehand but afterward they were chronic. (Individual 22: Mayo)

5.3.3 Perceiving health literacy as an individual responsibility

Having to advocate for your own health and the health of loved ones

Advocating for one’s own health and the health of loved ones was demonstrated in a number of different ways in relation to health literacy. Individual advocacy was observed in the confidence in health behaviour changes and decisions taken in relation to health literacy “if there’s a slight lifestyle to be changed, I would be prepared to read up about it and go down the road to changing it and like at the end of the day, it’s for my health” (Individual 4: Finglas and Cabra).

Advocacy for loved ones was found in relation to supporting overall health. This was particularly spoken of in terms of close family members, and with tones of frustration “I had to fight” (Focus Group 1: Finglas and Cabra) in chasing medical letters, appointments, referrals and medication. Participants within focus groups in both areas also spoke of the importance of asking questions, and sometimes this included preparing written notes before and taking notes during an appointment. Yet one participant identified that this responsibility was also on the person delivering the communication “I think we have to [ask questions], so as we have to learn to speak up and I think doctors have gotten much better at understanding that we don’t, you know, that we [need to] ask questions” (Focus Group 16: Mayo).

Particular groups of the community were mentioned as needing health literacy advocates as sometimes these appointments could be “too much” (Focus Group 16: Mayo), this included “the older generation of men that are unwilling to say they have something wrong” (Focus Group 14: Mayo). Commenting that in many cases, by the time men sought out medical treatment, it could be too late. Specific prevalent chronic health conditions were

also mentioned, for example “they have that Celtic curse, they [the locals] call it, hemochromatosis. Well. That’s the thing that’s very high on the island that people didn’t know about 20 years ago.” (Focus Group 14: Mayo).

Developing your own knowledge and understanding of health literacy

Developing one’s own knowledge and understanding of health literacy was observed in different ways, as participants explained how health knowledge and understanding was established. Notably, this was spoken of in a way that suggested individuals felt responsible for their own health literacy:

When you live on your own... my next step is a nursing home if something happens. You know, my kids won't be coming back and I'm not saying they wouldn't come back, what I'm saying is they're not, I would never have them come back for me. (Individual 8: Finglas and Cabra)

Developing health literacy included knowledge and awareness “I am becoming aware [of my health], and that’s where I am becoming more conscious [of my health]” (Individual 5: Finglas and Cabra), seeking out health information “you kinda learn yourself” (Focus Group 27: Finglas and Cabra), and applying health information “I made the decision to do something about it and that’s why I’ve been here with [Drug and Alcohol Taskforce], and I’ve been going and trying my hardest” (Focus Group 27: Finglas and Cabra).

There were many conversations around engaging in community based health services. In Finglas and Cabra the importance of access to a communication class in the Education and Training Board (ETB) to support health literacy was evident “I see there’s a difference with, there’s a difference with me from coming up here [communication class], I’ve noticed a difference in my spelling and my reading and writing. A major difference: (Focus Group 1: Finglas and Cabra). This also made a difference in taking medications and booking medical appointments “we just make it our business, myself and my husband to, we say each June we make an appointment with a doctor and we get all our bloods done and that’s it” (Individual 10: Finglas and Cabra).

In Mayo, knowledge and understanding of health literacy

was also focused on individual perception of health and their informed choices to become more health literate, whether this be in relation to physical activity “I know I needed to walk as well. Walking was the only thing that helped [an injury] and I also wanted to, to learn the stuff to keep my brain active right” (Individual 15: Mayo) or other health behaviours such as “alcohol, trying to cut that down” (Individual 18: Mayo), because “you’ve got to do that for yourself haven’t you. It’s no use getting all this [health] information and sitting back and just not doing anything” (Focus Group 21: Mayo).

Feeling ‘lucky’ when things go right

Consistently positive health outcomes were framed by individuals feeling lucky and grateful, whether this was around general health “I’ve been very lucky, touch wood, with health, I’ve really only in the last couple of years, I’ve had a few kind of issues” (Individual 7: Finglas and Cabra) or specific events “I had a cardiac arrest. No... that’s a good news story, a very good news story, because percentages are not, not great. So I’m in that lucky position” (Individual 11: Finglas and Cabra).

