The Optimisation and Evaluation of Public Health Literacy

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Abbreviations List

AAHLS	All Aspects of Health Literacy Scale
AHLS	Adult Health Literacy Scale
AIDS	Acquired Immunodeficiency Syndrome
AMA	American Medical Association
APA	American Psychological Association
ASQ-3	Ages and Stages Questionnaire-3 Item
CAN	Council for Information on Alcohol and Other Drugs
CCHLQ	2008 Chinese Citizens Health Literacy Questionnaire
CCHLS	Communicative and Critical HL Scale
CDC	Centers for Disease Control and Prevention
CDCo	Consensus Development Conference
CDMs	Consensus Development Methods
CELSA	Combined English Language Skills Assessment
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CRN	Clinical Research Network
CSES	Children's Self-Efficacy Scale
DHHS	Department of Health And Human Services
DM	Direct Message

DOI	Digital Object Identifier
EEF	Education Endowment Foundation
ERIC	Education Resource Information Center
ESL	English as a Second Language
ESSS	Elementary Student Self-Efficacy Scale
EU-HLS	European Health Literacy Scale
FCC	Functional, Communicative and Critical
FCCHLS	Functional, Communicative and Critical Health Literacy Scale
FHL	Functional Health Literacy
GAD-7	Generalised Anxiety Disorder - 7 Item
GDPR	General Data Protection Regulation
GSE-10	General Self-Efficacy Scale-10-item
HELIA	Health Literacy for Iranian Adults
HIV	Human Immunodeficiency Virus
HKACSS	Health Knowledge, Attitudes, Communication and Self-efficacy Scale
HL	Health Literacy
HLAT	Health Literacy Assessment Tool
HLAT-51	Health Literacy Assessment Tool-51
HLAT-8	Health Literacy Assessment Tool-8-item

HLHSS	Health Literacy for High School Students
HLQ	Health Literacy Questionnaire
HLS-APP-Q14	Health Literacy App Questionnaire
HLS-COVID-Q22	Health Literacy Survey COVID Questionnaire
HLS-EU	European Health Literacy Survey
HLS-EU-47	European Health Literacy Survey-47-Item
HLS-EU-Q16	European Health Literacy Survey-16-Item
HLSAC	Health Literacy for School-Aged Children
HLSBS-II	Healthy Lifestyle Behaviour Scale-II
HPLP-II	Health-Promoting Lifestyle Profile-II
HQ	Health Quiz
HRA	Health Research Authority
IBM	International Business Machines Corporation
IMD	Index of Multiple Deprivation
IQR	Interquartile Range
JAMA	Journal of the American Medical Association
JBI	Joanna Briggs Institute
LGHLQ	Lenartz's German HL Questionnaire
LQSAC	Lifestyle Questionnaire for School-Aged Children
LQSAC-10	Lifestyle Questionnaire for School-Aged Children-10-Item

MF	Me First
MRC	Medical Research Council
NERS	National Exercise Referral Scheme
NGT	Nominal Group Technique
NHS	National Health Service
NIH	National Institute of Health
NIHR	National Institute for Health and Care Research
NVS	Newest Vital Sign
OEPGK	Österreichische Plattform für Gesundheitskompetenz (translation: Austrian platform for health literacy
Org-HLR	Organisational Health Literacy Responsiveness
OSF	Open Science Framework
PACT	Parents and Communities Together
PAM	Patient Activation Measure
PBL	Problem-Based Learning
PCB	People and Communities Board
PhD	Doctor of Philosophy (Philosophiae Doctor)
PHE	Public Health England
PHQ-9	Patient Health Questionnaire-9-Item
PHS	Perception of Health Scale

PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analyses: Scoping Review
QOL	Quality of Life
RAHL	Rapid Assessment of HL
RAM	RAND/UCLA Appropriateness Method
RAND	Research and Development (Corporation)
REALM	Rapid Estimate of Adult Literacy in Medicine
REALM-T	Rapid Estimate of Adult Literacy in Medicine-Teen
S-S	Study-specific
S-TOFHLA	Short-form Test of Functional Health Literacy in Adults
S-TPBQ	Study-specific Theory of Planned Behaviour Questionnaire
SCT	Social Cognitive Theory
SD	Standard Deviation
SEM	Structural Equation Modelling
SF-12	Short-form-12-item
SMS	Short Message Service
SPSS	Statistical Package for the Social Sciences
TAFE	Technical and Further Education
TOFHLA	Test of Functional Health Literacy in Adults
TPB	Theory of Planned Behaviour

TV	Television
U.S.	United States
UCLA	University of California, Los Angeles
UK	United Kingdom
UKRI	United Kingdom Research and Innovation
UNA	United Nations Association
UNESCO	United Nations Educational, Scientific and Cultural
Organisation	
UNICEF	the United Nations International Children's Emergency Fund
VARK	Visual, Aural, Read/Write and Kinesthetic
WHO	World Health Organisation

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Covid-19 Impact Statement and Reflections

Preface

A brief summary of the implications of Covid-19 on this thesis are presented below, separated according to each study conducted.

Study 1 - Literature review

The initial data charting calibration phase of the scoping review commenced between March 2020 – July 2020, falling directly within the onset of the first Covid-19 pandemic wave. Social isolation was a key challenge, particularly given my limited experience in conducting a scoping review to an academic standard, and a number of challenges emerged as a consequence. The first barrier to progression concerned the notion of support. Assuming the pandemic had not occurred, this scoping review would have been conducted in an office setting, with support from colleagues and fellow PhDs from Pharmacy and beyond a simple door knock away. However, given the understandable enforcement of lockdown, this was not possible, and the transition to online communication commenced. Though my division in particular provided frequent, accessible communication, external networks became difficult to identify and converse with. This was particularly the case with more complex research enquiries, where support from colleagues within the school and external to our division proved challenging. Subsequent administrative delays led to difficulty transitioning from the data calibration phase to post-calibration. This led to longer waiting periods for feedback from key external members on review adjustments and developments.

The second barrier pertained to my personal motivation during the pandemic. Like many others, the home-based office environment proved a challenge from a motivational standpoint. Research exploring the challenges encountered on PhD education during the pandemic revealed the adjustment to online work and lack of practical advice from colleagues as challenging, and negatively impacting the PhD process (Börgeson et al., 2021). However, from my personal experience, the poor work environment described in this paper was not a factor underlying my motivation. A more plausible explanation was that my work was unchanged for an extensive period of time throughout the lockdown period. I conducted this review twice: once for pre-calibration, and again for the final post-calibration study. The repetition of a long and arduous task in reviewing the literature may have contributed to the motivation issues I faced during the initial lockdown period. In a recent study discussing workplace motivation, health information managers cited variation in their work as an important factor affecting their motivation (Nexhip, Riley, & Robinson, 2022). From my own experience, these findings also resonate with the latter portion of my first PhD year, potentially explaining the motivation issues which delayed progression on this review.

In hindsight, taking a more independent role in the review methodology and subsequent decision-making process may have reduced the impact of administrative delays. From a motivational standpoint, adjusting task variation where possible may diminish my own personal motivation issues moving forward, though I also believe that collaboration is useful for reducing the demand of tedious, lengthy tasks for otherwise fascinating research projects. Nevertheless, the review presented herein was a success, and identified a range of important practices within contemporary HL research.

Study 2 – Delphi method

The Delphi study presented several additional challenges. Importantly, the Delphi study presented internal and external communication problems, with longer timeframes for administrative tasks – both within the University environment and with external collaborators – being notable. Of particular note was recruitment for the Delphi panel, with email invitations sent in the first month yielding minimal responses. Though a range of academics were CC'ed in to the invitations to support the study and provide potential panellists with a sense of professionalism and rigour, recruitment was challenging. This could have been due to Covid-affected communication delays, or alternatively non-Covid considerations like academic workloads taking precedent around the time of recruitment.

Covid-19 did, however, impact the initial study conception phase. Initially, an in-person Q-sort methodology was to be considered – referring to a card sorting activity to rate a series of items in a pre-specified, fixed distribution, with the ratings often forming a quasi-normal distribution (Serfass & Sherman, 2013). Originally, a Q-sort was proposed in place of a Delphi study to identify HL measurement outcomes viewed as most important by experts for the same four HL contexts, however the lack of funds for online Q-sort software, in addition to Covid-19 threat and all-around lack of feasibility for in-person card sorting, led to a revision in the methodology. Upon reflection, the Q-sort was likely less appropriate than the Delphi methodology for the overall thesis aims, and consequently only minor delays to the project were experienced. The main Covid-19 impact therefore pertained to delays associated with communication and administrative duties.

Upon reflection, the Delphi study analysis was particularly complex. Although the first and second Delphi round was fairly typical, an initial cluster analysis was proposed for the final items from round 3. The idea was to replace a thematic analysis conducted on the final HL framework outcomes with cluster analysis, as this was expected to reduce researcher bias. Cluster analysis would be guided by statistical identification of patterns and trends rather than researcher-interpreted groupings, and was initially preferred to categorise the outcomes forming the final HL measurement framework. However, due to the violation of several assumptions, in addition to the dendrograms generating difficult to interpret clusters, researcher-led thematic analysis was viewed as most appropriate to categorise the data. Through the process of learning cluster analysis, I learned that the subjectivity to interpret low-sample dendrograms adds a surprising degree of researcher power in determining the end clusters. Due to this, the final decision to conduct thematic analysis to categorise the HL measurement items for each context led to a final framework with arguably more discrete items than if hierarchical or k-means clustering was employed.

The most time-consuming element of the Delphi study was developing the round 3 survey via Qualtrics. Round 3 required a unique layout, with the findings from round 2 for each participant being presented in a matrix table during round 3. This required a unique survey flow to be established, enabling previous responses from questions in round 2 to be embedded into one column of a matrix table in round 3 via the piped text function. This required round 2 responses to be collated via a participant email distribution database, which was then used as the basis to enable piped text into round 3 (due to round 3 being a separate survey to round 2). The process to identify this was the most complex hurdle, and the final outcome required numerous testing to ensure its efficiency before sending across to participants. This led to a slight delay in the delivery of round 3 to participants, and may have contributed to the lower sample retention observed. Nevertheless, a serviceable sample size was achieved despite the initial difficulties encountered during the survey design phase.

Although the Delphi study may have been impacted by delays relating to Covid-19, the majority of delays came from the development of survey materials and analysis for round 3, and the scoping review reported in Chapter 2 experienced more significant Covid-related delays due to the predecessor timeline of the studies.

Study 3 – Pilot school assessment

During the development of the child HL assessment, the initial intent was to conduct a full-scale HL assessment in children, rather than the pilot study presented within this thesis. An initial power calculation was set, with the ambition being to achieve a minimum sample size of 40 and a goal set of 110 to elicit a sample powered to yield a medium effect.

Initial recruitment attempts with regards to primary and secondary schools in England were unsuccessful, with the majority of schools and trusts not responding to research requests over email. When over-the-phone requests were employed, I was frequently informed that the research query would be passed on to the appropriate member of staff, or alternatively was asked to email information to the school/trust. Despite this, no schools or trusts became involved with the project, and no further communications were held with gatekeepers beyond the initial recruitment requests. An in-depth discussion is provided within this thesis with regards to recruitment difficulties (see Chapter 4, sub-section *discussion*), but Covid-19 may have played a role in a number of aspects relating to the low recruitment numbers for this study, and the dependence on non-education network recruitment strategies. As discussed at a later point within this thesis, the Covid pandemic may have negatively impacted how schools and trusts across England respond to research requests. Towards the end of the pandemic, school closures may have led to a shift in school priorities (Koutsouris, Nash, & Norwich, 2023) which, in-turn, may explain the minimal communication in response to the research request distributed in study 3.

Given the pressures on schools throughout the Covid-19 pandemic, schools and trusts may have responded slower to research requests. Due to delays in learning as a result of Covid-19-related school closures (Rose et al., 2021), the timing of this study may have coincided with a prioritisation on educational attainment over extracurricular endeavours. Consequently, study 3 within this PhD may have been negatively impacted by the timing at which recruitment occurred relative to the educational landscape brought on by the Covid-19 pandemic.

Nevertheless, important insight into the measurement of child HL in England was established, providing initial feasibility testing to inform future work in the area.

Summary of impacts

Overall, a number of administrative delays and potential low-priority valuations may have been caused, in-part, by the timing of this PhD project relative to the Covid-19 pandemic. Though the project concluded with a number of methodological adjustments, the timeline for completion and the sample sizes attained may have been different if the societal constraints imposed by the pandemic were not present. Despite this, the final form of this PhD project responds to several important grey areas within adult and child HL, and provides new knowledge to support public health advances in the years to come.

Abstract

Introduction: Health Literacy (HL) is a key skill for the prevention of adverse health and the maintenance and promotion of good health outcomes, and is generally agreed to reflect a person's ability to understand, access, appraise and apply health information. Due to HL reflecting a person's skill to navigate health information, public HL has become a high priority in recent times. This growth has, however, expanded in parallel with disputes – and varied interpretations - regarding its conceptualisation. This heterogeneity may therefore lead to reliability, validity, and comparability issues. Moreover, many HL models are formed in reference to adults, and do not include differences in children compared with adults. Children actively engage in health decisions, and understanding potential HL differences is thus essential for supporting the transition towards health autonomy. Clarity on child and adult HL measurement appears unmet currently, and minimal child HL assessments have been conducted across England.

Aims: Two aims were outlined: to investigate the conceptual nature of HL in community adult and child populations; and to gather preliminary data on the state of child HL in England.

Methods: A scoping review of community HL intervention outcome practices was conducted (Sawyers et al., 2022). An international Delphi study followed this to achieve consensus on best practices for HL measurement in community adult and child populations, with the outcome being the development of a HL measurement framework. Lastly, a pilot study was implemented to assess the feasibility of measuring HL in 10-13 year old children as guided by the framework.

Results: Three series of results are presented. Firstly, the review identified a unidimensional profile for direct HL measurement, contrasting previous inferences

of a convergence towards holistic practices. When proxy HL was analysed, substantial variation was reported, suggesting deviation in HL measurement beyond the direct domain. The Delphi study used four contexts as the base for the framework: adult direct (n = 12), adult proxy (n = 12), child direct (n = 15) and child proxy (n = 10). Within each context HL outcomes were identified, forming the final framework. The third study recruited a small pilot sample (n = 17), and provided an initial understanding of child HL measurement. Baseline figures for functional HL, communicative HL, critical HL, self-efficacy, health behaviours, and qualitative data for health learning were retrieved, and recruitment challenges through schools were identified as key barriers to a follow-up. Early, frequent communication, flexible research protocols, and school engagement at the project conceptualisation were highlighted as important for successful school recruitment.

Discussion: Current literature indications yield HL as multidimensional, but HL is frequently implemented in a unidimensional manner at the direct level and a variable way at the proxy level. Using expert consensus, a framework has been produced to clarify the HL outcomes important to consider in community adult and child populations. The framework aims to foster consistent, comparable, and valid community HL measurement practices, while encouraging researchers and policy stakeholders to consider child and adult HL research with a renewed focus. Though an initial pilot indicates feasibility of the framework, further follow-up is required to better understand child HL in England. Nevertheless, these findings support researchers in measuring adult and child HL more consistently, and provides suggestions when collaborating with primary and secondary schools in England on the basis of pilot study evidence.

Chapter 1 – Literature Review

Historical Roots of Health Literacy

In the present day, Health Literacy (HL) is understood as a multidimensional construct comprising a person's knowledge, competence and motivation to understand, access, appraise and apply health information across health promotion, disease prevention and healthcare for the promotion and maintenance of quality of life (Sørensen et al., 2012). While this currently accepted definition demarcates HL from a unidimensional construct to a multidimensional concept, only in recent years has this narrative been established.

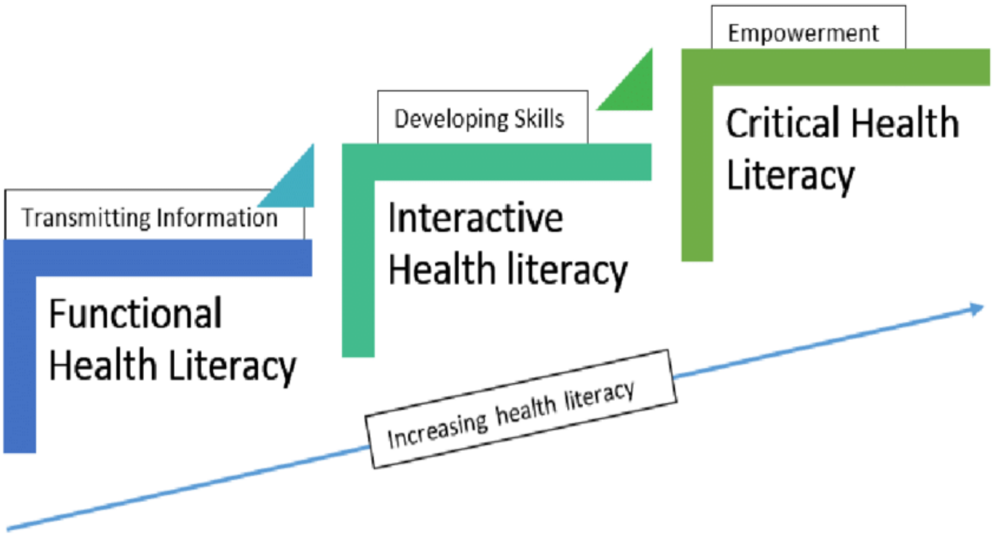
As a concept, HL has been present in the literature for more than half a decade (Hadi, Ghahramani, & Montazeri, 1970), but the notion of a person's literacy originated in the midst of the scientific revolution, with signature evidence in England dating back to the 17th century acting as the earliest interpretations of fundamental literacy skills (Stephens, 1990). The protestation of 1641, a bill passed by parliament in 1641 requiring people over the age of 18 to sign an oath of allegiance to King Charles I and the Church of England, provides one of the earliest historical accounts of the public's literacy skills on a population level. However, literacy in these times were vastly underdeveloped compared to contemporary society, with conjectural evidence estimating 15-40% of adults in 16th century England as possessing a basic level of literacy. In comparison, probable estimates of basic literacy at the turn of the 20th century in England equate to roughly 95% (Stone, 1969), with this figure rising to 99% in the last 10 years (UNA-UK, 2021). The initial development of fundamental reading and writing skills was essential to address in 17th century England, and while one in every 100 people are illiterate in the UK today, this figure has risen exponentially in recent years. It should come as no surprise then to see that HL, which arose as a key consideration for health promotion in the last 50 years, was developed as a context-specific literacy skill. The parent concept of literacy – that is, the ability to read and write at a basic level – is firmly solidified in the many depictions of HL available today, largely due to the importance of reading and writing skills across all health contexts. In modern-day HL research, public literacy in the context of health is now frequently referred to as functional literacy.