People also spoke of being grateful to get access to medical services and support “sometimes we don’t have enough, easy access to stuff [medical services and support]. And I might be lucky in the sense that I have a lot of access to stuff [medical services and support]. But not everybody would have that same access as I do” (Individual 5: Finglas and Cabra). The difficulty in accessing medical services was exemplified by another participant’s experiences, that despite having to wait nine months for a mental health related appointment, was still grateful:

I’ve been struggling a lot lately myself, but due to my own issues, and my husband’s, so like that, trying to get appointments for the doctor, trying to get a private [appointment], [getting to] go see a specialist it has taken nine months, waiting nine months, but I was lucky enough now I’m after getting it in to the secretary, asking that ‘could you please... like any cancellation?... And lucky enough I did [get an appointment]. (Focus Group 1: Finglas and Cabra)

Others spoke of how “It all depends on your local GPs, and we’re lucky” and “thank God we’ve got two good doctors” (Focus Group 12: Mayo).

Outside of clinical settings, ‘luck’ still played a part in health promotion “I’m lucky in the way where I do have role models, and I have people to look up to and people to steer me in the right direction, but like then, not everybody has that” (Focus Group 27: Finglas and Cabra). ‘Luck’ was also needed to keep health promotion programmes and projects going:

suppose the key thing is sustainability of, of, of keeping the links open and sustainability of, of how you progress a project. And, you know, it can be serendipity, really, because we were very lucky with the group of people [involved in the community project]. And then, that there were people willing to step up and continue an initiative and are happy to do so. (Individual 25: Mayo)

In terms of health literacy needs and suggestions for the future, the sustainability of existing community initiatives was also perceived to be in part down to luck. There was a perception that some health programmes may be a ‘once off’, and that health messages changed too frequently with these changes in programmes.

Having to become health literate through a lived experience

I think health sneaks... health issues sneak up on people. And I think until you are faced with a health condition, and this is not my opinion, I think I’m being general. I think until you have to contend with something... And then you have to look at the realities of how to manage it, then health is on the radar more so. (Individual 25: Mayo)

Health literacy was often spoken about in relation to participant’s prior experiences with health challenges, this included injuries, operations, illnesses and chronic conditions. Participants also spoke honestly of how illness and bereavement in those close to them had also impacted their own health literacy. Respectfully, these quotes are included here in full:

I would say lived experience as well. In relation to my area work if someone has died, you’re going to be more aware if you’ve experienced a bereavement. If you’ve experienced loss through suicide, you’re going to be more aware of the information in the you know, that’s out there, the resources, the supports, as opposed to someone else. (Individual 26: Mayo)

Well I would have went through a lot of that with my son. My son was an alcoholic. So I would have been, I would have, you know, I would have encouraged it [seeking help], I would have, you know, got him help, got him help twice, actually. Unfortunately, in the last two years, he was dry, but the damage... the damage was done. But I would encourage my husband and my own family [to seek help]. (Individual 9: Finglas and Cabra)

Like I have a brother, he was my foster brother, but he died of an overdose. And it was from methadone and actually turned out it was from a combination of different drugs. So if he had just been appointed opportunities, if he wasn’t let down... if he wasn’t... you know what I mean... there’s so many contributing factors. And that’s really a strong, a strong focal point as to why I’m here today. (Focus Group 27: Finglas and Cabra)

5.3.4 Interpersonal and community influences on health literacy

Influence of family and friends

The influence of family on health literacy was exemplified in how health was supported between family members. In a wider discussion around isolation, one participant acknowledged “we have a big family, so there’s lots of support” (Individual 18: Mayo). In another interview, a participant spoke of how she had encouraged her husband to attend a medical screening service:

Well I decided when I turned 60 I was going to do that [be more health conscious]. He ignored me completely. And then I did convince him to start going [to the doctors] I’d say when he was about 65, and I’m glad I did. Because he has an issue with cholesterol and stomach acid and I don’t know which blood [condition]... he did get some... anyway, but basically he, he did have his bloods done for the prostate. And that is a bit high. And so that was a good thing. Yeah. So he goes once a year, and they keep an eye on that. (Individual 10: Finglas and Cabra)

When sharing experiences in a community health support group, one participant reflected on sharing her new knowledge with her family “Like that now, my nanny

wouldn't have been aware of anything like that...anything like that I was after learning here... she's blown away" (Focus Group 27: Finglas and Cabra). For this participant, the experience was so positive, it presented as an opportunity for improving health literacy for others "once we reach out to one person who is able to distribute that information to their peers, to their family, in their home life, in their work life, anything" and that this should be the 'goal' of any future health literacy initiatives (Focus Group 27: Finglas and Cabra).

Formal and informal caring responsibilities within families and between friends were also noted to impact on a person's health literacy. One participant spoke of how she would support her Mother "I do eh often ask them [medical practitioners] more questions. My ma struggles sometimes with her memory. So when she gets told something she likes to have me there just for the extra support. And she doesn't understand a lot of things they're saying, so I'll have to translate" (Individual 28: Finglas and Cabra). Acting as a 'health translator' was also a role adopted by one participant who reflected on how she supported her best friend with additional needs "So I always write things down for her or tell her to write things down so that she doesn't forget, as well as I don't know... I'd help her fill out any forms, explain any information that I could" (Individual 28: Finglas and Cabra).

Beyond close family and friends, other interpersonal influences on health literacy development became apparent. Particularly for those already engaged in health promotion programmes and initiatives, the influence of groups of friends and peers was clear "we share a lot of healthy stuff like that [food recipes and health knowledge]. Yeah, since I came here really" (Individual 15: Mayo). In other instances groups of friends acted as a supportive network when faced with health challenges "she could pick up the phone and any one of us [in the communication class] would help her, she's not on her own with her husband. I told her that we're here to help her" (Focus Group 1: Finglas and Cabra). Friends also acted as motivators to engage in more healthy behaviours"

I come to the class every week and everyone in the class has their problems but we all help each other. They're lovely ladies in the class and I love coming every week.

Because then it'll give me the confidence back. Yeah, no, because when my mother died my confidence was gone, and then, I'm usually a happy go lucky person and always jolly, but I mean, sometimes you can't be jolly every day. So when I come to the class...The people in the class know you're not in your good form and they help you because they're a great bunch of women in this class, and I'd do anything to help any friend in this class, I would do anything. (Focus Group 1: Finglas and Cabra)

The good neighbour

This subtheme was spoken of as the "goodwill of people" (Focus Group 20: Mayo) where "everyone is looking out for each other" (Individual 15: Mayo), particularly in Mayo, where community inhabitants face rural isolation and loneliness. One situation highlighted how important that community connectedness was:

Recently [we] had a problem in swim club with one lady and she was struggling with an illness, and we have about six of us and we took it in turns to go to the hospital, one to her washing, whatever she wanted. We'd speak to her family in the UK. I think it was good that we all worked together. And we weren't the only ones that do it. They do it in some other towns as well. I know there's other places there that do it, so the community there that bit does help. (Focus Group 21: Mayo)

However, in some cases, this feeling of a shared community was waning. One participant shared that although they felt comfortable as they were healthy and mobile at present, this wasn't the case for everyone "for older people you know, more people knocking on the door saying 'Are you okay?' You know, it's kind of, that doesn't happen anymore" (Individual 9: Finglas and Cabra).

Community health literacy champions

In many cases, specific individuals were recognised as health literacy champions who 'gave back' to their community. In both areas, influential individuals in drug and alcohol addiction and recovery and education were highlighted, and in particular, how those individuals interacted with the community "you know, it literally, that's nearly how you change people, change people through the heart rather than through the mind sometimes" (Individual 24: Mayo).

Community health literacy champions were not always in formal roles. Participants spoke about how they themselves shared health promotion opportunities, in this quote, regarding the women's shed "I really encourage anyone to join. It is so, so good for you" (Individual 9: Finglas and Cabra).

Formally, community health literacy champions were found as they undertook a more active role with influencing the community in Mayo. In some cases these were supported projects for example a Men's shed member "found out about some scheme it's called easy trees or easy breezy. And they're planting trees across Ireland. So we can put in for it and we can get how many saplings we want and get them planted across the island and mark where they go" (Focus Group 20: Mayo). In other instances this support included training "three of us did a leadership training, one day training" (Focus Group 16: Mayo) and "well, because I go to the ICA [Irish Countrywomen's Association], and they came and did a presentation. And they wanted someone to do an hour a week, which is not much in the grand scheme of things. So I volunteered" (Focus Group 14: Mayo).

Within Finglas and Cabra, in both focus groups and individual interviews, discussions identified that participants were supportive of education in youth so that improvements in health behaviours and choices are supported early in life. Subsequently, teachers were seen as important, but with the understanding "it's not fair dumping stuff on the teachers, but it is a good place for, as in that most children go to school" (Individual 5: Finglas and Cabra).

5.3.5 Health access through a rural or urban infrastructure

Challenges for accessing services in the community was a theme evident for both Finglas and Cabra, and Mayo Sláintecare areas. Although access to services was found to be similarly challenging in some aspects, there also were different issues highlighted by communities that impacted on their health literacy needs.

Insufficient health literacy access and provision

Focus group participants and individuals reported their changing access to healthcare resources. This was discussed as healthcare professionals in the local area providing access to medical knowledge and treatment, as well as accessible health resources. Commentary on retirement of local GPs "when the doctor retired... It all went downhill" (Focus Group 17: Mayo) and the reduction of staff in local rural settings, formed part of the concerns raised by the rural community "if you can't get a doctor, like what do you do?" (Focus Group 20: Mayo).