A key component within modern-day HL, functional HL was initially termed by the Civilian Conservation Corps in America, being defined as possessing three or more years of school education. More sophisticated parameters and conceptualisations of functional literacy were later identified, ranging from a 6th grade education level in the 1950s to more recently expecting post-secondary level education as necessary to be literate enough to compete in the job market (Berkman, Davis, & McCormack, 2010). The notion of functional literacy later appeared in the Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs (AMA, 1999), which provided the foundations for contemporary functional HL, where they identified HL in general as the ability to perform basic reading and numerical tasks required within the healthcare environment – combining literature and numeracy considerations to delineate a person's HL. Though this definition provided the initial, context-specific HL overview, disagreement arose amongst scholars, particularly with regards to the unidimensional and narrow nature of the definition. This disagreement led to the innovation of HL as more multidimensional, with numerous discussion regarding HL as a skill beyond simply the functional level. Don Nutbeam was among the first to disagree with the definition proposed within the Ad Hoc Committee on Health Literacy, instead supporting the World Health Organisation's more broadly compatible definition of the construct (Nutbeam, 1998), identifying HL as a collaborative of cognitive and social skills determining a person's motivation and ability to access, understand and use information to promote and maintain good health. The World Health Organisation (WHO) further added that HL refers to more than being able to read and successfully manage health-related prose, documentation and numeracy information, with improvements to a person's access to information and their capacity to utilise it effectively being an essential means of health empowerment as well (Nutbeam, 1998).

Development of Models and Theories of Health Literacy

Nutbeam (2000) later proposed that, instead of HL being a unidimensional reading and writing skill, HL is comprised of multiple skill-centred levels. He proposed three levels to the construct: functional HL, referring to a person's reading and writing skills, being broadly compatible with the initial literacy and functional HL definitions posited previously (AMA, 1999; Berkman et al., 2010); communicative/interactive HL, denoting more advanced cognitive and literacy skills used in conjunction with a person's social skills to be an active participant in daily activities, to extract and derive meaning from differing modes of communication, and to apply new information to varying contexts; and critical HL, considering the most advanced cognitive skills alongside social skills to critically appraise information and foster increased control over a person's life (Nutbeam, 2000).

Figure 1. Infographic of Nutbeam's (2000) Model of Health Literacy.



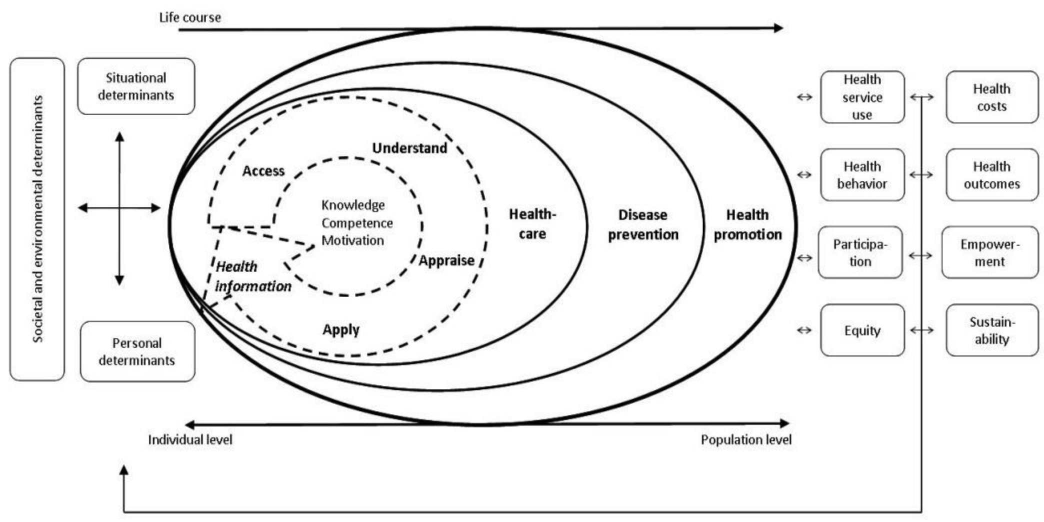
Note. Communicative and interactive health literacy represent the same level within Nutbeam's (2000) model.

The model of HL proposed by Nutbeam (2000) presents a dynamic nature of HL (see Figure 1), with each different HL level progressively enabling greater autonomy and personal empowerment. Progression through these levels is controlled by exposure to information and messages, which is then influenced by the individual's response to the relevant communications – an act that is also mediated by self-efficacy and a combination of personal and social skills. Key aspects to Nutbeam's (2000) model of HL are general literacy and cognitive development, meaning that the instruments and strategies needed to assess and improve HL will have inextricable links to more general literacy skills. However, literacy levels are not a guarantee for a positive response to health education and general health-related communication, which is partly why HL was proposed as a multidimensional triad of skills. While Nutbeam's (2000) model acted as the catalyst for HL being acknowledged as a multidimensional construct as opposed to a unidimensional reading and writing health skill, this proposal ultimately led to HL being regarded in a multifaceted manner. As a consequence, a range of multidimensional theories of HL have been proposed in recent years, marking an important stage for HL in being widely considered in a multidimensional fashion.

Shortly after the preposition from Nutbeam (2000) regarding HL as a multifaceted construct, Zarcadoolas, Pleasant and Greer (2005) proposed an expanded model of HL characterised by four HL domains: fundamental literacy, referring to the skills and strategies denoting reading, writing, speaking and numeracy; science literacy, denoting the level of competence with the sciences and technology, including elements regarding the scientific process; civic literacy, considering the abilities allowing people to be aware of public issues and becoming involved in the decision-making process; and cultural literacy, involving the ability to recognise and utilise collective customs, beliefs, social identities and world-views in reference to the interpretation and use of health information (Zarcadoolas et al., 2005). Several components within each domain were identified as comprising a person's HL. Fundamental literacy, for example, considers assumed knowledge, difficult language with no prior explanation or definition and complex syntax as the components forming the domain. Science literacy examines the success rate for explaining the scientific process and the implications of the scientific process to a given topic or context. Civic literacy considers individual decision making in the context of public health, and lastly cultural literacy reflects a person's cultural interpretation and/or reaction to information. The Zarcadoolas et al. (2005) model interpreted HL as a multidimensional construct, yet proposed a unique overhaul in how HL is viewed – focusing more on the systems affecting public HL within society and less on the individual skills forming a person's HL, the latter more reflective of Nutbeam's (2000) model. While the scholarly consensus shifted from HL being an applied literacy skill to a multidimensional construct, the added scope for interpretation promoted a continuum of HL conceptualisations being developed. Though these models are earlier interpretations of the new multidimensional view of HL, more recent findings highlight the consequences of an expansion to HL as a construct, with systematic review evidence identifying 250 different definitions of HL in the literature (Malloy-Weir, Charles, Gafni, & Entwistle, 2016).

While many HL scholars continued to utilise and promote their preferred multidimensional model of HL, a unique approach to identifying a 'gold standard' conceptualisation was proposed with the aim of streamlining the models being developed. As a response to the lack of consensus surrounding the definition and conceptual dimensions of HL as a construct, Sørensen et al. (2012) conducted a systematic review to identify the then-existing definitions and conceptual frameworks in circulation. They performed a content analysis of the extracted data to provide an evidence-backed conceptualisation of HL. What they found and presented was an integrated model conceptualising HL as a person's knowledge, competence and motivation to access, understand, appraise and apply health information across healthcare, disease prevention and health promotion (see Figure 2).

Figure 2. Sørensen et al's (2012) Integrated Model of HL.

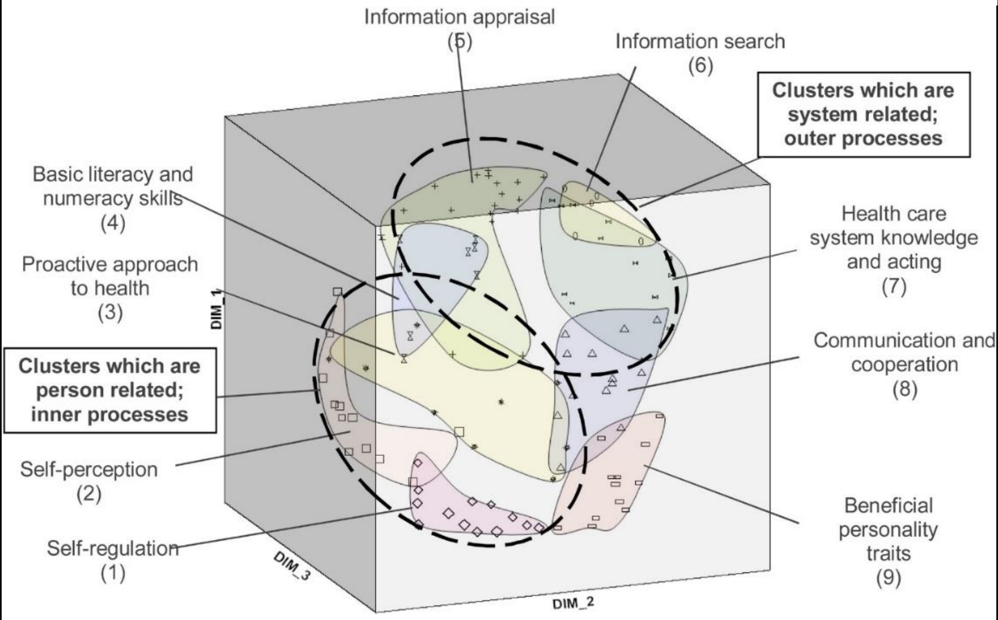


Antecedents and consequences of a person's HL were incorporated within the model, with distinctions made between distal factors, comprising social and environmental determinants of HL, proximal factors, considering the personal determinants of HL, and situational determinants, referring to components within a person's physical environment. Sørensen et al's (2012) model was one of the first, and most prominent, to provide an interpretation of the multidimensionality of HL through the-then literature, providing a more conceptually robust overview guided by multiple experts. Nutbeam's (2000) model guided the four competencies of access, understand, appraise and apply, and Zarcadoolas et al's (2005) model influenced the implementation of antecedents and consequences within the end model.

The Sørensen et al. (2012) integrated model of HL is widely implemented presently, frequently being used to define the construct of HL (Nguyen et al., 2020). Sørensen et al. (2015) later went on to develop and refine the European Health Literacy Survey (HLS-EU), allowing for HL measurement practice to begin incorporating the integrated model into measurement practice, acting as a framework for more robust multidimensional HL measurement (Sørensen et al., 2015). The demand subsequently led to the original HLS-EU questionnaire being refined, with shortened (HLS-EU 16-item) and brief (HLS-EU 6-item) versions being developed (Pelikan, Röthlin, & Ganahl, 2014). Context-specific variants have also been developed in recent times, with the coronavirus-related HL measure (HLS-COVID-Q22) formed on the basis of the Sørensen et al. (2012) model to explore public HL in the context of Covid-19, providing a better understanding and quantification of the efficacy behind public health practices and existing information efficiency during the pandemic (Okan et al., 2020). The Sørensen et al. (2012) integrated model of HL subsequently defined the new transition of HL into a construct spanning the ability to access, understand, apply and appraise health information based on individual competencies across a number of different contexts. This provided one of the intial points of agreement among HL experts on what contitutes a person's HL on a multidimensional plane, however not all experts agree that the integrated model is most appropriate, with scholarly interest in the conceptual nature of HL continuing despite the integrated framework proposed.

One of the more unique methodologies employed to better understand the multidimensionality of HL can be seen within the structural model of HL, proposed by Soellner et al. (2017). In response to existing conceptual HL models being developed without empirical methods, Soellner et al. (2017) collated HL ideas from experts via unstructured card sorting, and applied multidimensional scaling to partition the data into a map of HL ideas. Hierarchical cluster analysis was then performed to generate data clusters representing the HL dimensions comprising the structural model. From the analysis, nine HL dimensions were generated: self-regulation; self-perception; proactive approach to health; basic literacy and numeracy skills; information appraisal; information search; healthcare system knowledge and acting; communication and cooperation; and beneficial personality traits (see Figure 3).

Figure 3. Illustration of the Structural Model of Health Literacy.



Note. DIM = Dimension. Taken from Soellner et al. (2017).

The structural model of HL is unique to other conceptual models of HL in that the model and subsequent instrument developed is based on expert opinion and then concept mapping, rather than the self-generation or expert generation of appropriate dimensions alone (Soellner, Lenartz, & Rudinger, 2017). While the application of concept mapping enabled a more empirical interpretation of HL to emerge in the structural model, features of prior models from Nutbeam (2000) and Sørensen et al. (2012) are present, with basic literacy and numeracy skills, communication and cooperation, information search and information appraisal reflecting the three levels of Nutbeam's (2000) model and the four components of HL information posited by Sørensen et al. (2012). This infers that the structural model expands upon existing HL models, rather than replacing them, but does provide a useful indication of the potential factors important to consider for future HL measurement practices beyond the traditional domains of functional, communicative and critical HL. However, given the novelty of the conceptual model of HL, the limited availability of HL measures validated for use across varying populations, and its scarce application (Stassen, Grieben, Sauzet, Froböse, & Schaller, 2020), a true evaluation of the model is challenging until studies use the model and instruments are developed.

While the structural model of HL holds promise, foundational HL models proposed by Nutbeam (2000) and Sørensen et al. (2012) are generally well-accepted and established, with validated and reliable instruments available across a multitude of community populations (Fretian, Bollweg, Okan, Pinheiro, & Bauer, 2020; Mahdizadeh & Solhi, 2018; Sukys, Cesnaitiene, & Ossowsky, 2017) guided by these models. Through the earliest interpretations of HL as a fundamental literacy and numeracy skill, to HL now being considered as a multidimensional construct, there are a number of disagreements surrounding how HL is conceptualised. A prominent view within the literature is that Nutbeam's (2000) bottom-up model of HL is a useful guide for measurement due to its simplicity, with the three levels frequently incorporated as outcomes for community HL interventions (Carolyn et al., 2019; Ishikawa et al., 2018; Khaleghi, Shokravi, Peyman, & Moridi, 2019). While the Sørensen et al (2012) model appears to provide the most well-regarded definition and interpretation of HL as a concept, the Nutbeam (2000) provides a more simplified guide for HL measurement. In line with this view, this thesis refers to the Sørensen et al (2012) definition when the concept of HL is measured, but will frequently mention the Nutbeam (2000) domains when discussing the evidence base in the field.

The chronological breakdown of HL as a concept thus far highlights the need to understand the dimensions comprising a person's HL, but they also demonstrate the importance of a person's capacity to access, understand, appraise and apply health information with regards to the health-related demands of society. This second consideration is particularly prevalent in the contemporary literature, with notable examples beyond the previously mentioned conceptual models of HL discussing how the complexities, demands, and eventual HL level of a person is influenced by the essential systems and tasks within a person's wider environment (Baker, 2006; Liu et al., 2020; Parker & Ratzan, 2010). As a more recently established view, there has been a shift from a deficit-centred model blaming the individual to a holistic model encompassing both individual and systems-level components to a person's HL. This indicates that, although the dimensions within existing HL models revolve around dimensions pertaining to a person's ability, the person's HL environment plays an equally important role in determining the true extent of a person's true HL. An accurate interpretation of a person's true HL score would subsequently consider a person's HL as it relates to both individual and systems-level perspectives. The subsequent development and validation of an organisational HL instrument has recently been conducted to provide the tools to further understanding this largely unknown element (Trezona, Dodson, Fitzsimon, LaMontagne, & Osborne, 2020; Trezona, Dodson, & Osborne, 2018). So while HL is undoubtably an important consideration from a person's perspective, the wider systems-level components are also necessary to capture. Going back, it is hard to imagine HL as the simple applied literacy skill it was over 30 years ago.

From this chronologically brief review of the history behind HL as a concept, there appears to be an abundance of models which provide useful conceptualisations of HL, though the convoluted nature of a multidimensional construct yields a range of alternate perspectives. Nevertheless, we can see two clear aspects. Firstly, HL is a multidimensional construct, and secondly, both personal and systems considerations play a role in a person's HL. A person's environment may act to trigger a person's HL into action, calling on an array of HL-related cognitive processes and behaviours in response to health information. Alternative health psychology models like the Health Belief Model, Capabilities, Opportunities, Motivation – Behaviour Model and the Theory of Planned Behaviour provide useful frameworks for predicting such cognitive and/or behavioural patterns which may provide a greater understanding of a person's health, but these are not used to conceptually address HL directly. From a fundamental applied literacy skill to a multi-layered construct, the recent identification of HL as multidimensional presents a number of new challenges, but also provides greater scope for improving public health outcomes. As a factor, HL is broad in scope – regardless of its true interpretation. Focusing on the improvement of public HL therefore has a number of important benefits.

Importance of Public HL for Adults and Children

A breadth of evidence identifies HL as a key consideration for the improvement of population health. This is likely a consequence of a person's HL influencing health-related decision making, which subsequently contributes to a range of public health outcomes and general behaviours. For example, adult HL has been associated with physical and mental health-related quality of life (Lee & Oh, 2020), physical activity levels (Buja et al., 2020), general maternal and neonatal health outcomes (Yee et al., 2021), hand hygiene (Or, Wong, & Chung, 2020), non-medication (Miller, 2016) and medication adherence (Zhang, Terry, & McHorney, 2014), overall mortality rates (Fan, Yang, & Zhang, 2021) and both healthy eating index scores and sugar-sweetened beverage intake (Zoellner et al., 2011), to name a few. Similar HL associations are present in child and adolescent populations as well, with obesity (Chari, Warsh, Ketterer, Hossain, & Sharif, 2014), health behaviours (DeWalt & Hink, 2009), quality of life (Ran et al., 2018) and self-efficacy (Guo et al., 2020) being some of the key findings. These examples emphasise the wide-ranging impact of HL, demonstrating the importance of adequate HL for a healthy and self-manageable life. Increases in public HL therefore enable people to live healthier, more sustainable lives and understand, interpret, appraise and apply health information for the benefit of themselves, their family and their peers.

In recent times, HL research has grown in prevalence, expanding beyond the predominant publication centres of the UK, Australia, and America. Research outputs on adult and child HL has, for instance, expanded to encompass populations in Africa, Asia, and South America. Such research in Ghana, for example, suggests up to 48% of adults, children, and adolescents had inadequate FHL. Other findings from Nigeria in child and adolescent populations demonstrate an association between HL levels and obesity (Adewole, Ogunfowokan, & Olodu, 2021). Similar HL assessments have taken place in Iran and Brazil, with adult populations reporting an estimated 25.5% and 26.2% as possessing inadequate HL, respectively (Maragno et al., 2019; Javadzade, Sharifirad, Reisi, Tavassoli, & Rajati, 2013).