I think it's on their mind that, you know, it's an ageing, they're [community members] very aware that they are an ageing population, and they're very aware that their health services are reduced, because of the number of GPs that have been reduced. (Individual 25: Mayo)

Waiting times to access GP services in Finglas and Cabra Sláintecare area was observed as a concern:

I can remember the GP, you could phone the GP and I remember him calling down to see my mam or dad or whatever it was, and, you know, he would say yeah, I'll be down in half an hour or whatever. And he'd come down. Now, you can't, if you were trying the clinic oh yeah you're gonna have to ring the d-doc. Yeah, I think we've lost a lot. Yeah. We've lost a lot on our modernisation. (Individual 5: Finglas and Cabra)

The knock on effect of this was commented on in one interview, where the anticipation of the difficulty in getting a doctor's appointment meant people "put things on the long finger. And then there's a crisis situation" (Individual 11: Finglas and Cabra).

Insufficient access to healthcare practitioners with experience and knowledge on specific health needs was a concern for communities. A female participant highlighted her concern in supporting women's health, "there's not a lot of help out there for women going through menopause. I mean I have a male doctor and I'm even a bit reluctant even going down to him" (Focus Group 1: Finglas and Cabra). Further to this, the insufficient breadth of resources was spoken about as one individual highlighted "... going into the health system, it's fairly obvious that I'm clinically obese, I'm very heavy and I have difficulty with that. And

it's more difficult to get to get practical information about perhaps diet, or snacking are all the contributory things" (Focus Group 12: Mayo).

In Mayo this was particularly poignant due to limited healthcare practitioners available in a rural area, coupled with lack of specific knowledge in addiction and recovery support:

"some of them [GPs] don't, still don't understand, some of the older ones don't really understand the drug problem, my GP didn't even really, ... I don't know if I was the first person that went to him with a bad [addiction] problem" (Individual 22: Mayo).

The pressures on health care providers was acknowledged by participants. However, this was perceived to impact health literacy of patients "I find is that sometimes the GP is kind of rushed, and doesn't particularly have time to maybe elaborate or be a bit more wanting to hear what you're thinking about" (Individual 5: Finglas and Cabra).

Diet and nutrition formed focal themes in this context for Finglas and Cabra Sláintecare community as challenges to access quality food were reported due to the limited provision, affordability and availability of nutritional resources to support health in an urban area:

So I don't really have time to exercise regularly, I try to eat more on the better side, but that's also hard when the access to just good quality food is horrific and the price, so you can't even buy it. So you just have to be stuck with the not the best food anyways (Individual 28: Finglas and Cabra)

In line with this, incentives were suggested to support population behaviour change in how urban community members plan their diet and access community resources. These covered mostly financial aspects in supporting health needs. Suggestions were also made to utilise existing community resources to their full extent to support the community needs in connecting with others in their area. For example, this included halls, beaches, parks etc. These locations were also viewed as a platform to, sharing information on community initiatives to support wider health aspects "it would probably be good to have like a community notice board. I know we all have our own individual groups. But if there was something

that you could put up what's on locally?" (Focus Group 14: Mayo). Advertising, social media and local radio were also identified as potential avenues for sharing health information.

Insufficient transport/ travel to access health literacy needs through a rural infrastructure

In Mayo, distance and time required to access specific healthcare services were a common issue, as primary services were limited in the rural community setting, with one participant stating "Our district hospital has been completely let down in the last 20 years" (Focus Group 12: Mayo). This was seen as a particular barrier for older people in the community "it's not right, that they [older members of the community] have to travel these bad roads to get to services that should be on our doorstep" (Focus Group 17: Mayo), and a particular worry for medical emergencies "If you have an emergency. We have the worst road to travel on to get help...You could be waiting up to four hours for an ambulance to come to you" (Focus Group 17: Mayo).

Challenges to general life in a rural community were prominent in conversations that provided descriptors of access in relation to insufficient infrastructure and public spaces. The general community facility landscape provided a challenge in differing ways including road networks, public transport, and community pathways. The financial implications of limited infrastructure was also a focal point regarding conversation on supporting family life in general, including the financial implications of infrastructure within a rural community:

We had a chiropodist, a HSE chiropodist in this area. She was taken out to the areas about three, four years ago, her contract was not renewed. So if you need footcare, you have to go to Castlebar. Or pay privately for it. (Focus Group 17: Mayo)

In line with this subtheme, many calls were made to develop and improve infrastructure (e.g improve roads, set up primary care clinics) and consideration was given by participants to different challenges in engaging specific groups (e.g. male only sessions).