Though assessments and associations have been observed internationally, research outputs on HL are more prevalent in the UK, Australia, and America (Qi, Hua, Xu, Zhou, & Liu, 2021), but the increasing output of HL research internationally is promising. Given the aforementioned HL assessments taking place beyond the Western world, a broader international view of HL is emerging. The recent generation of HL research exploring both adult and child HL associations – including evidence on the association between HL and household income (Hamzah, Suandi, & Ishak, 2016), smoking (Amoah & Phillips, 2020), and oral health outcomes (Batista, Lawrence, & Sousa, 2017), provides a demonstration of the growing body of international HL research. While less evidence exists for child HL beyond the big three HL research nations, an increase in HL research production is notable globally, and echoes the need to address HL for better health outcomes.

While HL has a broad scope of main, direct effects from its promotion, as demonstrated by international evidence, indirect benefits also exist from progressing public HL. Improving a person's HL, for example, can act to mediate the relationship between other health-related factors and outcomes. More recently, HL has been indicated to mediate the relationship between low socioeconomic status and health behaviours, health status, quality of life and the use of preventive health services like the influenza vaccination (Stormacq, Van den Broucke, & Wosinski, 2019). This exemplifies HL as having a wider range of influence than perhaps is initially assumed, and further puts forward the view of HL as an essential component to consider in the context of public health. This is further accentuated by recent public HL estimates reported from the now defunct PHE, who indicate an estimated 42% of adults as unable to understand or utilise health information appropriately (PHE, 2015b), with this figure rising to 61% where numeracy skills are also required (Rowlands et al., 2015). According to National Voices, who act as a coalition for health and social care charities across England, HL poses the strongest correlation towards ill health, surpassing deprivation scores, ethnicity, education level and age (PCB, 2017). With the prevalence and wide-ranging impact of public HL on varying health-related and general variables, NHS England have recently responded by establishing a national collaborative between Health Education England, NHS England and PHE to provide joint support for an array of HL site activities in the East Midlands (PCB, 2017).

The development of this HL site led to the delivery of the Skilled for Health programme, a well-established health literacy resource which acted as the foundations for a well-received adult HL education intervention in Australia (McCaffery et al., 2019). While the re-deployment of the Skilled for Health programme has been an important part of the NHS England-led collaborative to tackle low public HL in recent years, this is yet to extend beyond the East and West Midlands. Moreover, the Skilled for Health programme was designed to support adult HL, and the lack of available information surrounding child HL levels indicates that the intent behind supporting child HL rests upon the view that improving parent HL will lead to better child HL. Although there is evidence to suggest that parental HL is associated with child health outcomes (DeWalt & Hink, 2009; Harrington, Zhang, Magruder, Bailey, & Gerald, 2015), recent suggestions to consider children as active health practitioners (Fairbrother, Curtis, & Goyder, 2016) infers that their HL could also be considered directly, rather than through parent-proxy HL inferences alone.

When considering PHE's (2015) recent publication "Improving health literacy to reduce health inequalities", child health and mental HL are identified as important targets for ongoing initiatives in England. The MindEd programme, an online portal intending to help adults identify, understand and support young people with any mental health problems, and the Healthy Eating for Young Children programme, an early years healthy eating and skills for life course, were highlighted as ongoing national interventions for improving child HL-related outcomes (PHE, 2015b). However, while these programmes hold promise as effective tools for the promotion of HL and mental HL, they primarily target adults, aiming to provide them with the skills to foster HL skills in their children. Although the social environment plays an important role in a person's HL (Sørensen et al., 2012), these initiatives assume the child's social environment is the primary mechanism impacting their HL, and they do not acknowledge their status as active health practitioners (Fairbrother et al., 2016). This is an important, and currently unmet, consideration in contemporary society, which is concerning given that one of the key NHS Five Year Forward View ambitions relates to providing the public with greater control over their care (NHS, 2014). With 14% of all children in England having long-standing illness, over 50% of mental health problems surfacing by 14 years of age, and 43% of children and young people not being as actively involved in decisions around their care as they would like to be (MF, 2020), treating the younger generation as active health information practitioners is a necessary step for health literacy policy and practice in England (Fairbrother et al., 2016). There is a clear and unambiguous role for public HL in promoting the health and wellbeing of adults and children in England, yet there remains a lack of national action guided by key, multidimensional HL principles – perhaps due to the convoluted nature of HL as a construct; more on this later. This is not a new perspective, with global calls for action being observed for public HL in recent times.

Internationally speaking, HL is frequently considered in a general sense, with a greater focus on health promotion more broadly. The World Health Organisation (WHO), for instance, has called for further investment to strengthen public HL, citing increasing rates of noncommunicable diseases and low literacy levels as feeding into health equity concerns on an international scale (WHO, 2013). Further attention was drawn towards HL in the recent Shanghai Declaration on Health Promotion (2016), which identified HL as one of the three key health promotion pillars necessary in achieving the WHO's sustainable development goals within the 2030 sustainable development agenda (WHO, 2016). A number of countries have consequently directed resources towards the improvement of public HL, with America, Australia and England noted as the leading international countries based on HL publication output (Qi et al., 2021). These countries in particular have produced national or local action plans (DHHS, 2010b; PHE, 2015b; Tasmanian Government, 2019), spotlighting

HL on a national level and furthering the 2030 sustainable development agenda in the promotion of health equity. Other countries, however, are yet to do so to date.

The international HL landscape has more recently made the case for supporting and enabling child HL in addition to adult HL, with an array of backing for considering the child as an active HL practitioner. Several perspectives have emerged to support the view that children are actively considering and navigating present-day health information. The first, the clinical perspective, posits that the self-management of lived childhood health conditions like diabetes require the appropriate HL skills to cope with. This may not be of relevance to many children, however, as the appropriate navigation of health systems and medication adherence is frequently considered with reference to an adult's HL. The second, the health promotion perspective, indicates children engage in broader health activities and are naturally exposed to, or actively seek, health information in everyday life, suggesting children require HL skills to make sense of the world on a frequent basis. The third, the developmental perspective, indicates the natural alignment of independence within the progression of early developmental stages and the subsequent need for HL skills. The marked progression from childhood into adolescence requires unsupervised decision-making across a range of health components, including physical activity, sleeping, sexual expression and food and dietary habits (Velardo & Drummond, 2017), and therefore the demand on HL skills rises during the developmental transition from childhood to adulthood.

While adult HL is equally as important for many health promotion reasons, the primary concern is that child HL is neglected. Many ongoing and prior interventions and general research projects fixate on adult HL internationally, and while this does not propose that research should cease on adult HL, it does indicate that child health equity is negatively impacted given the significant role of HL on health equity and the lack of resources aiming to address child HL (Okan, 2019). While recent observations identify a number of child HL programmes in circulation (Nash, Patterson, Flittner, Elmer, & Osborne, 2021) and ongoing research attempting to better understand the associations of child HL (Qiao et al., 2021; Riiser, Helseth, Haraldstad, Torbjørnsen, & Richardsen, 2020) over the present decade, health policy has only recently considered child HL on an international scale, with the World Health Organisation publishing a policy brief on investing in HL for children and younger people (McDaid, 2016). The recent focus on child HL has led to an increased production of child HL interventions, and consequently an increased need to measure HL in children. Given that adult HL measurement practices are still inconsistent (Liu et al., 2018), child HL measurement practices are even less understood and thus an important consideration to foster rigorous and reliable assessments. The view from the literature is clear: public HL is 1) an essential component to consider to improve general population health outcomes, 2) an unclear construct hampering measurement in adult and child populations, and 3) is both a national and global challenge to address.

While the first and third perspectives denote a need to increase the resources employed on an international scale to improve public HL, the second consideration presents a bottleneck for tackling the public HL problems facing adults and children everywhere. Up until this point, this literature review has described both the importance of HL for public health and the numerous interpretations of HL over the years. The next two sections provide literature on how HL can be measured, but also how disagreement on the conceptual nature of HL as a construct leads to inconsistent practices and incomparable data. After this, the reader should begin to form an understanding of how HL measurement is hampering progress in the field, and also the next steps to a streamlined collective of practices.

How and Why we Measure HL

Taking one of the more well-regarded conceptual views of HL, we understand the construct to signify the ability to access, understand, apply and appraise health information (Sørensen et al., 2012). Measuring such a construct therefore relies on approaches which consider multiple dimensions. In terms of the assessment tools used, surveys are the predominant method to capture public HL scores across a range of HL-related dimensions, with the majority of validated tools documented in the National Library of Medicine and Boston University School of Medicine's Health Literacy Tool Shed being surveys (Harnett, 2017). Importantly, surveys are not the only method used to capture an individual's HL. One intervention intending to improve child HL via IMOVE, a classroom-based health education programme, used Nutbeam's model of HL to act as a theoretical framework for conducting thematic analysis on lesson transcripts gathered from in-class observations (Bruselius-Jensen, Bonde, & Christensen, 2017). The resulting data provided a qualitative overview of the three HL levels proposed by Nutbeam (2000), allowing the authors to subjectively, and depthfully, evaluate the intervention impact on child HL. However, the natural subjectivity of this approach, combined with researchers within the team conducting the analysis – albeit independently – may lead to a trade-off in objectivity, with confirmation bias potentially taking effect. Nevertheless, unique approaches beyond the traditional survey are present in the field.

Assessment tools measuring public HL can be sub-divided into objective, performance-based assessments; subjective, self-report assessments; or combined assessments, utilising a combination of the two (Okan et al., 2018). These categories reflect the ‘instrument type’, and come with inherent advantages and disadvantages when measuring HL. Objective HL instruments challenge the individual with standardised test stimuli with the intention of measuring an underlying factor or factors, and in doing so provides a more legitimate depiction of a person’s HL. One such example of an objective HL instrument is the Test of Functional Health Literacy in Adults (TOFHLA), which includes a 50-item reading comprehension section followed by a 17-item numeracy section – aiming to assess functional HL in adults (Parker, Baker, Williams, & Nurss, 1995). More specifically, the reading comprehension test utilises a modified cloze procedure, with every 5-7 words omitted from a given passage. Four multiple choice response options are provided to the testee, with each passage of text contextually based on patient instructions in preparation for an upper gastrointestinal series procedure, their rights and responsibilities in reference to a Medicaid application form, and a generalised hospital informed consent form.

The TOFHLA provide a useful inference into the frame of questioning within objective HL instruments, and in the context of the reading comprehension component, can include questions like “Your doctor has sent you to have a (**stomach**/diabetes/stitches/germs) X-ray” and “I understand (thus/this/**that**/than) if I DO NOT like the (marital/occupation/adult/**decision**) made on my” (Parker et al., 1995). The numeracy section forms a slightly different approach, with the questions based on forms used in hospitals and prescription medicine labels. More specifically, the numeracy sections aims to assess a person’s ability to comprehend medication use directions, manage medical appointments, attain financial support, and monitor blood glucose levels. The numeracy section provides the testee with cards and labelled prescription bottles, and asks questions orally to the participant. These relate to the items presented to participants, and, in the case of prescription bottle labels, can include questions like “If you take your first tablet at 7:00am, when should you take the next one?”. General prompt cards can be presented with relevant information, such as information regarding the ideal range for normal blood sugar levels and an example blood sugar measurement. Oral questions for these prompts include examples like “If this was your score, would your blood sugar be normal today?” (Baker, Williams, Parker, Gazmararian, & Nurss, 1999).

The TOFHLA – and its associated variants – are regularly applied in adult HL research, having been used to measure HL in studies exploring the interrelatedness of various factors in patient populations (Gomes et al., 2020; Papp-Zipernovszky, Csabai, Schulz, & Varga, 2021), evaluate the effectiveness of health promotion interventions (Khandehroo, Tavakoly Sany, Oakley, & Peyman, 2022), and wider general population HL assessments (Ganguli et al., 2021). Though the TOFHLA is frequently implemented in adults, alternative objective HL assessments for children and adolescents have become more established in the last decade.

Examples of child objective HL assessments include the Health Literacy for High School Students (HLHSS) and German Health Quiz (HQ) instruments (Wallmann, Gierschner, & Froböse, 2011; Wu et al., 2010), which follow different formats to the adult TOFHLA variants. The HLHSS uses 48 items with an open-ended question format succeeding several health-related extracts, intending to assess a person’s ability to understand and evaluate health information. The HQ consists of 49 items across nutrition, body, prevention, and leisure dimensions, with a four-option multiple choice response format. Unlike the HLHSS, the HQ assesses HL through an assessment of health knowledge, though in terms of application both the HLHSS and

HQ are not notable in the literature when compared with other objective HL measures.

Instead, instruments like the Rapid Estimate of Adult Literacy in Medicine-Teen (REALM-Teen) may be preferred (Davis et al., 2006), according to a brief literature consultation (Chisolm, Manganello, Kelleher, & Marshal, 2014; Dharmapuri et al., 2015; Park et al., 2017). The REALM-T is a modified version of the Rapid Estimate of Adult Literacy in Medicine (REALM), and makes use of an interviewer to complete a word recognition test to evaluate a person's functional HL (Davis et al., 1993; Murphy, Davis, Long, Jackson, & Decker, 1993). The REALM and its associated variants provide a list of terms for the interviewee to read, in which the interviewer records the number of correct pronounciations, thus garnering an estimate of an individual's functional HL. With regards to its application, the REALM-Teen has been used to evaluate the relationship between HL and various clinical factors in teens with sickle cell disease (Caldwell, 2019), for general HL population assessments (Sfeatcu et al., 2015), and additionally in HL intervention assessments (Bhatt, Boggio, & Simpson, 2021). The more frequent application of the REALM variants compared with the HQ and HLHSS may be due to the historical prevalence of the REALM, which has been available since 1993 (Davis et al., 1993; Murphy et al., 1993). Additionally, the administration time for the REALM is short, with the longest version typically taking no longer than 5 minutes to complete (Dumenci, Matsuyama, Kuhn, Perera, & Siminoff, 2013).

Although the empirically grounded, positivist approach to data collection from objective instruments is valuable, the test-like manner in which objective assessments are conducted can lead to stigma in participants, and particularly in those who do not fair well in a test environment. Other limitations of objective testing include the all-but-required in-person format to be used for testing (Nguyen, Paasche-Orlow, & McCormack, 2017), although this is disputable given recent findings supporting over-the-phone administration practices for objective instruments (Russell et al., 2019). Perhaps more relevant is the view that objective HL instruments frequently hold a unidimensional preference for measurement, and typically focus on one dimension of HL in isolation (Davis et al., 1993; Parker et al., 1995; Weiss et al., 2005).

Subjective HL instruments take an alternative approach to HL measurement, with question items focusing on participant experiences and likert scale response options used to quantify the findings. A frequently employed subjective HL measure in adults is the Health Literacy Questionnaire (HLQ), which is a 44-item measure assessing 9 dimensions, with all items using four or five-point likert scale response options (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013). The types of questions presented by respondents include “I set my own goals about health and fitness” and “Find information about health problems”, and can be implemented across population assessments, needs-based assessments, and intervention studies (Epstein, 2021). The survey has been widely implemented in recent years, with examples investigating the potential link between HL scores and health behaviours and self-reported health scores (Aaby, Friis, Christensen, Rowlands, & Maindal, 2017) and variation in HL by broader population characteristics (Simpson, Knowles, & O'Cathain, 2020).

Though many HL instruments are formed with adults in mind, subjective HL assessments also exist intended for use in child populations. The 10-item Health Literacy for School-Aged Children assessment (HLSAC), for example, is a subjective, child-friendly instrument with five theoretical dimensions, accompanied by four-point likert scale response options for each item. Having undergone validation testing in Finland (Paakkari, Torppa, Kannas, & Paakkari, 2016), Norway (Bjørnsen, Moksnes, Eilertsen, Espnes, & Haugan, 2022), and Denmark (Bonde et al., 2022) in recent times, the HLSAC has been used to support large-scale national HL assessments in children (Paakkari et al., 2016), aid the exploration of factors associated with child HL (Fretian et al., 2020), and evaluate the impact of a school nurse placement intervention on child HL levels (Buhr et al., 2020).

The benefit of self-reported, subjective measures rests within the simplicity of testing. These instrument types typically involve less cognitive demand than their objective counterparts, and provide a broader scope for HL assessment given the non-test format employed, allowing research to determine whether healthcare systems meet the needs of the greater population (Nguyen et al., 2017). The key limitation of subjective instrument types is that there is no way to know whether a person's response to question items relates to their actual skill in the factor or factors being measured. Each individual's lived experience, particularly in the context of HL, is different, and consequently people may view HL items within a self-report question in a different light. For instance, people who were exposed to the healthcare system throughout their life due to previous adverse health events may perceive health information use, application, appraisal and navigation differently to people who have not had that level of exposure. This may contribute to inflated responses for low-exposure participants, meaning participant responses are more confounded than their objective counterparts and do not necessarily relate to their true HL skills.

Though adults and children may take the HLQ and HLSAC and self-report they are able to understand health information and decide if health information is right and wrong, objective HL instruments may contrast this. This may be supported by data from studies utilising both objective and subjective HL assessments. For instance, in a recent investigation exploring the independence of both assessment types and their subsequent associations with information source judgements, only a weak association was established between the two measurement types (Schulz, Pessina, Hartung, & Petrocchi, 2021).

Given the benefits and limitations of objective and subjective instruments, with objective instruments serving well as true skill assessments and subjective instruments providing a wider scoping view of population health needs, combined objective-subjective approaches have been recommended more recently (Okan et al., 2018). One such instrument – named the Health Knowledge, Attitudes, Communication and Self-efficacy Scale (HKACSS; also known as the GeKoKids Questionnaire) in recent systematic reviews (Guo et al., 2018; Okan et al., 2018) – incorporates a series of short likert scales and dichotomous questions to assess purported HL domains in children (Schmidt et al., 2010). The survey considers five dimensions of HL, including self-efficacy, communication, behaviour, knowledge, and attitudes, and is comprised of 17 items. Objective question elements include a four-option multiple choice response format, with questions having a single correct answer. These questions act as general health knowledge assessments, with examples ranging from *"What teeth do you have to take care for in particular when tooth brushing?"* to *"How can vaccinations be administered?"*.

For the subjective HL component, a combination of 4 and 5-point rating scales and dichotomous closed question response formats were used. The subjective HL component acts to identify self-reported communication, attitudes, behaviours and self-efficacy from the participant in the context of their health, including statements like *“It is important to me to eat fruit and vegetables (Yes/No).”* and *“If I am in trouble, I can usually think of a solution (Not at all true/hardly true/moderately true/exactly true).”*, and questions like *“Do you smoke? (Yes/No)”*. Though this survey has previously been identified in child and adolescent HL review studies (Guo et al., 2018; Okan et al., 2018; Perry, 2014), it is unclear whether additional studies have implemented the measure.

According to review evidence (Guo et al., 2018), a second combined objective-subjective HL instrument is available, being implemented in undergraduate students. The Health Literacy Assessment Tool-51 (HLAT-51) – not to be confused with the Health Literacy Assessment Tool-8 (Abel, Hofmann, Ackermann, Bucher, & Sakarya, 2015; Harper, 2014) – measures four dimensions of HL, presenting participants with Yes/No response options and differing multiple choice formats. More specifically, the sentence variation and cloze techniques were employed, with the former asking participants to determine if sentences presented have the same semantic meaning as those presented in the original passage, and the latter requiring participants to fill in the blank spaces within text passages. Moreover, numeracy questions based on statistical, analytical, computational, and basic areas were used, in addition to further performance-based, objective lines of questioning with regards to media literacy, assessing audience and authorship, representations and reality, and messages and meaning in the context of health websites. Lastly, digital literacy was considered, with a subjective HL measurement component in regards to self-report sections on a respondent’s health information seeking behaviours, combined with objective correct-incorrect questions on digital literacy and questions based on various health scenarios (Harper, 2014). Once more, though, while the HLAT-51 has been identified in recent review evidence as a combined objective-subjective HL instrument in circulation (Guo et al., 2018), its wider use in the field appears unclear.

Combined approaches allow for a more all-encompassing overview of HL due to their broader scope for inquiry, and have recently been recommended for the measurement of HL, especially in children (Okan et al., 2018). Combined objective-subjective HL instruments are, however, few and far between, with objective-only and subjective-only HL instruments more prevalent (Haun, Valerio, McCormacck, Sørensen, & Paasche-Orlow, 2014; Okan et al., 2018). With the HLAT-51 and HKACSS both difficult to find beyond the initial sources of development (Harper, 2014; Schmidt et al., 2010) and review findings (Guo et al., 2018; Okan et al., 2018), combined objective-subjective HL instruments may not be considered as much as HL instruments using objective or subjective approaches in isolation.

Regardless of the instrument type employed, researchers have taken a key interest in measuring HL for a number of years. At its core, researchers seek to measure the HL of a person to improve societal health. More specifically, measuring HL provides initial needs assessments for members of the general population (Simpson et al., 2020), while monitoring and evaluating policies for HL promotion (Arriaga et al., 2022). Comparatively, measuring public HL levels yields important information which can be used to inform the development of initiatives and strategies to address problem areas. These can come in the form of education interventions (Keikha, Ansari, khosravi, & Seraji, 2021; Woods-Townsend et al., 2021), but can also include the integration of new roles across institutions and services (Buhr et al., 2020), physical health initiatives (Carolyn et al., 2019), and mentoring support (Beauchamp et al., 2017), to name a few. Public HL assessments can also contribute to a better understanding of factors associated with a person's HL, providing a more informed view of antecedents and consequences attached to a person's HL. Such studies can shed light on important HL associations, including the role of HL in facilitating access and navigation of health services (Vandenbosch et al., 2016), and its association with quality of life (Halverson et al., 2015), amongst other variables.

Measuring HL is also considered beyond an individual level, with organisational HL measures used to determine the HL demands of information within societal infrastructure and health services, and evaluate the conformity, and success, of HL practices at a organisational level (Murfet et al., 2023). Such instruments include the Organisational Health Literacy Responsiveness (Org-HLR) self-assessment tool, an assessment of HL responsiveness and supportive tool for quality improvement. The tool uses three components – reflection, self-rating, and priority setting – which are divided into 6 dimensions, with each further split into between 1-5 sub-dimensions, providing a total of 135 different organisational HL performance indicators (Trezona et al., 2018). Rather than following traditional self-assessment processes, a more comprehensive three-step process is employed, using a combination of group workshops, qualitative and quantitative data collection techniques, and priority setting to enable a broad view organisational HL. Questions asked within the Org-HLR can include, but are not limited to, "What do we currently do well to support the health literacy needs of consumers and the community?" and "Do we currently have the available expertise, capacity and system capability to implement the required improvements?", to name a few, though the tool cannot be defined by these examples alone due to the various techniques and assessment strategies employed. The Org-HLR is intended for the Australian healthcare context, however, and has been suggested to require extensive adjustments for systems which have different infrastructure or unique considerations. Adjustments to the Org-HLR have been made in recent times, including semantic and syntax adjustments and the elimination of various items, with the focus on improving its utlity across a range of health and social care contexts (Trezona et al., 2020).

Measuring organisational, as well as individual, HL can lead to sustained, system-wide HL change across wider health infrastructure. Such improvements can include embedding HL policies across health systems and services, improved engagement from service users, and the generation of user-friendly information and training resources (Kaper et al., 2019). Using objective, subjective and combined objective-subjective instruments is an important component for better understanding the HL landscape and both implementing and evaluating initiatives to address individual and organisational HL needs. Instruments to measure HL capture the reality of health needs from an individual and environmental perspective, while enabling the evaluation of strategies implemented across society. Ensuring the measurement of HL is done well is therefore essential to accurately meet the individual and environmental health needs of the general population, while also gathering accurate evaluations of initiatives to address these.

Importantly, the scope for existing reviews on HL measurement practices is somewhat limited, particularly in the context of the general population. Grey literature is seldom searched in HL measurement reviews across community populations, and many recently developed HL instruments were unavailable to interventions included in a recent community HL review (Nutbeam, McGill, & Premkumar, 2018). As a consequence, there remains a gap behind the true extent to how HL is measured in community populations in the present day. To better understand existing measurement practices, and enable a better understanding of HL needs and evaluations, a broader view of adult and child community measurement methods must be sought.

Deviation in Health Literacy Measurement

Though HL measurement practices have not been explored in full, inferences can be obtained through general population assessments and intervention studies in the literature. While instrument type – whether an instrument is objective, subjective, or a combination of the two – is an important consideration, deviation in HL measurement is particularly notable when the conceptual nature of HL is explored. When viewing literature interpretations of the multidimensionality of HL, inconsistent measurement practices and data comparisons become the centre of attention in HL research.

Given the expansion of HL as a construct in recent years, having moved from a prose-based skill in the health domain to a more all-encompassing public health consideration (Frisch, Camerini, Diviani, & Schulz, 2012), discussion has arisen in the literature regarding the appropriateness of different model-centred interpretations of HL (Baker, 2006; Frisch et al., 2012; Nutbeam, 2000; Parker & Ratzan, 2010; Rask, Uusiautti, & Määttä, 2014; Schulz & Nakamoto, 2005; Soellner et al., 2017; Sørensen et al., 2012; Zarcadoolas et al., 2005). While the academic HL discourse can be described as a broad-scale, professional difference of opinion, HL models play an important role in guiding the development and validation process of HL instruments. Without the HL models, it would be almost impossible to provide an evidence-based consensus on what to measure with regards to a person's HL. These conceptualisations guide the items forming the tool, and shape the dimensions assessed within a HL instrument.

These underlying conceptualisations subsequently determine the elements of a person's HL being assessed, meaning that HL measurement practices can evaluate a range of multidimensional components. Naturally, there is numerous disagreement on the most appropriate HL model, with existing HL instruments guided by different models. The retrieval of data for different dimensions of HL leads to components across different models being assessed, which in-turn makes for more challenging comparisons to be made and conclusions drawn on the data. This more convoluted pool of data then requires further subjective interpretations within the literature and runs the risk of unreliable conclusions being formed. When considering the many HL models in circulation (as discussed previously), it is unlikely that general population HL assessments follow the same conceptualisations.

This is not a problem if the HL measurement practices meet the aim of the study, but an overview of the literature suggest that assessing for improvements in community participants' HL follow different, and inconsistent trends. For example, a brief view of general population HL research yields three distinct measurement practices: theoretical HL assessed via study-specific HL scales and closed question formats on health knowledge on current and future health (Woods-Townsend et al., 2021), general HL measured via Lenartz's German HL questionnaire – assessing 6 scales from the structural model of HL (Stassen et al., 2020), and general HL again measured with the rapid assessment of HL scale (Zhuang, Xiang, Han, Yang, & Zhang, 2016). Three different HL instruments were used, with three separate conceptualisations of HL guiding data collection. Drawing comparisons between these findings is therefore challenging as the underlying HL constructs being measured differ, despite two of the three studies assessing the same outcome in general HL. While both studies assessing general HL, for example, will attain overall values for a person's HL, the dimensions being assessed to form these deviate. Without an understanding of the convergent validity these tools possess, it can be difficult to ascertain whether HL data are sufficiently comparable. In-turn, a lack of validity testing – specifically with regards to convergent validity – can lead to an unclear view of the degree of interrelatedness between HL conceptualisations guiding assessments. Though convergent validity is important to understanding whether assessments make sense in comparison with other instruments (Abma, Rovers, & van der Wees, 2016). The notable divergence in conceptualisations of HL and prevalence of different HL instruments may make it challenging to determine convergent validity across the board.

This problem also persists when studies using the same HL conceptualisation are considered. Nutbeam's (2000) hierarchical levels are commonly incorporated within community HL assessments, with community populations referring to non-patient specific characteristics. Once more, if studies provide an appropriate rationale for investigating one specific dimension within the model, this is understandable. However, a brief view of the literature indicates this is not the case. For example, one recent intervention – aiming to empower African-American adult churchgoers – measured the impact of an education and behavioural intervention with the Newest Vital Sign, a measure of functional HL in isolation (Carolyn et al., 2019). On the other hand, another recent intervention, aiming to incorporate school nurses in German elementary and secondary schools to improve HL, used the European HL Short Scale survey to measure HL outcomes, acting as a more all-encompassing functional, communicative and critical HL instrument (Buhr et al., 2020). Both studies aimed to evaluate the impact of an intervention on public HL and other health outcomes, yet two differing approaches were taken within the same HL conceptualisation – one unidimensional, and the other multidimensional. Although this is more comparable given that the same interpretation of HL was used across both studies, it infers that additional information was ascertained which may not have been relevant given that both studies had the same intent. Nevertheless, it is important to understand why measurement practices differ when limited study rationales for such practices exist.

To re-emphasise, this deviation is not necessarily an inherent problem within the field as long as HL outcomes are properly justified with respect to the study and/or intervention aims. For example, one community HL intervention utilised the Test of Functional Health Literacy in Adults (TOFHLA) to assess public HL. Given that the intervention aimed to familiarise low-to-moderate English proficiency Spanish-speaking adults with complex literacy demands in health settings, the TOFHLA was an appropriate fit given the focus on functional information outlined in the intervention aim (Soto Mas, Ji, Fuentes, & Tinajero, 2015). However not all academics ascribe to the view that HL can be considered in a unidimensional manner in any respect. Evidence from a recent review on community HL interventions indicates that, while the academic rhetoric around the concept of HL is exciting and frequently incorporated into community interventions, studies frequently omit important dimensions which form the concept of HL, instead focusing on functional HL and omitting communicative and critical HL (Nutbeam et al., 2018). The academic rhetoric ascribes HL as a multidimensional, skills-based construct (Hibbard, 2017), yet current evidence, albeit limited in scope, suggests that HL should be measured multidimensionally, regardless of the rationale in place.

Though the debate surrounding the measurement of HL persists in the field, this has historically been discussed with reference to community adult populations – making reference to the general population with no specified disease, condition or illnesses (Nutbeam et al., 2018). This disagreement is problematic in adult HL research, given the negative implications on the comparability and reliability of findings produced, but the recent shift in attention towards child HL demonstrates an even more prominent lack of consensus. Systematic review evidence investigating child and adolescent HL instruments found that, while one instrument was observed as suitable for the assessment of primary school children, none were designed for early years HL measurement. Furthermore, the majority of instruments extracted did not provide sufficient conceptual HL information and instead assessed their own perceived understanding of HL (Okan et al., 2018). Inconsistent child HL measurement practices are arguably more problematic than community adult HL practices, and this perspective is exacerbated by the current academic rhetoric the suitability of certain HL instruments for children. Most recently, debate has arose around the use of the Newest Vital Sign (NVS), a gold-standard assessment of functional HL in adults, in measuring child HL. Initial findings suggested the NVS as a suitable measure of child HL in children (Driessnack, Chung, Perkhounkova, & Hein, 2014; Warsh, Chari, Badaczewski, Hossain, & Sharif, 2014), but more recent findings contradict this belief, indicating the NVS as unsuitable for children aged 7-13 years (Howe, Van Scoyoc, Alexander, & Stevenson, 2018).

This debate extended into open editorial letters, with Weiss – who led the research team who helped develop the NVS – writing to Howe and colleagues that these findings are unsurprising given that adults have difficulty interpreting the many complexities associated with functional HL information (Weiss, 2019). This was later rebutted by Howe and colleagues who presented the view that parental proxy HL scores for children are insufficient in the assessment of child HL. Instead, they recommended that the priority for child HL rests on investigating the processes by which children develop HL and developing a series of best practices (Howe, Alexander, Van Scoyoc, & Stevenson, 2019). Understanding the mechanisms by which child HL develops has become a key consideration across the field of HL in recent years, with recent discourse highlighting child HL as an asset for future health-related outcomes (Velardo & Drummond, 2017). The primary difference between adult and child HL measurement is that, while there remains disagreement around how adult HL is measured, there are commonly accepted models which can guide adult HL measurement, like the Nutbeam (2000) model. This enables HL instruments to be developed which are generally accepted by researchers and enable further insight in adult HL, though there remains inconsistent practices and hard-to-compare data via current approaches.

While adult HL has a number of guiding models to conceptualise and measure HL, the relatively new focus towards child HL means the field is less developed. Definitions and models of HL are fundamentally lacking in primary school children and those under the age of 10 (Bröder et al., 2017), and no consensus towards a given model all-around (Okan et al., 2018). A lack of agreement towards what constitutes a child's HL may exacerbate comparability and reliability problems for child HL data. Instead of providing an accurate overview of child HL, researchers may be comparing child HL findings gathered through instruments which test different elements of the same construct (Bollweg & Okan, 2019).

As opposed to adult HL measurement practices, child HL measurement is scarce, particularly when studies measuring HL as a direct outcome are considered. More frequent are knowledge-based assessments based on intervention content which relate to health topics, frequently being study-specific surveys (Riley, Cloonan, Baigis, & Strobel, 2007), or mental health literacy assessments for child education interventions (Liddle, Deane, Batterham, & Vella, 2021; Ojio et al., 2015). To date, there are few studies which have conducted general population child HL assessments based on model dimensions, or have conducted HL interventions in children with direct HL assessments embedded. One of the few was a practical and theory-based education intervention conducted across 38 secondary schools, attempting to engage pupils with science through an education intervention to improve their HL. As the primary outcome, theoretical HL levels were assessed through a study-specific HL assessment, comprising of knowledge of lifestyle choices and their impact on a person's life and future generations (Woods-Townsend et al., 2021). Due to the lack of available child HL assessments, it is harder to ascertain contradictory practices with child HL research compared with adults.

Given that one of the few known HL education interventions in children uses a study-specific measure of HL with unclear HL dimensions, consistent practices may be difficult to abide by without more stringent child HL measurement guidelines. As discussed previously, the majority of conceptual models or theories have historically been formed with adults in mind. This may lead to a lack of comparable findings from child HL research, or inappropriate comparisons being drawn – both of which are notable observations across the adult HL literature (see Chapter 2, sub-section *deviation in health literacy measurement*) – and consensus-driven guidelines for measuring HL in community child populations could be beneficial for the field.

While progress in adult and child HL fields are different, and the measurement problems deviate, both have an underlying lack of conceptual clarity. If measurement practices remained obscure, this could lead to problems understanding how adults and children deal with accessing health information, how much they understand what they learn in the context of health, and how much they are able to critically appraise health-related information.

Current HL measurement practices provide unclear overviews of adult and child HL due to the inconsistent measures and conceptualisations employed, and as a consequence it may be challenging to elicit policy and practice-centred change to improve HL in England. This problem forms an important concern for the field, and addressing this could be vital to catalyse HL-guided public health improvements for the general population. Agreement on what constitutes important HL components to consider for adult and child HL measurement would enable a well-rounded, structured approach for identifying specific HL issues in England, while enabling the development of appropriate HL instruments – if required – in community adult and child populations. A more calculated approach into the intricacies of child and adult HL in England can subsequently be achieved, as a framework of key HL components can be generated to guide research practices, and suitable HL instruments can be employed or developed to assess these. Expert consensus on measuring HL is therefore essential for the advancement of community adult and child HL in England, and the field of HL as a whole.

There have been prior attempts to reduce the deviation in HL practices, but few have successfully achieved scientific consensus beyond traditional workshop and roundtable discussions (Hernandez, 2009; Hernandez, French, & Parker, 2017; RCGP, 2022). These are not facilitated via the scientific process, limiting the reliability and validity of potentially important perspectives on HL measurement. Delphi studies, on the other hand, provide a systematic approach to developing consensus on complex topics, and can be evaluated to determine their overall quality (Nasa, Jain, & Juneja, 2021). Given that the identification of important HL measurement components may direct future HL practices, and therefore limit the deviation in HL practices, Delphi methodology could play an important role in addressing the inconsistent child and adult HL measurement practices in England. While Delphi studies have been conducted in the field, they typically investigate adult patient populations (Karuranga, Sørensen, Coleman, & Mahmud, 2017; Toronto, 2016) and mental health literacy in children (Bale, Grové, & Costello, 2020), and none have considered community adult and child HL measurement practices. The unagreed upon measurement practices are a key challenge facing community adult and child HL research, and are important to address to enable policy and practice-level HL changes to occur. A Delphi study in the area may be the first important step for improving public HL in England and beyond. A more refined conceptual overview of adult and child HL may in-turn reduce conceptually varied HL measurement practices and clarify the next steps for improving public HL in England.

This is the first important gap in the field which this thesis seeks to address. So far, the focus has been on the HL measurement practices employed, and has attributed the unclear, existing conceptual HL variation as problematic. However, a key perspective within this thesis posits that there are two discrete elements to consider when measuring HL: the model-based, existing conceptual HL measurement practices in circulation; and the components which are uncredited within existing models of HL – those which have been overlooked. In order to establish a consensus towards HL measurement practices in community adult and child groups, both known and unknown HL practices must be identified and agreed upon.