Summary of evidence and recommendations for Section 5.

	Summary of evidence	Health literacy recommendations from authors	Alignment with WHO health literacy recommendation
5.1	Many community participants access health information in different ways. The ease and accessibility of the internet to obtain health information and fact check specific health issues can be challenging.	Given the wide range of misinformation and disinformation readily available on the internet, it is crucial that adequate health literacy education is provided so that people can critique the health sources and health information provided online.	Action area 4: Target priority groups that are not receiving or easily accessing health information or health care Action area 4.1: People at risk of digital health exclusion
5.2	Participants highlighted the importance of delivering health literacy education at a young age in order to inform young people on how best to make healthy choices, live healthier lives and build healthier families.	Prevention of unhealthy behaviours earlier in life through targeted intervention. Education to develop health literate and informed communities. The development of sustainable, long term school-based health literacy education that aims to tackle the context specific health issues and provide young people with the necessary knowledge and ability to lead healthier lives.	Action area 2.5: Incorporate health literacy-responsive practice into health education curricula and continuing professional development
5.3	Within the workshops, many of the participants discussed how they felt personal responsibility to develop the knowledge and competencies to manage their own health and the health of their loved ones.	It is important that there is an adequate provision of supports and methods to empower individuals to develop the knowledge and competencies to manage their own health and the health of their loved ones, as well as a clear signposting of the healthcare services available within the specific context to remove the pressure on the individual.	Action area 1.5: Overcome barriers to health literacy development and responsiveness
5.4	The importance of interpersonal relationships and community influence when it comes to managing one's health. For example, the influence of the support systems provided by family and friends on making positive health choices.	The provision of accessible opportunities in the local community for individuals to interact socially, share their experiences and learn from one another. Furthermore, ongoing social activities should be clearly communicated through the appropriate channels as to reach those most in need.	Action area 3: Build community health literacy
5.5	The inaccessibility of medical services, such as lack of GP surgeries, long waiting times for a GP appointment, poor communication of healthcare information, and inadequate transport to/ from healthcare providers.	Educate health literate healthcare practitioners working in communities that are targeted for health literacy development.	Action area 2: Build health literacy responsive health systems Action area 2.4: Improve the health literacy responsiveness of health workers

Section 6:

Using a multi-stakeholder experience-based design process to co-develop health literacy recommendations

6.1 Introduction

Driven by the local needs, strengths and challenges identified in Section 5, and the wider knowledge from the earlier sections of this report, the final portion of this research project proposed to co-design a series of recommendations with stakeholders, suggesting targeted actions for the future.

Among other advantages, co-produced research can: i) recognise, value, and utilise experiential knowledge, ii) support the prioritisation of research topics, aims, and questions by people who are typically excluded from or marginalised in the research process, iii) address inequities in power and amplify marginalised or excluded voices through the recruitment of a diverse range of research participants and iv) deliver impactful research that can provide solutions to problems and positively influence people's lives (Smith *et al.* 2022). Therefore utilising a co-design process to check, challenge, collaborate and create recommendations for health literacy solutions in each case study area wholly aligned with the wider purpose of this project.

A specific method of experience-based co-design is the Double Diamond Design Approach (DDDA) that has been used to develop service improvements in health and social care (Design Council, 2015; Wolstenholme *et al.*, 2017). The DDDA is a framework often used in design thinking to tackle and solve complex problems. Co-design, within the context of the Double Diamond, refers to involving end-users, stakeholders, and relevant parties throughout the design process, ensuring that their perspectives, needs, and insights are integrated into the solution. With DDDA,

stakeholders progress through a four-stage reflective process to discover, define, develop, and deliver an innovative solution to a problem.

The specific aim of this study was to revise the strengths, barriers, needs, and propose potential recommendations for health literacy in each Sláintecare Healthy Community, using an adapted DDDA.

6.2 Methods

6.2.1 Participants

Purposive sampling was used to identify participants for these workshops. The stakeholders, in each respective case study area, were specifically invited to promote a representation of the different demographics, local authorities and a range of experiences. This included participants who had previously been involved in earlier phases of the project, and had indicated a willingness to continue their participation (Section 5). Stakeholders were contacted via telephone and/or e-mail and invited to register online for the workshop in their respective area. All participants gave informed consent to take part in the study (namely, for the discussions to be recorded).