The Forgotten Element – Proxy Health Literacy

Thus far, a myriad of community adult and child HL measurement practices and conceptualisations of HL, leading to an abundance of public HL instruments being developed. HL instruments can be conceptually distinguished by the types of variables, or dimensions, being assessed. Two variable types in particular, latent variables – representing items that cannot be measured directly – and observable variables, describing directly measurable items (Lei & Wu, 2007), form the conceptualisations guiding HL measurement practices. In the context of HL, researchers may use Structural Equation Modelling to assess factorial validity of a given model, with examples ranging from the psychometric testing of a HL in Dentistry scale (Ju, Brennan, Parker, Chrisopoulos, & Jamieson, 2018) and replicate the existing factor structure and ascertain discriminant validity in the HLQ (Elsworth, Beauchamp, & Osborne, 2016). An understanding of the latent and observable variables forming HL conceptualisations guiding a HL instrument is important, as these indicate the HL conceptualisations researchers use.

While various HL measurement practices have been discussed so far, literature understandings stem from model-based views of HL. The models forming HL measurement have undergone extensive psychometric testing in recent decades, and the psychometric testing of variables like functional, communicative, and critical HL by researchers has led to strong associations being established (Ishikawa, Nomura, Sato, & Yano, 2008; Moeini, Rostami-Moez, Besharat, Faradmal, & Bashirian, 2019; Shan, Ji, Dong, Xing, & Xu, 2023). As discussed previously, numerous disagreement from academics has led to alternate models of HL being produced, with accompanying reliability and validity testing to support claims of the correct conceptualisation (Osborne et al., 2013; Rouquette et al., 2018; Soellner et al., 2017). Although an important consideration in the field is HL, minimal discussion exists around the presence of alternative, non-model latent or observable variables – or dimensions – which may be appropriate for the measurement of HL.

As numerous model-based interpretations exist in the field (see Chapter 2, sub-section *development of models and theories of health literacy*), the current research environment may limit discussions of HL to the models in circulation, and might exclude HL-relevant variables not in mainstream models. Existing models may consequently take precedence when debates occur around HL, with a recent commentary discussing HL in reference to the functional, communicative, and critical HL model (Nutbeam & Lloyd, 2021) and another valuing HL in the context of an individual and organisational model (Gugglberger, 2019). Though this is logical and important for the scientific process, unknown HL-relevant areas may not be accounted for in current discussions. Proxy, non-model considerations have not been discussed by experts collectively to ensure breadth of consideration, and current perspectives of HL measurement consensus may be rooted on individual, model-based conceptualisations alone. To ensure breadth of consideration and enable a true understanding of expert perspectives on the conceptualisation of HL in the general population, it may be beneficial for experts to consider direct, model-based interpretations of HL and proxy, non-model measurement components.

Guided by an understanding of available models of HL and the potential to broadly capture conceptualisations not formed from models, this thesis proposes that there are two important HL measurement categories to consider when evaluating current practices: direct HL, reflecting the most frequently discussed and employed model-based components of a person's HL; and proxy HL, referring to domains which are not directly attributable to known HL models, or those identified by experts to be useful adjunctive outcomes to determine a person's HL. Prior review findings have used model-based dimensions of HL as a gauge for defining the type of HL instrument used, suggesting that HL model dimensions can be used to delineate between HL measures (Haun et al., 2014). Although thus far the discussion has revolved around the importance of clarity and consistency of HL measurement, this has been discussed relative to direct, and not proxy, HL measurement, as the former represents the predominant literature in circulation (Nutbeam, 2000; Soellner et al., 2017; Sørensen et al., 2012; Zarcadoolas et al., 2005).

While direct HL measures are simple to identify, given that they can be found in existing HL models, proxy HL measures do not currently conform to a clear and discernible detection mechanism, and require more creative approaches to be identified. Literature evidence provides an effective point of identification for proxy HL outcomes, with relationship studies – often in the form of correlation, regression, mediation and moderation analysis – providing a useful indicator of the potential interrelatedness between HL and proxy markers (Kafle, 2019). Evidence from systematic reviews is useful for superimposing the available relationship evidence for HL with potential proxy HL outcomes, and provides a more centralised overview of possible proxy HL components. Some examples of conceivable proxy HL outcomes can be seen from a recent review, which identified several direct HL concepts, including media literacy and functional HL, as associated with adolescent health behaviours (Fleary, Joseph, & Pappagianopoulos, 2018). Additional evidence suggests HL acts as an independent predictor of more specific health behaviours in adults, including exercise, diet, social support and stress management (Chang, 2011). Similar evidence has been documented across a range of adult populations (Aaby et al., 2017; Rueda-Medina et al., 2020; Von Wagner, Knight, Steptoe, & Wardle, 2007), indicating adult HL may be related to a range of health behaviours, providing scope for health behaviours as a proxy HL measurement consideration. Further regression findings imply trust as a proxy consideration for adult HL as well, identifying link between adult HL and trust in health information – with low HL associated with lower odds of visiting medical websites and trusting health information from specialist health professionals, and increased trust in social media, peer and television sources (Chen et al., 2018).

The difference between adults and children, in this regard, is that potential proxy HL outcomes for children can be detected through a combination of parental HL proxy assessments and child-reported HL assessments, with the former a frequent occurrence in the field. Although proxy HL outcomes cannot be definitively determined in child groups which use this approach, this provides a rough indicator of the proxy HL outcomes to initially consider in children. While direct assessments of child HL are likely more accurate predictors of proxy HL considerations, data from both approaches are nevertheless highly prevalent. In recent years, child HL has been associated with a range of health outcomes, including child oral health status (Bridges et al., 2014), child vaccination (Johri et al., 2015) and reduced night sleep time (Bathory et al., 2016). These indications are wide ranging, with child and adolescent obesity, assessed via body mass index scores, also associated with parental and adolescent HL, indicating that anthropometric elements may also be important proxy HL considerations (Chari et al., 2014). Systematic review evidence on the association between child HL and a range of health outcomes found that child and parent HL was associated with several negative health outcomes, including worse health behaviours, lower health status, increased asthma emergency department visits and hospitalisation rates, and lower prenatal screening rates (DeWalt & Hink, 2009), suggesting the scope for proxy HL outcomes in children is broad.

There exists evidence for various outcomes associated with public HL, across both adult and child community populations. These outcomes provide an important understanding towards the allocation of resources to foster improvements in public HL. The direct HL outcomes inform us of how the public access, understand, appraise and apply health information, but outside of highly context-specific literacy demands like media literacy, direct HL outcomes provide less context on important considerations required for the improvement of the public's HL skills. These proxy considerations allow for a more well-rounded view of public HL, enabling an understanding of not just the skills required for the management of health information within a person's lived environment, but also the areas requiring improvement – both at an individual and a systems level.

Throughout this thesis, the view of HL considering two key, and discrete, community HL measurement categories – direct and proxy HL – will be notable. The concept of HL being sub-divided into direct and proxy HL is well observed in the literature, with the introduction of HL measurement often bifurcated to capture direct testing and proxy inferences (Hanchate, Ash, Gazmararian, Wolf, & Paasche-Orlow, 2008; Hoffman-Goetz, Meissner, & Thomson, 2009; Koay, Schofield, & Jefford, 2012). This separation provides a broad, but focused, overview of public HL in adult and child community populations, and the development of a framework to guide measurement encompassing this view allows for future measurement practices to view HL without existing model-based limitations. Holding this perspective guides the methodology proposed in this thesis (see Chapters 2 and 3, sub-section *methodology*), and enables a broad overview of the field, allowing the consideration of both individual and system contexts which are important presently (Liu et al., 2020), and alternatively explore further conceptual measurement views not presently accounted for.

The presence of proxy HL outcomes may thus be identified by the HL evidence base, and combined assessments of direct and proxy HL provide a well-rounded overview of a person's HL. Consensus towards the measurement of community HL, however, appears minimal. It may also be difficult to develop a framework to guide community HL measurement in adults and children at the proxy level if the only proxy HL outcomes identified are in the academic literature. An inherent limitation of the notion that there are 'proxy' HL outcomes is that it is a notion. In the present-day literature, this is a perspective, and there are a myriad of different perspectives towards HL measurement available. Nevertheless, prior research has considered proxy HL measurement as those which do not consider model-based dimensions of HL (Haun et al., 2014). The literature provides an important starting point for potentially relevant proxy HL items, but it does not provide a full overview, and it cannot be guaranteed that all available literature will be synthesised. Some potentially relevant proxy HL considerations for the framework may be missed by guiding the identification of proxy HL outcomes from a literature review alone, and is largely impractical by nature.

To account for this, methodological triangulation of the evidence base can be employed. An initial synthesis of literature evidence for the potential presence of proxy HL outcomes provides the initial series of proxy HL outcomes to consider, and an expert HL panel subsequently can provide additional recommendations to form a cohesive pool of proxy HL components. This enables a greater synthesis of proxy HL items to be considered for a community HL measurement framework for adult and child populations. Triangulation improves the credibility and validity of the framework as a whole (Noble & Heale, 2019) by allowing experts to add to and feedback on the initial direct and proxy item pool. Moreover, if the view of HL measurement being divided into direct and proxy HL is flawed, HL experts will be able to identify this and inform the development of a HL measurement framework based on an alternative principle. A combination of literature review and expert perspective enables the primary goal of developing a rigorous HL measurement framework for community adult and child populations.

From this section, the reader should be able to see why proxy HL is an important, and seldom considered aspect of public HL measurement, and how such a broad component of HL measurement can be investigated where consensus is the primary aim. In order to develop a framework to improve the inconsistent HL measurement practices in circulation, consensus must be attained on adult and child HL measurement practices at the direct and proxy level, and both literature recommendations and expert consensus provide an appropriate platform for the development of a community HL measurement framework. Although this thesis proposes that the presentation of proxy HL as a novel concept is an important consideration for HL measurement, it cannot be guaranteed that similar disagreements on the conceptual nature of HL will not arise in the same way conceptual disagreements persist for direct, model-based HL. However, a triangulated approach incorporating review evidence and expert consensus fosters a collaborative approach to facilitate further discussion in the field, and further refinements to a framework in the future. Consequently, this will form the predominant methodology employed within this thesis. A scoping review forms the initial synthesis of current HL measurement practices from a direct and proxy perspective, eliciting an important overview of HL measurement components in circulation. When complemented with the Delphi process, important disregarded measures will also be considered and further discussion on HL measurement is enabled, supporting the identification of more standardised direct and proxy HL measurement practices moving forward.

The overarching aim of this approach is subsequently to reduce conceptual variance in HL measurement for adult and child general population research, and support the development of robust HL evidence to inform policy and improve population health outcomes. Focusing on direct and proxy HL, in my view, enables a well-rounded investigation into community adult and child HL measurement practices in England. Given that prior research has bifurcated HL measurement to reflect direct and proxy HL (Hanchate et al., 2008; Hoffman-Goetz et al., 2009; Koay et al., 2012), and that support for its operationalisation as model-based versus non model-based exists (Haun et al., 2014), a broad view of community HL measurement may be implementable. From the origins of HL being considered an applied literacy skill, to the 21st century emergence of HL as a multidimensional skill, there are a number of important measurement considerations to understand the dimensions factoring in to a person's HL. The above approach allows an in-depth synthesis and discussion of HL measurement practices, supporting a broad scope of potentially novel and pre-existing considerations to be captured by academics.

Implications of Clarified Health Literacy Measurement

This review so far provides a clear indication of inconsistent HL measurement practices, but a clear explanation of the benefits of clarifying HL measurement is not so apparent. This section aims to enlighten the reader on the policy and practice implications for a more standardised community HL measurement process.

Two immediate benefits of consistent HL measurement practice are notable, with the first being consistency of application. As mentioned previously, current HL measurement practices from both an outcome (Liu et al., 2018) and instrument (Buhr et al., 2020; Carolyn et al., 2019) perspective are inconsistent. This may lead to difficulty drawing comparisons between findings guided by different conceptual dimensions of HL, which in-turn may lead to ambiguity in literature interpretations or, more problematically, misrepresentation of the evidence-base – leading to validity concerns and an overall lack of rigour (Flake & Fried, 2020). Inconsistent HL measurement practices are problematic for many of the reasons that meta-research was established to address, referring to the study of research processes more generally, and these inconsistent practices represent a key problem for the scientific method in the field of HL (Ioannidis, 2018). To improve the rigour and general validity of the evidence base and avoid a further contribution to the reproducibility crisis in science (Begley & Ioannidis, 2015), enabling more consistent HL measurement practices may lead to the generation of more easily comparable, and replicable, HL findings. Given that methodological rigour requires clarity in methodology (Devezer, Navarro, Vandekerckhove, & Ozge Buzbas, 2021), ascertaining a series of conceptual HL measurement practices to a framework enables consistency of application in the outcomes assessed, clearer HL data comparisons, and improved reproducibility of HL research. Consistency of application is therefore an important benefit arising from developing a community HL outcomes framework for adult and child populations.

The second clear benefit of a HL outcomes framework pertains to the implications for policy moving forward. Clarity on the components important to consider when measuring community adult and child HL creates more consistent and comparable data. This data can subsequently be used to inform future policy around public HL, highlighting the importance of varying public HL domains for guided action plans and/or resource allocation. At its core, policy-centred decision-makers make executive judgements on resource allocation for public health in England. Having a HL outcomes framework of standardised, agreed-upon HL measurement practice allows for the generation of data on the expert-identified important areas within community adult and child HL. Given that this data would naturally be more comparable due to the more standardised approach employed via the HL outcomes framework, health policy decisions can be steered by the evidence-base generated through guidance from the framework. Policymakers will be more inclined to make decisions favouring public HL in England, as more comparable, factual evidence for the framework items begin to surface (Lunn & Ruane, 2013).

The UK Government has long intended to develop an evidence-based culture within health policy (Macintyre, Chalmers, Horton, & Smith, 2001). In more recent years, the focus of attention for evidence-based public health policy has shifted to three key domains: process, content, and outcomes (Brownson, Chriqui, & Stamatakis, 2009). Developing a HL outcomes framework is thus essential to consider – given the focus on outcomes as a constant for public health policy – before more conceptually rigorous HL measurement data can be used to inform wider policy. The need to achieve a degree of consensus on what constitutes an adult and child's HL is a fundamental component for meaningful public HL change and improved public health outcomes in England. The recent trend towards outcomes as a domain to consider for evidence-based policy practices demonstrates the need to map the outcomes important for HL as a public HL construct. The added spotlight from public health policy on HL in England supports the generation of clarified HL-improvement strategies, which in-turn increases the prevalence of guided HL interventions. Although current policy in England presently was most recently steered towards local action, a range of areas were highlighted to improve the state of public HL in England, including the cost-effective assessment of HL initiatives, the improvement of HL in disadvantaged and vulnerable communities, and the adoption of school intervention approaches for HL (PHE, 2015b). Clarification on the outcomes forming adult and child HL enables a clear overview of how research can be integrated within these areas, while also steering future policy decision-making for upcoming government priority discussions.

Given the recent crisis of misinformation reported during the Covid-19 pandemic (Zarocostas, 2020), public HL skills have been thrusted into the limelight as an area requiring attention (Naeem & Boulos, 2021; Paakkari & Okan, 2020). As a consequence, a number of calls have arisen to address public HL on a global scale, and in a multidisciplinary capacity (Abdel-Latif, 2020; Abel & McQueen, 2020; Bray et al., 2021). A subsequent rise in policy surrounding public HL is therefore expected, and the development of a framework to clarify HL-relevant outcomes to guide future policy is timely. With HL being regarded as a promising 'social vaccine' for public health promotion (Okan, Messer, Levin-Zamir, Paakkari, & Sørensen, 2022), understanding the elements important to consider for HL policy is vital for successful initiatives to be developed and subsequent public health promotion to be attained. The implications for devising a HL outcomes framework are primarily driven by a transparency of general HL data and a clarity in future HL policy, supporting the development of key HL 'outcomes' to investigate and simplified public HL policy processes.

A Summary for Public Health Literacy, and Incorporating a Pragmatist's Philosophy

Public HL has evolved from that of a foundational and personal literacy skill to a multidimensional, all-encompassing individual and systems-level construct. Evolution of the construct in recent years has led to inconsistent HL measurement practices, casting doubt on the validity, reliability and overall rigour of data-driven claims made in the field. Understanding the landscape of public HL is essential for the subsequent development and implementation of resources to address public HL issues and improve health outcomes, but inconsistent practices make for difficult conclusions to be drawn and decisions made. In addition to this, the recent movement to consider children as active health practitioners (Fairbrother et al., 2016) has led to a surge in interest around understanding child HL further (Bray et al., 2021; Nash, Patterson, Flittner, Elmer, & Osborne, 2021; Velasco, Gragnano, Lombardia, & Vecchio, 2021), leading to additional deviations in practice and further convoluting the interpretation of HL evidence across the field. As a consequence, there exists an urgent and unmet need to clarify how HL is measured from an outcomes-based perspective across adult and child general population research, as existing evidence to inform future policy is difficult to interpret accurately and may negatively skew the scientific consensus in its current state.

Given the increasing prevalence of public HL as a topic of interest in recent years, largely being a consequence of the Covid-19 pandemic, the triangulation of review evidence and expert consensus enables a more objective understanding into the intricacies of adult and child HL on a conceptual level. The end product –a HL measurement framework – subsequently enables conceptual guidance for public HL in adult and child community populations, providing researchers with a concise understanding of conceptually relevant HL areas to consider during the study design phase. In-turn, this may enable greater consistency in community HL measurement practices, and further simplify comparisons between HL datasets. This forms the basis for this thesis, with the aims and objectives outlined below:

Table 1. Aims and Objectives for the PhD Thesis.

Aims	Objectives
1. To investigate the conceptual nature of HL in community adult and child populations. 2. To gather preliminary data on the state of child HL in England.	1. To synthesise and understand current HL measurement practices across community HL interventions. 2. To develop an expert-led consensus on the HL measurement outcomes important to consider at the direct and proxy level for adult and child community populations. 3. To pilot-test a child HL assessment in England.

Abbreviation: HL, Health Literacy.

The measurement of HL is an important and convoluted topic, with the conceptual nature of adult HL being complicated and the conceptual scope for child HL being poorly understood. In order for an appropriate methodological approach to be established for the research aims and objectives, a mixed-methods approach was employed (see Figure 4).

Figure 4. PhD Thesis Study Flow Chart.

Stage 1

Review investigating health literacy measurement practices across community interventions.

↓

Stage 2

Round-based survey study to facilitate consensus on community health literacy measurement in adult and child populations.