6.2.2 Overview

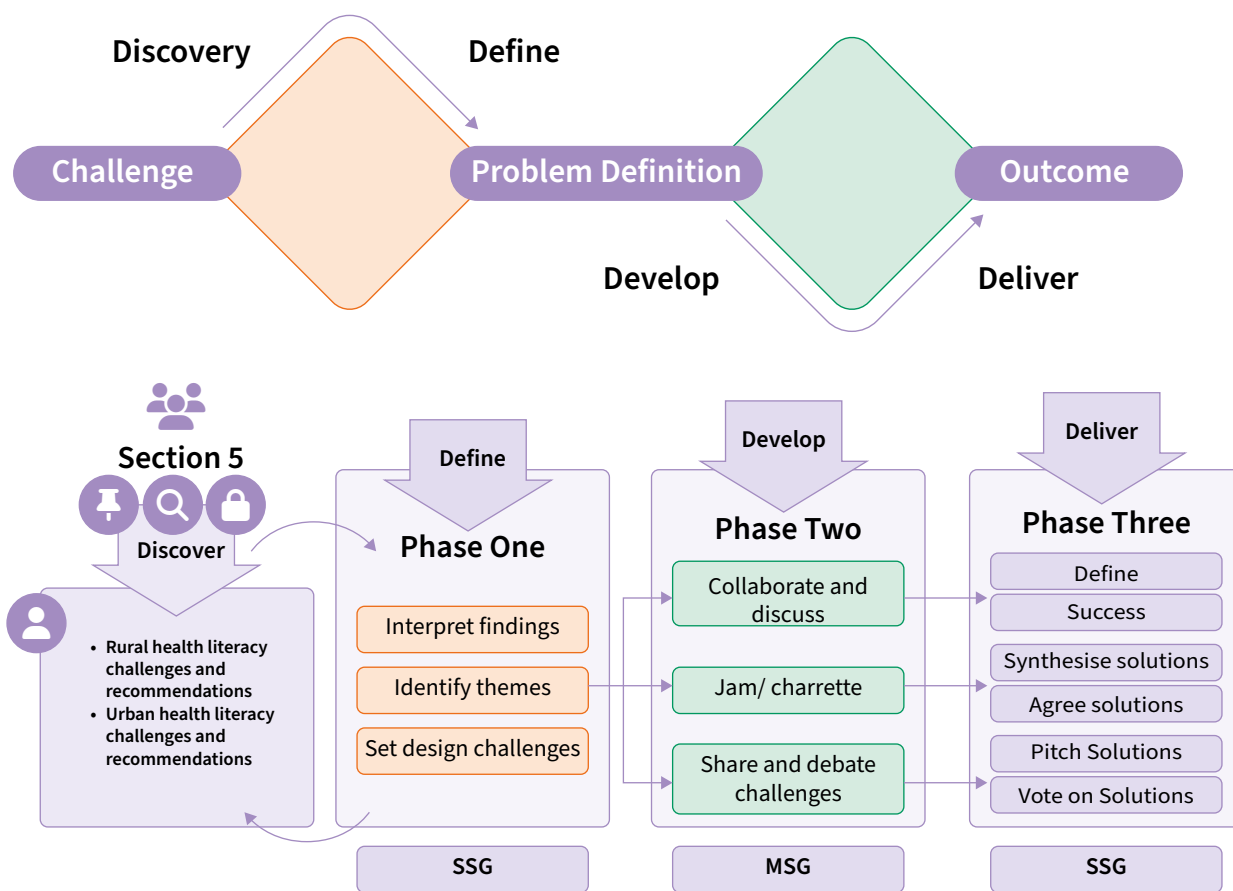
Two co-design workshops took place in March 2024, one in each case study area. At the start of the day, participants were provided with written information on the project

to date (this included two options: a one page summary, and/or a five page summary). A brief presentation was also given by the lead researcher giving an overview of the different work packages undertaken, highlighting some key considerations, outlining the format of the workshop and aims of the workshop.

An adapted DDDA was divided into three phases with one or more tasks per phase (outline; Fig. 6.1). Within each phase, stakeholders worked in the same stakeholder groups (e.g. physical activity promotion) or mixed stakeholder groups. All discussions were recorded via dictaphones on each table. Stakeholders were allocated to mixed stakeholder groups, ensuring at least one member from each of the initial same stakeholder groups were present in each group. Dependent on attendance numbers, in some cases more than one member of the initial same stakeholder group may have been present in the mixed stakeholder group. In Mayo, owing to travel disruption, the decision was made to combine two similar, same stakeholder groups to maximise discussion, resulting in five same stakeholder groups. Each group had a researcher

present on their table to facilitate discussion (using a semi-structured interview guide), point towards provided resources outlining previous work, and to take notes. Flip chart paper, pens, post-it notes were provided on each table for the participants to engage with as they wished.