↓

Stage 3

Pilot survey testing the feasibility of measuring health literacy in children based on the consensus achieved in stage 2.

To understand the justification behind selecting a mixed-methods approach for a thesis on HL measurement, a broader philosophical discussion on scientific enquiry must first be held.

The social sciences have been defined in a number of ways, but generally refer to the scientific study of human society and broader social relationships, and includes social policy, social psychology, sociology, human geography, political science, social policy, economics, and various interdisciplinary fields including global health, technology, and migration studies (Greenhalgh, 2018). Social sciences frequently use a range of diverging and comparable philosophical assumptions to address research aims and objectives. Central to these assumptions are three concepts important for distinguishing different scientific research paradigms: ontology, epistemology, and methodology (Belharar, Laamrani, & Chakor, 2023).

Ontology can be considered the study of being, capturing the exploration of what exists in the world in which humans are able to acquire knowledge about (Moon & Blackman, 2014). In the context of research, ontology allows researchers to outline a degree of certainty with regards to the nature or existence of elements being researched. In reference to community HL measurement, the nature of reality of questioned when the conceptual nature of a construct is investigated. Where the meaning of a given concept – in this case, HL – is questioned, this forms an ontological consideration; one in which the essence of the empirical world is being debated (Goertz & Mahoney, 2012). Variations in ontology types exist across differing research paradigms. A positivist ontology may view reality as objective, and governed by natural laws in a given order which can be comprehended through experience in the world. Alternatively, an interpretivist ontology may assume that reality is experienced internally, and instead socially constructed rather than being governed, with interpretation of reality based on the perspective of the individual (Tombs & Pugsley, 2020). Examples of opposing ontological assumptions can be seen when comparing naïve realism – where one reality exists, which can be understood with the proper methods – against relativism, which suggests multiple realities exist across non-physical mental constructions specific to a given person (Moon & Blackman, 2014).

Epistemology, on the other hand, relates to the nature of human knowledge, its limitations, and its justification (Hathcoat, Meixner, & Nicholas, 2019). Essentially, epistemologies refer to what humans think can be known about the world (Gaudet & Robert, 2018). Understanding how knowledge can be known is critical for research, and epistemology provides a philosophical foundation for which types of knowledge are possible, adequate, and legitimate (Crotty, 1998). Crotty (1998) argued that, in the development of a research proposal, four key elements are present and inform one another. More specifically, Crotty (1998) posited that epistemology informs a theoretical perspective in research, which in turn influences the methodology considered, which subsequently determines the methods used. Central types of epistemology are objectivism, subjectivism, and constructivism, with each providing differing assumptions of knowledge (Al-Ababneh, 2020).

An objectivist epistemology considers reality independent of a person's mind, with a central contention being that an objective truth can be discovered which is empirically valid, generalisable, provable, and independent of social components (Crotty, 1998). Subjectivism, alternatively, purports the opposite, suggesting that meaning is determined by a person's mind, with the object contributing nothing to the perspective. Through this, perception is defined as the reality, and the true reality cannot be independent of a person's perspective (Crotty, 1998; Feast & Melles, 2010). A subjectivist interpretation of knowledge is therefore both plastic and pluralistic, allowing a flexible and multi-expressive view of knowledge (Moon & Blackman, 2014). Lastly, a constructivist epistemology views learning as interconnected with experience (Kumar, 2006). In this, Crotty (1998) differentiated constructivism in valuing no objective truth able to be discovered, and instead, truth or meaning is identified through engagement with the realities in our world. In this epistemology, meaning cannot be attained without a mind, and is not able to be discovered, but instead is constructed through the development and revision of cognitive schemas.

Both ontology and epistemology are closely linked, given that answers to questions on knowledge are dependent on ontological assumptions of reality being made. Knowledge is shaped by reality, as the essence of reality may determine the very formation of knowledge (Pranas, Jolita, & Regina, 2018). In forming a philosophical basis for social science research, three key elements are considered: epistemology, ontology, and philosophical perspective (Moon & Blackman, 2014). Where a research project is designed, the researcher presents a philosophical perspective of the world, as certain research methodologies and the methods within align with different philosophical underpinnings of the world.

Lastly, before an understanding of the thesis methodology can be established, a brief overview of the differences between research methodologies and research methods must be considered, along with their innate links to philosophical positions. A research methodology, according to Wahyuni, represents the model for conducting research, and includes a series of beliefs encompassing ontological and epistemological assumptions (Wahyuni, 2012). These methodologies, more commonly referred to as research paradigms, have historically been dichotomised in the form of qualitative versus quantitative paradigms. More recently, however, frequent debate from scholars has led to the development of mixed-methods as a third research paradigm, comprising of an integration of epistemological and ontological assumptions. Within a given research paradigm lie research methods, which are practical tools or applications for conducting research (Wahyuni, 2012).

At the commencement of research design, the research questions, aims, objectives, and project intent are recommended as starting points to identify the substance of interest (Wahyuni, 2012). This may then inform the research methods most appropriate and, in-turn, determines the research paradigm and associated ontological and epistemological assumptions of the project. For this thesis, the decision was made to follow this process to determine the research methodology.

When conceptualising the methods to explore the aims and objectives within this thesis, three key methods were established: a scoping review, a Delphi study, and a pilot survey comprising quantitative and qualitative data. The methods forming this thesis do not subsequently present a uniquely qualitative or quantitative paradigm, but instead forms a mixed-methods paradigm. Each method described considers potential variation in philosophical assumptions, with the use of both qualitative and quantitative methods (Creswell & Creswell, 2017). In the context of this thesis specifically, the aims and objectives intend to explore the conceptual nature of HL, and additionally test the feasibility of a framework to guide community adult and child HL measurement. As the conceptual nature of HL at the time of writing this thesis was inconsistently applied in community adults (Jensen, Aaby, Ryom, & Maindal, 2021; Simpson et al., 2020), and has not achieved international consensus in children (Bollweg & Okan, 2019), a flexible philosophical approach and perceived reality is required. Additionally, a philosophical basis for research enabling pluralistic approaches for the derivation of knowledge was viewed as the best fit. With the project aiming to understand the state of community HL measurement practices, explore and achieve consensus on HL measurement, and test the feasibility of newly devised consensus in measuring child HL, various approaches to the generation of knowledge were required.

An appropriate philosophical position for this thesis was subsequently determined to be pragmatism. Pragmatism as a philosophical position was conceptualised in the early 20th century by many scholars, including George Mead, William James, and John Dewey, among others (Cherryholmes, 1992). Though various forms of pragmatism exist, the general view depicts reality as normative, and dependent on what works. Generally, pragmatism contends that broader philosophical discord cannot be resolved, as meaning cannot be distinguished from human experience and needs are dependent on a given context (Dillon, O'Brien, & Heilman, 2000; Kaushik & Walsh, 2019).

Importantly, pragmatists do not see society as unity, and do not ascribe to one philosophical system or reality (Creswell & Creswell, 2017). More specifically, in the context of research pragmatists consider the *what* and *how* of research, and base their perspectives on the consequences of the methods, but this is not without justification. As pragmatists do not have to ascribe to either post-positivist or constructivist/interpretivist philosophies, they can apply different methods, analyses, philosophical positions, and assumptions from quantitative and qualitative paradigms (Shan, 2022). As such, they are not limited to methods aligned with certain ontological and epistemological assumptions. During the development of the methodology for this thesis, a mixed-methods approach was decided with a pragmatist philosophy, primarily due to the process for scientific enquiry being unclear with regards to achieving community HL measurement consensus. Firstly, investigating the state of HL measurement must be considered. From there, depending on the findings, consensus could be the intention of a follow-up study where HL measurement was determined as inconsistent from the initial study. Alternatively, it may be that community HL measurement is not viewed as problematic in community adult and child populations. To ensure the appropriate methods could be established based on the knowledge required, the philosophical position of pragmatism was adopted, with the view that a sequential mixed methods design be followed to allow an exploratory approach to HL measurement.

By ascribing to a sequential mixed methods design with a pragmatic lens, the process of scientific enquiry is not limited by restrictions on research paradigms, and instead is informed by knowledge claims (Creswell & Creswell, 2017). A common practice for research philosophically aligned with pragmatism, using a sequential mixed methods design enables the application of a range of methods which fit the purpose of providing socially meaningful knowledge (Feilzer, 2010).

As a field, HL has undergone numerous conceptual adjustments in recent times (Brach & Harris, 2021; Liu et al., 2020; Parnell et al., 2019). I viewed this as important to consider at the conceptualisation of this thesis, and aimed to ensure the methodology and philosophical assumptions captured the numerous knowledge types available, both presently and in the future. To address this in a rigorous, scientific manner, a sequential mixed-methods research design was used. Pragmatism supports the unification of beliefs and action through a process of enquiry (Morgan, 2014), and employing this philosophical perspective through a sequential mixed-methods may help address the conceptual nature of HL more than a positivist or singular paradigm approach. The HL research can subsequently be guided by the findings of each study, rather than the researcher's personal preference. This is particularly relevant to the Delphi methodology, which is a pragmatic tool for achieving consensus on a complex topic (Brady, 2015).

Each of the three objectives outlined will be tested by three separate research studies, using predominantly quantitative methods – with qualitative methods complementing them – in a sequential, explanatory and temporally spaced manner. The mixed methods approach supports a continuous cycle of abductive, inductive and deductive reasoning throughout, producing knowledge beneficial for the research (Mitchell & Education, 2018). For health psychology research in particular, a mixed methods design enables the identification of approaches which best fit the aims and intent of the research (Bishop, 2015). When considering these perspectives, alongside the view that mixed methods designs naturally provide a pragmatic and complementary lens (Dawadi, Shrestha, & Giri, 2021), the methodology forming this thesis will follow a sequential-explanatory mixed methods design with pragmatism as the philosophical foundation for enquiry. Sequential-explanatory mixed methods designs typically have a quantitative lean, and combining qualitative data typically occurs when the quantitative evidence informs the later qualitative elements. This may explain the predominant quantitative lens forming the methodology behind this thesis. The benefit of a sequential, explanatory mixed methods approach is the flexibility provided, with the design practical for a pragmatic philosophy where unexpected results are observed (Creswell & Creswell, 2017).

I, myself, have considered pragmatism my driving philosophical approach to research prior to this thesis. I believe that the generation of knowledge can be best yielded with pragmatic foundations. In my view, pragmatism considers the broader research intent more than any other philosophical position, and aligns with the research aims and objectives substantially more than a given research paradigm. Though the positivist perspective that one objective, external, and independent reality for a research phenomenon (Alharahsheh & Pius, 2020) resonates with me, I believe that, particularly in the context of HL, research questioning the conceptual essence of the construct may omit important conceptual information where alternative philosophical assumptions guide the process of enquiry.

By proceeding with this research design and philosophical view, I believe the conceptual nature of community HL in adults and children can be established, and appropriate inferences drawn in the assessment of child HL in England. Though additional resources are required for the conduct of mixed methods research designs (Wasti, Simkhada, van Teijlingen, Sathian, & Banerjee, 2022), the approach is feasible in reference to the thesis timeline and, in my view, promotes a more holistic approach to knowledge production than approaches with a paradigm-specific research foundation.

Chapter 2 – The First Study: A Scoping Review of Community Health Literacy Measurement Practices

Introduction

As discussed during the opening Chapter, HL reflects a person's knowledge, competence, and motivation to understand, access, apply and appraise health information across a range of health contexts (Sørensen et al., 2012). The transition towards multidimensionality in recent decades has led to an increase in HL measurement complexity, with a range of inconsistent measurement practices noted in recent non-patient, community HL interventions, which form the focal point for improving public HL and subsequent health outcomes. At an immediate glance, two adult education interventions intending to improve public HL amongst other factors assessed HL outcomes in a varied manner. One incorporated a series of study-specific thermometer, food and medicine label interpretation tasks in addition to five dimensions of the HLQ (McCaffery et al., 2019) – the former a measurement of functional HL and the latter an assessment of communicative and critical HL – and the other incorporated two functional HL outcomes: the Short-form Test of Functional Health Literacy in Adults (S-TOFHLA) and the Adult Health Literacy Scale (Ayaz-Alkaya, Terzi, Işık, & Sönmez, 2020).

Given the multifaceted, skills-based nature of HL as a construct (Hibbard, 2017), it is important to understand whether further consideration for HL measurement is required for existing evaluations of HL-improvement strategies such as community interventions. While not all HL interventions should begin to incorporate the same outcomes, a brief observation of current practices contrasts prior suggestions of a convergence towards all-encompassing HL measurement (Altin, Finke, Kautz-Freimuth, & Stock, 2014), though this does not infer that varied HL measurement practices alone are problematic. Nevertheless, there exists minimal review evidence to identify the state of HL measurement practices across health promotion interventions in community populations.

Community populations can be defined as any non-disclosed disease/condition/illness or otherwise healthy member of the general population – a definition used in a recent community HL intervention review (Nutbeam et al., 2018). Recent review evidence regarding community HL interventions identified unidimensional and limited overviews of HL within both methods and evaluations. Though this provides a useful indication of potential concerns in the field, the investigation was narrow, grey literature was not explored, the inclusion criteria was restrictive, and the focus of attention was on methodological intervention components and reporting, rather than outcome measurement practices.

To reiterate, the promotion of public HL cannot be overstated, particularly given that 43% of working-age adults are unable to comprehend or utilise health-related information, rising to 61% when numeracy information is also concerned (PHE, 2015b). Progression in the field is therefore vital, and accurately assessing the performance of HL interventions may subsequently lead to improved HL interventions and a reduction in adverse influences associated with low HL, including: lower receipt of influenza vaccinations and mammography screening (Berkman et al., 2010), reduced medication and non-medication adherence (Miller, 2016), all-domain quality of life deficits (Panagioti et al., 2018), non-compliance with preventive health practices (Patil et al., 2021) and increased mortality rates (Bostock

& Steptoe, 2012). The identification of measurement practices for the principal mechanisms of HL change – community interventions – is therefore necessary to determine whether progress in the field is assessed appropriately.

As discussed in Chapter 2 (sub-section *deviation in health literacy measurement*), measuring HL effectively at the domain or instrument-specific level may lead to misleading conclusions and difficulty drawing HL data comparisons. For intervention research, poor HL outcome measurement could hinder the reliability and validity of interventions by reducing the evaluative certainty by which HL-promoting techniques are effective, potentially limiting progress in the field. Understanding existing HL measurement practices is therefore valuable, and synthesising outcomes and instruments by their unidimensional or multidimensional profiles is needed. A true, holistic depiction of HL, however, requires consideration beyond model-specific domains alone.

Though direct HL measurements are important, the inclusion of proxy HL measurements may provide further insight into a person's overall HL. To distinguish direct and proxy HL measurement, the definitions proposed in Chapter 2 (sub-section *deviation in health literacy measurement*) is used. In order to ascertain whether HL measurement practices require improvement, as indicated via recent evidence (Nutbeam et al., 2018), a measurement-oriented overview of current community HL intervention practices is therefore needed which incorporates a broad scope. Consequently, a scoping review was conducted to identify the direct and proxy HL outcome measurement practices across recent community population HL interventions. The primary focus for the review was in the synthesis of measurement trends from an instrument and study-specific level, with instrument-specific patterns reflecting the HL tools incorporated and study-specific aspects considering the HL outcomes assessed. A range of existing reviews on HL measurement do exist, but are either now dated (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011), narrow in scope (Nutbeam et al., 2018) do not consider proxy HL outcomes (Okan et al., 2018) and/or focus predominantly on identifying HL instruments (Tavousi et al., 2015). The current scoping review subsequently aimed to provide a comprehensive update on HL measurement practices across interventions targeting the general population, with the main aim being to clarify whether existing practices align with the assumed convergence towards holistic measurement suggested previously (Altin et al., 2014).

Method

Protocol and Registration

To ensure transparent scientific conduct and unnecessary research duplication (Peters et al., 2017; Peters et al., 2015), a protocol was developed a priori. The scoping review protocol was drafted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses: Scoping Review (PRISMA-ScR) Checklist and Explanation guidelines (Tricco et al., 2018), with the final protocol registered with the Open Science Framework on the 11th August, 2020 (DOI: 10.17605/OSF.IO/4WRMQ). This review has subsequently been published in Health Science Reports, with the methodology and results information being used to guide the write-up for this thesis Chapter (Sawyers et al., 2022).

Previous evidence has demonstrated substantial variation in the reporting and conduct of scoping reviews. In a scoping review exploring practices of available scoping reviews, only 13% of scoping reviews used a protocol (Tricco et al., 2016), which may explain the inconsistent reporting and methodological conduct found from the same review. Methodological guidance prior to the conduct of the review were captured in the PRISMA-ScR, meaning that abiding by this guidance enables the conduct and reporting of a scoping review in line with evidence-based suggestions from JBI (Peters et al., 2021) – a leading international research group with expertise in the use of review methods.

Inclusion/Eligibility Criteria

Studies were included if they:

1. Sampled from the general population.
2. Included HL as a significant outcome of interest.
3. Involved a HL intervention aiming to improve person-centred/environmental HL.
4. Used quantitative, qualitative, or mixed-methods approaches.
5. Were English-text publications.
6. Were published ≥ 2010.

Studies were excluded if they:

1. Sampled from a distinctive subgroup that are not typical members of society, like prison populations.
2. Involved participants with disclosed health conditions, illnesses or ailments of interest.

The focus of this review was to understand recent measurement practices as they pertain to HL in the general population, hence interventions and investigations focusing on HL were included for synthesis. Items in non-English language were excluded due to the limited resources available for the review at the time and translation being a costly route which does not always lead to accurate manuscript retrieval. Given the previously discussed aim of the review, interventions conducted recently formed the topic area to be synthesised. This was primarily due to reviews covering HL interventions either now being dated (Berkman et al., 2011) or having stringent inclusion criteria which considered well-defined HL measures only (Nutbeam et al., 2018). With the review seeking to understand the state of HL measurement practices at the direct and proxy level, interventions employing HL as a key outcome of interest were considered to ensure the relevance of measures and outcomes being synthesised. A mixture of quantitative, qualitative, mixed-methods and grey literature interventions were included to achieve maximum breadth towards community HL interventions conducted recently.

Community participants, who we define as those with no existing health conditions or ailments of interest (Nutbeam et al., 2018), will be the primary recruitment focus. This is predominantly due to a standardised approach for HL outcome assessment not being feasible for clinical groups, as consensus regarding the measurement of HL in clinical populations would likely not capture the variance in unique clinical characteristics with one framework alone.