In phase three, the researcher summarised the recommendations decided on by their same stakeholder groups, and participants were invited to vote for the draft recommendations they felt best achieved the aim of the brief. Each participant received three votes with a maximum of two votes being allowed for any one recommendation. After voting, the lead researcher concluded the day, reminded participants of how this process was fitting in with the wider project, and informed them that they would all be sent a copy of the lay summary of the project's final report.



SSG: Same Stakeholder Group; MSG: Mixed Stakeholder Group

Figure 6.1 The Double Diamond Approach to Co Design Health Literacy Solutions

6.3 Results

Following final voting by stakeholders on the presented group solutions at phase three, recommendations were generated for each co-design workshop. These co-design recommendations are presented here as they were presented during the workshop sessions by stakeholders. For the purposes of this report, these recommendations have been displayed in a table format in order of participant preference voting. Table 6.1 illustrates the Finglas and Cabra Sláintecare area recommendations and added descriptions. Table 6.2. illustrates the Mayo Sláintecare area recommendations and added descriptions.

Recommendation	Additional description provided by groups
Early intervention	<ul style="list-style-type: none"> • Such as a paid school post to cover all aspects of health literacy e.g. Physical Education, mental health and hygiene, social • maintenance scheme: local clubs/ health centres/ community groups
Infrastructure (long term)	<ul style="list-style-type: none"> • Funding supports – help people get funding • Primary care access • Schools and early interventions
Resource development (both digital and physical)	<ul style="list-style-type: none"> • n/a
Community engagement	<ul style="list-style-type: none"> • Community kitchen/ garden/ supermarket/ health eating/ cooking/ growing • Schools engagement – social/ mental health benefits and signposting • Peer to peer learning
Community hub	<ul style="list-style-type: none"> • Classes to train locals to deliver training

Table 6. 1 Finglas and Cabra Sláintecare Health Community Recommendations

Recommendation	Additional description provided by groups
Community outreach officer	<ul style="list-style-type: none"> • Local authorities? HSE? • Salary position
GPs	<ul style="list-style-type: none"> • Community healthcare nurse (local) • Use district hospitals more (take pressure of GP and district nurse) • Stepdown beds • Develop primary healthcare centres properly • Have pharmacies take pressure off GPs
Network (of funding)	<ul style="list-style-type: none"> • Coordinating the disconnect • Prioritise grants • Central person (known) to help
Activities	<ul style="list-style-type: none"> • Social; Physical • Intergenerational • Communication
Preventative – access where people are at	<ul style="list-style-type: none"> • Mobile primary care unit – women’s health; people’s general health/ population health • Health check evenings that are sustainable, linked back to the mobile unit etc • Can be advertised using Mid-West radio to share information

Table 6. 2 Mayo Sláintecare Health Community Recommendations

Results demonstrate community recommendations that span a wide range of contextualised considerations for health literacy development in their Sláintecare Healthy Community area. In Finglas and Cabra, there was emphasis on recommendations that supported health education and early intervention spanning across school and community settings. It was also established that recommendations required engagement with community members through established programmes. Throughout discussions, there were excellent initiatives highlighted that indirectly linked to health literacy. These initiatives however often struggled to achieve sustainable funding. There was also discussion on the development of these community elements to enable the sharing of resources and training for local community 'champions'. Resource development in respect to both physical and digital elements was also recommended in supporting health literacy.

In Mayo, recommendations reflected community based calls for support in the development, and success, of access to funding. Recommendations also were made in relation to the communication, advertisement, timing, transport, and engagement of community based activities. In respect to the rural location of Mayo Sláintecare area, improvements to healthcare access was recommended to support health literacy, with proposed solutions reflective and contextualised to a rural population.

Summary of evidence and recommendations for Section 6.

	Summary of evidence	Health literacy recommendations from authors	Alignment with WHO health literacy recommendation
6.1	There is a need for effective early intervention to prepare young people to manage their own health throughout the lifecourse.	Adequate funding and policies to provide the platform for adequate health education for young people within the school setting, as well as the local community.	Action area 2.5: Incorporate health literacy-responsive practice into health education curricula and continuing professional development
6.2	There is currently a lack of appropriate community engagement initiatives across the populations studies, as well as poor communication and advertisement of existing programs.	Regular community events, that are widely advertised, which would provide individuals with an opportunity to easily engaged in a wide range of educational and social activities that would reduce social isolation. This would also empower community members to manage and navigate their specific health needs.	Action area 3: Build community health literacy
6.3	There is a clear lack of accessibility to, and availability of, health care services.	Increased number of healthcare providers servicing the local community; improved transport infrastructure to allow those in need to travel; provision of more realistic appointment times to allow for travel.	Action area 4: Target priority groups that are not receiving or easily accessing health information or health care