There are a number of independent considerations for health information in patient populations compared with non-patient, general members of the public. People with intellectual disabilities, for example, may be less independent and cognitively proficient than members of the general population and therefore require unique HL conceptualisations and subsequent measurement considerations (Geukes, Bruland, & Latteck, 2018). For HL research investigating patient HL, measurement practices may understandably deviate and are not therefore expected to be comparable across different patient groups. This is not the case for community populations, however, and uncovering current practices towards HL outcome assessment in community HL interventions has greater scope for measurement consensus and comparability of findings than patient/non-community samples. Similarly, the feasibility of a review incorporating all clinical populations for extraction would also be problematic, as the breadth of studies extracted would be logistically impractical unless the clinical group or groups were specified in advance. Clinical populations were subsequently excluded because 1) they may have unique HL measurement considerations to members of the general public; and 2) addressing the gap in knowledge regarding the application of general population-intended HL instruments and outcomes was the primary focus of the review. With this focus, the findings of this review may inform the need for expert consensus on HL measurement practices in community populations, further justifying the need to broadly scope the community HL intervention literature.

The Decision to Conduct a Scoping Review

Scoping reviews refer to a form of knowledge synthesis which uses a systematic and iterative approach to investigate and integrate a group of literature on a topic area (Mak & Thomas, 2022). More specifically, scoping reviews focus on enabling a broader scope of scientific inquiry than other review methods (Peterson, Pearce, Ferguson, & Langford, 2017), and can be a useful method when aiming to better understand and disseminate research data on heterogenous topic areas (Peters et al., 2015). Scoping reviews closely relate to a hypothesis generation process, with an exploratory lens (Tricco et al., 2016), and can be useful for determining current practices in research areas (Munn et al., 2018). Furthermore, scoping reviews can extend beyond mapping the literature, and has utility in clarifying concepts and identifying knowledge gaps (Munn et al., 2022). Unlike some review methods, scoping reviews typically do not include study quality evaluations (Levac, Colquhoun, & O'Brien, 2010). While scoping reviews may not be the most appropriate for providing quantitative study quality appraisals compared with other review methods, the broad scope of enquiry and synergy with heterogenous data supports a broad overview of complex topic areas. A scoping review was thus one of three review methodologies considered to explore community HL intervention measurement practices given its applicability for mapping heterogenous evidence.

Other reviews methodologies were also considered, such as the systematic review. While the definitive nature is ambiguous and vague across research and wider review resources (Krnic Martinic, Pieper, Glatt, & Puljak, 2019), a systematic review can generally be understood as a comprehensive, detail-oriented identification, synthesis, and appraisal method for investigating studies in a topic area. Unlike scoping reviews, systematic reviews can include a meta-analysis, enabling the use of statistical methods to further synthesise data from various studies into one numerical value or summed effect size (Uman, 2011). Where scoping reviews resemble hypothesis generation, a systematic review can be seen as a hypothesis testing process (Tricco et al., 2016). According to the Cochrane Handbook, systematic reviews seek to minimise bias, and do this through explicitly structured approaches (Lasserson, Thomas, & Higgins, 2019). Systematic reviews may be appropriate to studies assessing the feasibility, meaningfulness, effectiveness, or appropriate or given practices, whereas scoping reviews may be better placed to assess questions of a non-singular nature, such as those interested in identifying characteristics or concepts in a given area, or providing a mapping, a report, or a discussion of such aspects (Munn et al., 2018).

Scoping reviews typically provide a narrative presentation of the evidence-base, and have limited statistical input (Peterson et al., 2017) compared with systematic reviews. When taken with the view that this review aims to explore current HL measurement practices across interventions in the general populations, the heterogenous topic nature may be better suited to a review type enabling a narrative approach, such as a scoping review.

A narrative – or traditional – review was also considered given that a narrative approach was valued for the topic under investigation. As a research method, narrative reviews can be defined as a summary provided by scholars through the use of interpretation and critique, leading to an evidence-informed overview of the literature (Greenhalgh, Thorne, & Malterud, 2018). Narrative reviews typically present an overview of a large, diverse topic area (Nundy, Kakar, & Bhutta, 2022), and may or may not utilise systematic search methods with fixed criteria for inclusion or exclusion (Furley & Goldschmied, 2021). Importantly, various sub-types of narrative review exist, including hermeneutic reviews, realist reviews, meta-narrative reviews, with each having explicit methodological approaches, but more general styles also exist, such as integrative and critical reviews (Greenhalgh et al., 2018). Though each sub-type has distinct approaches, the narrative review methodology can support knowledge production from a theory development perspective (Furley & Goldschmied, 2021), can address multiple research questions, and is able to adopt appraisal in a narrative form (Ferrari, 2015). A limitation of narrative reviews, however, is the potential to cherry pick evidence to enhance a given perspective within the review, though this has to be balanced against the purposive intent of doing so in reference to the review intent (Greenhalgh et al., 2018).

While narrative reviews provide a broad scope for inquiry with the data identified, the HL intervention measurement landscape is currently unclear, and adopting a review methodology which allows a broad, but systematic approach may enable greater literature coverage than a narrative review. Consequently, due to scoping reviews providing a broad scope for inquiry with a more systematic, mappable methodology than narrative reviews, a scoping review was used. As scoping reviews are particularly useful for determining research conduct in research areas with heterogenous practices (Munn et al., 2018), such as in the variable measurement practices observed in general population research (see Chapter 2, sub-section *deviation in health literacy measurement*), the scoping review methodology is suitable to support the review aims herein. Moreover, given that the current review aimed to determine the consistency or inconsistency by which current HL measurement practices are implemented, the review does not test a specific hypothesis and instead may help generate a HL measurement hypothesis for future testing. As a scoping review acts as a hypothesis generation process (Munn et al., 2018), it was determined to be most appropriate review method for the study aims. A narrative review may make a broad, but comprehensive search more difficult, but a scoping review supports a broad, but systematic synthesis, without sacrificing a narrative style (Peterson et al., 2017). Ultimately, a scoping review provides an appropriate middle ground between a systematic review and narrative review, providing flexibility in capturing grey and wider literature with an explicit search strategy and inclusion/exclusion criteria, and enabling mapping and narration with simpler approaches to reducing bias.

The main aim of this review was to provide a comprehensive overview of HL measurement practices across interventions targeting the general population, across both direct and proxy HL measurement.

Search Strategy and Procedure

Preliminary Search Strategy, Procedure, Findings, and Conclusions Drawn

The decision to use the databases was initiated from a preliminary review, which pilot-tested the databases alongside an initial search strategy (see Table 2).

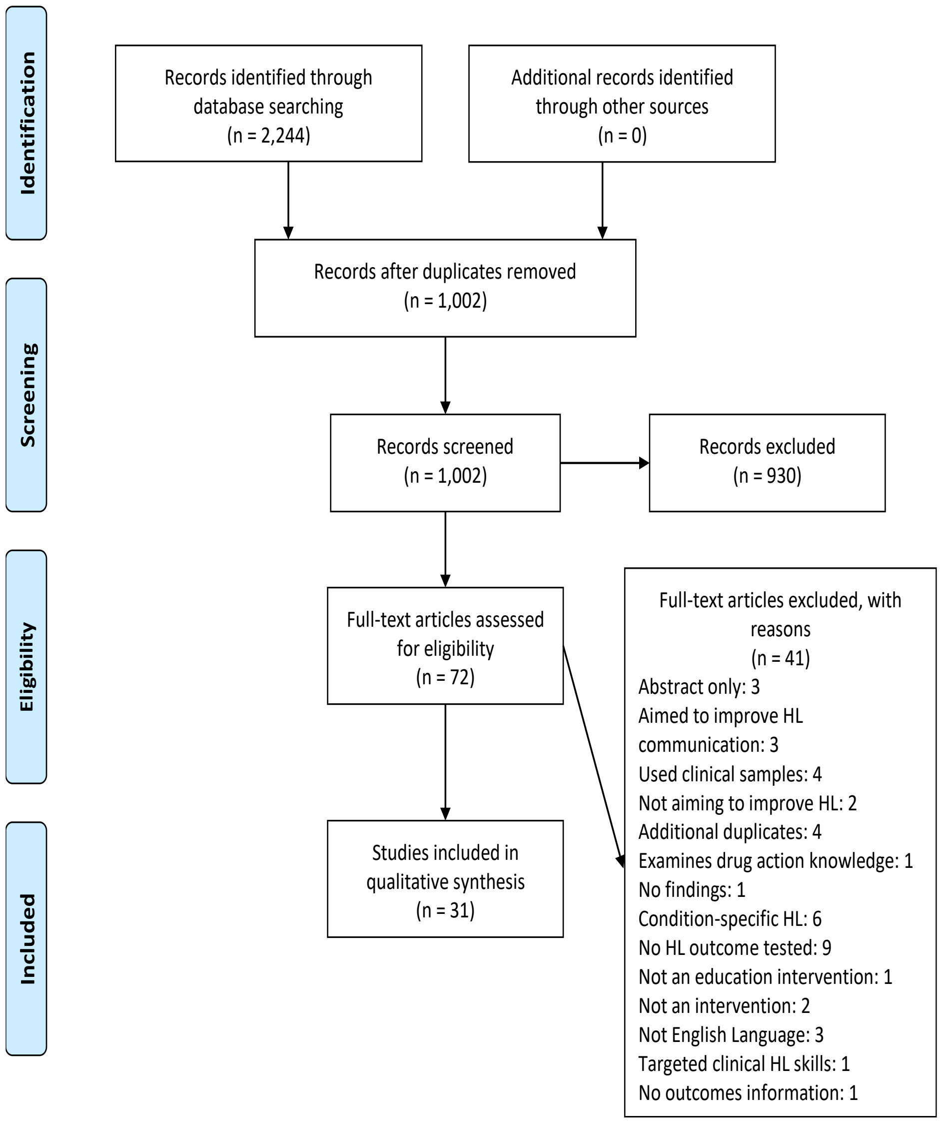
Table 2. Preliminary Search Strategy for Medline

Search Line	Input
1	Health literacy AND education* AND intervention OR workshop OR seminar
2	Health literacy AND education* AND community AND intervention
3	Health literacy AND education* AND workshop
4	Medicine literacy AND education* AND intervention
5	Medication literacy AND education* AND intervention
6	Medication literacy AND education* AND intervention AND adult*
7	Medication literacy AND education* AND intervention AND adolescen*
8	Medication literacy AND education* AND intervention AND child*
9	Pharmacotherapy literacy AND education* AND intervention
10	Pharmacotherapy literacy AND education* AND intervention AND adult*
11	Pharmacotherapy literacy AND education* AND intervention AND adolescen*
12	Pharmacotherapy literacy AND education* AND intervention AND child*
13	Health literacy AND education* AND intervention AND adult*
14	Health literacy AND education* AND intervention AND adolescen*
15	Health literacy AND education* AND intervention AND child*
16	Health literacy AND education AND randomi?ed control trial AND community
17	Health literacy AND school AND education AND intervention
18	Health literacy AND primary school AND education AND intervention
19	Health literacy AND curriculum AND education AND intervention
20	Medicine literacy AND curriculum AND education AND intervention
21	Medication literacy AND curriculum AND education AND intervention
22	Pharmacotherapy literacy AND curriculum AND education AND intervention

During the preliminary search, the following databases were identified to form the preliminary search: Medline (Ovid; 2010-present), PubMed (2010-present), Scopus (2010-present), the Cumulative Index to Nursing and Allied Health Literature (CINAHL; 2010-present), Education Resources Information Center (ERIC; 2010-present), Web of Science (2010-present) PsycINFO (2010-present) and Embase (2010-present). The aforementioned databases were initially chosen due to having previously demonstrated good reach for HL-relevant publications (Berkman et al., 2011; Nutbeam et al., 2018; Stormacq, Van den Broucke, & Wosinski, 2018). In addition to testing the traditional databases via a pilot search for relevance in extracting studies, pilot-testing reviews can be a useful tool for identifying meaning and themes in the data, which in-turn can aid in the extraction process in the final review, improving the validity of findings and overall efficiency of the review process (Long, 2014).

For the preliminary review, I scanned and retrieved the publications during the initial data extraction process. I then screened the items retrieved from each database in reference to the inclusion and exclusion criteria (see Appendix 1 for the criteria used in the preliminary review). For the preliminary review, the screening was undertaken by one researcher due to resource limitations at the time. The preliminary review led to the generation of 30 items relevant for synthesis (see Figure 5), with three items extracted from CINAHL, two from ERIC, four from PsycINFO, four from Scopus, one from Web of Science, none from Medline, 12 from PubMed, and four from Embase.

Figure 5. PRISMA Flow Chart for the Preliminary Review Data Screening and Extraction Process.



Abbreviations: HL, Health Literacy; n, Sample Size.

The preliminary findings were data charted (see Appendix 2) to form a range of initial direct and proxy outcome tables and figures (see Appendices 3, 4 and 5). No additional references were identified through other sources, such as manual reference list searching of eligible items, as this was not conducted in the preliminary review. After this phase, the preliminary review was complete, and the search strategy was provided to a senior librarian at the University of Nottingham for additional feedback. Several changes were proposed by the librarian, with the following changes implemented into the final review:

1. Subject headings were implemented within the search strategy for databases supporting the use of them.
2. PubMed was removed as a database for the final review due to both PubMed and Medline (Ovid) sourcing from the same National Library of Medicine, but PubMed not allowing proximity operators whereas Medline (Ovid) does.
3. A new set-based search strategy formulated by the senior librarian (see Table 3) to improve the accuracy and reach of database searching.
4. The use of short search lines and basic Boolean operators for the grey literature and website searching (see Table 4).

An initial round of searching across both the traditional databases and grey literature was used to determine the number of hits retrieved for the traditional literature and the accuracy of the new search strategy. This was conducted by myself, and after discussing the findings with the senior librarian, it was determined that the search strategy was appropriately positioned to begin the final review – citing a combination of accuracy of the hits in reference to the review aim and broadness of scope for the search strategy.

Traditional Literature Database Searching

Database searching was conducted across Medline, PsycINFO, Web of Science, Education Resources Information Center, Embase, Scopus and the Cumulative Index of Nursing and Allied Health Literature. Forward searching was used to scan reference lists of identified articles meeting the inclusion criteria to broaden the scope for extraction.

The search strategy was devised, refined and evaluated by the research team with support from a University Senior Librarian. The strategy was then refined and evaluated by members of the team (L.S, L.S.T, C.A, P.A, G.D) and the Senior Librarian. The following search was utilised for Medline and translated across the remaining databases (see Table 3):

Table 3. Search Strategy for Medline

Search Line	**Input**
1	exp Health Literacy/
2	exp "Surveys and Questionnaires"/
3	exp Health Education/
4	communit*.mp.
5	exp Community Participation/
6	general population.mp.
7	public.mp.
8	((health or medicine or medical or medicat* or pharmacotherap*) adj2 literac*).mp.
9	((educat* or behavio?r or ehealth or online or web or internet or complex or prevent* or environ*) adj2 (intervention* or survey* or questionnaire* or program* or curricul* or semina* or session* or workshop*)).mp.
10	1 or 8
11	2 and 3
12	4 or 5 or 6 or 7
13	9 or 11
14	10 and 12 and 13
15	Limit 14 to (English and last 10 years)

Abbreviations: exp, Explode; adj, Adjacency; .mp., Multi-purpose.

Grey Literature Search

Grey literature was included to achieve maximum reach regarding existing community-focused HL intervention research. Characterised by its non-commercial nature, lack of bibliographic control, non-peer reviewed nature and general elusiveness (Tillett & Newbold, 2006), grey literature is recommended in the Cochrane Handbook for a comprehensive intervention-focused review (Higgins & Green, 2008). Evidence sourced from grey literature can include dissertations and theses, government documents, conference papers and reports, academic publications, committee papers, newspaper columns, and more (Paez, 2017). Reliance on peer-reviewed literature exclusively, such as Medline, Embase, and PsycINFO, can lead to the omission of potentially relevant items, as the lag between research conduct and publication is long (Pappas & Williams, 2011). There are limitations of capturing grey literature, however, particularly with regards to the time-consuming nature of searching across multiple search domains and lack of gold standard search conduct (Paez, 2017). Nevertheless, the potential for grey literature searching to uncover relevant community HL interventions outweighed the limitations of conducting the search.

Nevertheless, grey literature is an important, and at the time of writing this thesis, unexplored area in community HL intervention reviews. The decision was subsequently made to include grey literature to meet the aim of the review in capturing a broad overview of community HL measurement intervention practices. This was particularly important given that, at the time of conducting the review, no HL reviews exploring community HL intervention measurement practices had been undertaken. The search was conducted in accordance with recommendations for a systematic grey literature search, including four strategies to minimise the risk of potentially relevant omissions: 1) grey literature databases, 2) customised Google search engines, 3) targeted websites, and 4) consulting with contact experts (Godin, Stapleton, Kirkpatrick, Hanning, & Leatherdale, 2015). Providing a framework to guide the grey literature search strategy was important, particularly given that no gold standard view exists here (Paez, 2017). As a consequence, a pragmatic approach was taken, with the above-mentioned guidelines a useful method for developing a systematic approach to formulating a grey literature search strategy. The grey literature database search incorporated ProQuest Dissertations and Theses, using a translated version of the Medline database search strategy. Google Scholar was incorporated as the Google search engine of choice (see Table 4).

Table 4. Search Strategy for Google Scholar

Search Line	Input
1	allintitle: “Health literacy” AND intervention
2	allintitle: "Health literacy" AND community OR public AND intervention

The targeted websites consisted of the following:

1. The Centers for Disease Control and Prevention (CDC; http://www.cdc.gov).
2. The United States Department of Health and Human Services (DHHS; https://www.hhs.gov/).
3. United Nations Educational, Scientific and Cultural Organisation (UNESCO; https://en.unesco.org/).
4. Public Health England (PHE; https://www.gov.uk/government/organisations/public-health-england).
5. World Health Organisation (WHO; http://www.who.int).
6. Australian Government Department of Health (ADE; https://www.health.gov.au/).