Section 7:

Limitations and learnings for the future

This report presents a detailed presentation of the rigorous project undertaken to understand the key focusses of health literacy in Ireland. Throughout the development of this work however, there are some limitations that need to be acknowledged, and crucially learnings to be taken for future similar projects. Notably, this report was completed between July 2023 and May 2024, and the authorship team acknowledge they were ambitious with the work packages completed, and as such had to place feasibility related limitations on these studies. For example, the time frames searched within the reviews. Additionally, within these reviews, only published research available in English was included, and may not reflect wider health literacy content available in other formats.

As project methods for data collection strove to be equitable and target hardly reached (as opposed to 'hard to reach') community members, challenges were observed in recruitment during a timebound study. Sampling of community members from both areas at most stages was established through networks of relationships with Sláintecare Healthy Communities. These methods supported the time restrictions in completing qualitative research investigation. Although a large sample size for community engagement was observed (>100), this report recognises that data collection did not capture all participant target groups and community members. In the development of co-design workshops, limitations around lead in time and equity of access to materials, resources and a central workshop location were observed due to the geographical descriptors of each Sláintecare area.

Papers detailing more information on these specific studies undertaken as part of this project are under development for publication in peer-reviewed journals (as of May 2024). These will be published open-access, and links will be made available to Sláintecare Healthy Communities to attach in the dissemination of this report when appropriate.

Section 8:

Conclusion

This report has undertaken a thorough examination of health literacy in Ireland, aiming to understand health literacy within local, national and international contexts, identify current initiatives among the Irish population, and explore community health literacy responsiveness. Our research has uncovered significant insights that not only meet these objectives, but also suggest critical directions for future policy and practice.

Addressing the Objectives:

1. Contextually Relevant Understanding of Health Literacy

- **Finding:** Health literacy encompasses a range of abilities allowing individuals to access, understand, appraise, and apply health information to make informed health decisions.
- **Implication:** Policies should emphasise a transparent and contextually appropriate definition of health literacy that supports educational programs and healthcare provider training, aligning with international best practices to ensure consistency and clarity in health literacy initiatives.

2. Identifying Current Levels of Health Literacy

- **Finding:** Previous research identified that approximately 40% of adults in Ireland demonstrate limited health literacy, which poses challenges to effective healthcare engagement and disease prevention.
- **Implication:** This highlights the need for targeted interventions designed to improve health literacy across diverse population segments, particularly in communities with historically lower education and health access.

3. Assessing Impact on Health Outcomes

- **Finding:** Low health literacy is linked to poorer health outcomes, including increased hospitalisations, higher utilisation of emergency services, and less frequent use of preventive care.
- **Implication:** Future health related policies must integrate health literacy as a core component of health promotion and NCDs prevention strategy. Enhancing health literacy is crucial to reducing healthcare costs and improving patient care outcomes.

Future Policy and Practice Recommendations:

1. Integrate Health Literacy into National Health Strategies

Ensure that health literacy is embedded in all aspects of health policy development and practice, recognising its role in achieving better health outcomes and more efficient use of healthcare resources.

2. Educational and Training Programs

Develop comprehensive educational programs that address health literacy from early education through to adult learning. Simultaneously, implement ongoing training for healthcare professionals on effective communication practices to enhance patient comprehension and engagement.

3. Community Engagement and Empowerment

Support local initiatives that foster community engagement in health literacy. These should utilise culturally and linguistically appropriate materials and involve local champions to increase their reach, impact and effectiveness, and ensure nobody is left behind.

4. Research and Continuous Monitoring

Commit to ongoing research to monitor health literacy, and the impact of health literacy interventions/actions, and update practices based on emerging data. This will help adapt strategies to meet changing demographics and health needs.

5. Cross-Sector Collaboration

Encourage collaboration across health, education, social services, and private sectors to develop a multi-faceted approach to health literacy. The WHO suggest this as a national, cross-sector 'health literacy coordination unit'. This collaboration should aim to create an environment where all sectors work together to support the population's health literacy needs.

Enhancing health literacy is more than an educational imperative—it is a vital public health strategy that can lead to substantial improvements in the nation's health. By addressing the outlined objectives and implementing the recommended policies, Ireland can significantly advance its public health agenda. A co-ordinated approach, involving multi-sector, top-down and bottom-up practices is needed to develop health literacy at an individual, community, organisational and national level.

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