Given that the CDC and DHHS are specifically recommended for public health grey literature intervention searching, they were included (Turner, Liddy, Bradley, & Wheatley, 2005). In reference to the fourth strategy for effective grey literature searching, consulting with contact experts, consultations with HL experts (Mr Gregory Duncan and Prof Parisa Aslani) yielded various HL-relevant websites as appropriate resources to search. Consultation with the literature was also employed to guide the target websites used. For instance, the CDC and DHHS are recommended where public health intervention grey literature searching is undertaken due to the breadth of public health data within each site (Turner et al., 2005). For the remaining websites, medication literacy research has been demonstrated as prevalent in America, England, and Australia in particular (Liang, Luo, & Zhong, 2018). Due to medication literacy forming a potentially relevant sub-dimension of HL, this was used as a rough guide to determine countries of relevance in the context of retrieving grey literature. Though this narrowed the potential public health websites of relevance, to ensure the grey literature was not restricted to these countries, international websites like the WHO and UNESCO were searched to ensure breadth in data extraction. Triangulating the websites to search through expert perspective and literature consultation subsequently led to the above-mentioned websites being selected for grey literature searching. The search strategy for the targeted websites were as follows:

Table 5. Search Strategy for Targeted Websites

Search Line	**Input**
1	Health literacy AND intervention
2	Health literacy AND community AND intervention
3	Health literacy AND public AND intervention

General Search Details

Filters used across all search strategies included a custom date of publication range (2010-2020) and a publication language (British/American-English). For Google Scholar and targeted websites, the first 5 pages of items were extracted per each search line inputted, being retrieved irrespective of relevance. This was done across each search line. If less than 5 pages of items were identified by a search line, the items across the pages identified were retrieved. Page filters were modified to contain 10 references per page for Google Scholar and Targeted Websites where possible.

Review Process and Data Charting

One reviewer worked independently (L.S) to screen eligible abstracts for full-text review. After the initial screening phase, two reviewers (L.S and S.J) worked independently to screen full-text items for inclusion. Once reviewed, both members discussed the decisions made and verified the screening accuracy. A third reviewer (C.A) was available to make final decisions on any items in the event that discrepancies arose between the first and second reviewers. The researchers resolved disagreements that could not be resolved by consultation with the third reviewer through discussion with the remaining members of the team (G.D, P.A and L.S.T).

The data charting form was developed by the principal investigator (L.S) and later refined with feedback from members of the research team (C.A, L.S.T, P.A, G.D). Once the prospective data charting form draft was ready, further literature suggestions were implemented (Levac et al., 2010). The form was iteratively managed, and underwent a process of calibration via pilot testing across 5-10 papers (L.S) from the sample to ensure data extraction was consistent and relevant to the research (See Appendix 6).

The scoping review was managed through EndNote, with database extraction, duplicates removal, study screening and full-text review conducted on the software.

Synthesis of Results and Analysis

Measures were extracted and categorised into either direct or proxy measures. Direct instruments were further categorised by instrument type, and were catalogued into the following types: objective, referring to performance-based measures; subjective, involving self-report data; or objective and subjective, taking inspiration from a recent HL measurement review (Okan et al., 2018). Frequencies were computed for instruments and studies in accordance with the above categories, and additionally for the domains assessed at the direct and proxy level. Direct measures were categorised according to Nutbeam's (2000) model of HL, denoting measures which assessed functional, communicative and critical HL. This is primarily due to this model being the most abundant for guiding HL measurement, and was expected to form the majority of outcomes retrieved. To account for additional HL model domains, measures directly assessing HL in reference to domains outside of Nutbeam's (2000) model were categorised as 'other' direct HL domains, and those unable to be categorised were labelled 'unidentified' due to insufficient or unavailable information to determine categorisation.

Proxy measures were categorised via Braun and Clarke's six-step thematic analysis (Braun & Clarke, 2006) to logistically manage the volume of measures extracted. Qualitative themes were generated by the principal investigator (L.S), which were then cross-checked by members of the team (L.S.T, C.A).

Results

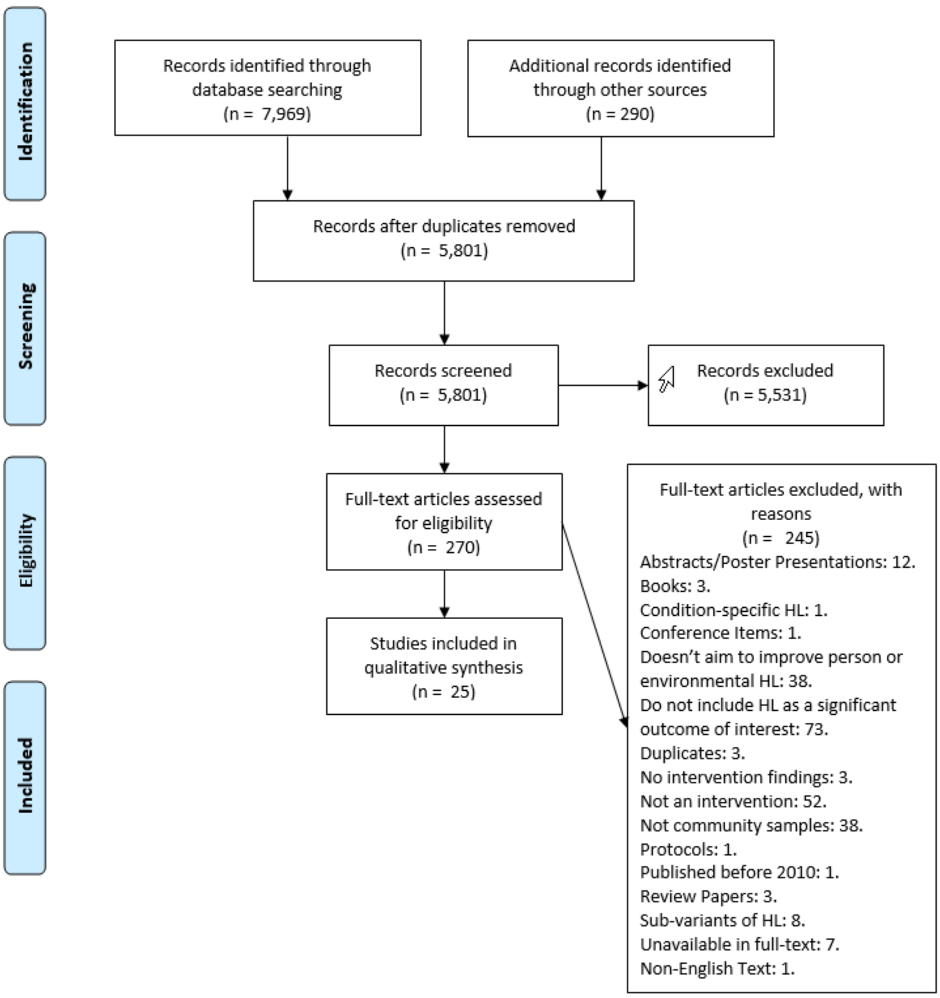
Statement of Credit

The majority of the results section presented for this study Chapter are also available online, as this study has been published in Health Science Reports (Sawyers et al., 2022). The publication presents a succinct overview of the scoping review methodology, alongside the same results presented below (Sawyers et al., 2022).

Screening and Extraction

The scoping review yielded 270 items after the initial screening, with full-text review identifying 25 items for synthesis (see Figure 6).

Figure 6. PRISMA Flow Chart for the Data Screening and Extraction Process.



Abbreviations: HL, Health Literacy; n, Sample Size.

Data Charting Table

A plethora of study characteristics and outcome practices were retrieved, including author and publication details, listed under the study column; sample characteristics, sizes and nationality, identified within the sample and sample size column; intervention delivery, type and material covered, extracted in the intervention column; direct and proxy instrument names, provided under the namesake columns, and the instrument domains assessed at the direct and proxy level, listed under the direct and proxy outcomes column (see Table 6).

Table 6. Data Charting Table of Intervention Characteristics and Outcome Practices.

Study	Sample and Sample Size	Intervention	Direct Instruments	Proxy Instruments	Direct and Proxy Outcomes
(Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen, & Helseth, 2012)	Sample: Norwegian parents with children < 4 years old (baseline n = 96). Study aim: evaluate impact of web intervention vs. no intervention.	Delivery: online web portal. Type: education. Material: health info tasks and TPB-based self-report survey. Int. aim: improve generic public HL.	S-S internet health info searching task; S-S critical appraisal task (DISCERN tool); TPB survey.	Honeycomb model feedback; PAM[a].	Direct: other HL. Proxy: satisfaction; patient activation.
(Ayaz-Alkaya et al., 2020)	Sample: Turkish women from family health centers in Ankara (baseline n = 42). Study aim: identify whether healthy lifestyle education int. improved HL and	Delivery: in-person. Type: education. Material: home healthy lifestyle-related visits from trained public health nurses. Int. aim: improve HL and health behaviours.	Adult health literacy scale; S-TOFHLA.	HLSBS-II/HPLP-II; PHS.	Direct: unknown[b], FHL. Proxy: health behaviours/lifestyle; health status and self-perceived health.

	healthy lifestyle behaviours.				
(Bayati, Dehghan, Bonyadi, & Bazrafkan, 2018)	Sample: health ambassadors from Iran (baseline n = 256). Kazeroon residents on the Persian integrated health system. Study aim: determine effect of int. on HL and health behaviours in Kazeroon health network ambassadors.	Delivery: in-person/self-study. Type: education. Material: based on the Ministry of Health and Treatment's Self-care in Minor Morbidities book. Int. aim: improve HL and health behaviours of Kazeroon health network ambassadors.	HELIA/HL inventory for adults.	HLSBS-II/HPLP-II.	Direct: FCC HL. Proxy: health behaviours/lifestyle.
(Bolton et al., 2020); Two study designs.	Case-control study: *Sample:* baseline int. (n = 68) and ctrl. (n = 67); both pregnant women at 22 weeks gestation). Community evaluation study: *Sample:* baseline (n = 61) mothers from the PACT programme. Sampled around London, England. Overall study aim: provide a new service to benefit maternal mental health, HL and social capital, and	Delivery: in-person. Type: education. Material: health education (parent-focused healthcare topics) and social support (parents/children socialising and parent-led workshops) intervention. Int. aim: apply developmental health science findings, social	Case-control study: NVS-UK.	Case-control study: adapted social capital integrated questionnaire; ASQ-3; ASQ:SE. Community evaluation study: Arizona social support interview schedule. Both studies: PHQ-9; GAD-7.	Direct: FHL. Proxy: *case-control study:* social capital; infant outcomes/physical development. *Community evaluation study:* social capital/support. *Both studies:* depression; anxiety.

	engage local populations to reduce statutory services contact.	support and health education to improve health outcomes of new mothers and their children.			
(Bruselius-Jensen et al., 2017)	<u>Sample:</u> 5th (n = 4), 6th (n = 4) and 7th (n = 4) grade classes across 4 Danish public primary schools; pupils (n – 281) and teachers (n = 9). Baseline sample. <u>Study aim:</u> observe the IMOVE int.	<u>Delivery:</u> in-person. <u>Type:</u> education. <u>Material:</u> processes supporting being physically active, while improving application/use of statistics. <u>Int. aim:</u> improve physical activity-related HL and statistics skills.	Deductive thematic analysis of lesson transcripts.	None.	<u>Direct:</u> FCC HL. <u>Proxy:</u> N/A.
(Carolyn et al., 2019)	<u>Sample:</u> African-American adult churchgoers (baseline n = 321) from African Methodist Episcopal churches in Florida. Could understand/read at sixth-grade level. <u>Study aim:</u> examine impact of Health-Smart church int. on health outcomes of African-American adult churchgoers.	<u>Delivery:</u> in-person (church-based). <u>Type:</u> education and behavioural. <u>Material:</u> health empowerment and health promotion. <u>Int. aim:</u> empower people to overcome barriers to health-promoting behaviours.	NVS.	HLSBS-II/HPLP-II; health-smart behaviour frequency scale; bodyweight scales; sphygomomanometer.	<u>Direct:</u> FHL. <u>Proxy:</u> health behaviours and lifestyle; health behaviours engagement; weight; blood pressure (Diastolic/Systolic).

(Chervin, Clift, Woods, Krause, & Lee, 2012)	Sample: adults (n = 2,412) in education centers (n = 6) predominantly serving minority groups. Teachers (n = 21) and center directors (n = 6) also took part. Sample represents baseline exposed to int. Mid-Atlantic America. Study aim: determine efficacy of infusing HL instruction in adult education on adult HL.	Delivery: in-person. Type: professional development grant to enable adult HL education curriculum interventions. Material: 'Study Circles', allowing adult education professionals to learn/discuss novel research for classroom use. Int. aim: increase HL in adult learners.	S-TOFHLA.	Self-efficacy assessment; skills learned essays; phone interviews; unspecified support received surveys.	Direct: FHL. Proxy: self-efficacy in using HL; HL project experience; capacity to teach HL for center directors and center teachers.
(Cook, 2021)	Sample: African-American faith center adult parishioners (n = 14) around west Chicago. Baseline (no drop-out reported) Study aim: implement HIV stigma reduction/HL int. at a cross-generational African-American faith center.	Delivery: in-person (faith center). Type: education. Material: in-person adult HIV/AIDS and HL education. Int. aim: to shift stigma about HIV/AIDS and expand HL skills and HIV knowledge.	Short assessment HL-English.	Stereotypes about AIDS questionnaire; HIV knowledge questionnaire; focused observation questions.	Direct: FHL. Proxy: AIDS-related stereotypes; HIV knowledge; disease comprehension and reflection.
(Buhr et al., 2020)	Sample: primary (n = 12), high (n = 13) and integrated primary-high schools (n = 3) schools in Hessen (n = 10) and Brandenburg	Delivery: in-person Type: education and behavioural. Material: nurses given vocational training/intensive	HLSAC; HLS-EU-Q16.	HLSAC.	Direct: other HL; FCC HL. Proxy: health behaviours.

	(n = 18), Germany. Baseline sample (children n = 2,773; parents n = 3,978; teachers n = 420). Study aim: examine observed changes in HL from a school int.	education to provide primary care/health education to schools. Int. aim: for nurses to address healthcare needs in schools and impact health-related outcomes.			
(Fernández-Gutiérrez, Bas-Sarmiento, & Poza-Méndez, 2019)	Sample: immigrant adults in Spain (n = 93). Baseline sample. Study aim: evaluate a mobile health intervention for improving cognitive and social skills to improve access and use of health services in migrants.	Delivery: mobile phone-based. Type: education. Material: health education promoting phone health, awareness, education and navigation of Andalusian sociomedical system. Int. aim: to promote access and facilitate navigation of the sociomedical system and promote/maintain wellness.	HLS-EU-Q16; HLS-APP-Q14; S-S practical HL tests.	S-S satisfaction, usability, functionality and applicability for mobile device app survey.	Direct: FCC HL; unknown[c]. Proxy: app intervention evaluation.
(Grebner, 2014)	Sample: adults ≥ 18 years of age from central Illinois (n = 86) at baseline. Study aim: determine whether participant-	Delivery: in-person. Type: education. Material: tailored to learning styles. Material based on patient radiologic	S-TOFHLA.	VARK questionnaire.	Direct: FHL. Proxy: VARK learning.

	matched learning styles improve HL education.	exam and Medicaid information scenario. Int. aim: determine whether information displayed with participant-matched learning styles improved HL.			
(Ishikawa et al., 2018)	Sample: Japanese adult community members (baseline n = 67). Study aim: evaluate a HL community programme.	Delivery: in-person. Type: education. Material: Japan healthcare system/healthcare issues, active patient role development, communication and patient collaboration. Int. aim: improve knowledge of healthcare policy, systems and issues in Japan, patient roles/relationships with healthcare providers and interpersonal skills.	CCHLS.	Abbreviated five-item measure of patient trust in the medical profession; open question with thematic analysis.	Direct: Comm and Crit HL. Proxy: trust in the medical profession; programme learning.
(Khaleghi et al., 2019)	Sample: second year students aged 18-25 from Islamic Azad University, Shahr Rey Branch, Iran; (baseline n = 120).	Delivery: in-person/social media. Type: education. Material: physical and psychological health education via buzz groups,	TOFHLA.	SF-12.	Direct: FHL. Proxy: health-related quality of life.

	Study aim: evaluate HL-based training via social networking to improve health quality of life.	networking and brainstorming. Int. aim: address physical and psychological health education needs.			
(Liu et al., 2018)	Sample: Chinese nursing home residents ≥ 60 years (baseline n = 263). Study aim: explore the efficacy of teach-back for improving nursing home resident HL.	Delivery: in-person. Type: education. Material: teach-back following "66 Indicators for Chinese Citizens' HL" brochure. Int. aim: improve older adult HL.	2008 Chinese citizens HL questionnaire.	Teach-back assessment index interviews (int. only).	Direct: other HL. Proxy: intervention material knowledge.
(McCaffery et al., 2019)	Sample: basic education students from New South Wales (≥ 16 years of age), graded as level two learners via the Australian Core Skills Framework (baseline n = 308; int. = 167, ctrl. = 141). Study aim: evaluate HL adult education int. for low literacy and numeracy adults.	Delivery: in-person (TAFE colleges). Type: education. Material: health promotion, wellbeing and shared decision-making themes. Used real-world scenarios with reading, writing, speaking, listening and numeracy in the health context. Int. aim: improve adult HL.	Interpreting thermometer, food, and medicine label tasks; five dimension HLQ.	Health confidence S-S scale; PAM; S-S student satisfaction scale; 12-item curriculum measure; self-report diet and physical activity measure.	Direct: FHL; Comm and Crit HL. Proxy: confidence in health skills; patient activation; student intervention satisfaction; health knowledge; health behaviours.
(Panahi, Ramezankhani, Tavousi & Niknami, 2018)	Sample: second/third year undergraduate students in Shahid Beheshti University of	Delivery: instant messaging (Telegram). Type: education.	HELIA/HL inventory for adults.	Study-specific 46-item questionnaire; 8-item smoking knowledge and	Direct: FCC HL. Proxy: susceptibility, severity, barriers, benefits, self-efficacy,

	Medical Sciences dormitories (baseline n = 130). Study aim: develop an extended health belief model with HL elements to assess whether a smoking prevention int. is effective.	Material: HL and Health Belief Model-based education; covered perceived benefits, barriers, harms, self-efficacy, perceived susceptibility, severity and benefits of physical activity for smoking. Int. aim: impact smoking prevention behaviours.		associated adverse events questionnaire.	cues to action and smoking preventive behaviours; smoking knowledge/adverse effects.
(Simonds et al., 2019)	Sample: American fourth-grade children from an elementary school near the Crow reservation (baseline n = 44 across two or more int. programme components; 9-13 years old). Study aim: feasibility evaluation of environmental HL int. for children.	Delivery: in-person (elementary school and surrounding areas of the Crow reservation). Type: behavioural and education. Material: water-related environmental knowledge. Int. aim: enhance environmental functional, interactive and critical HL in children.	Functional literacy survey: water-related basic knowledge; interactive literacy – sharing with family: newsletter activities; functional, interactive and critical literacy: behaviour and attitude survey.	Qualitative interviews.	Direct: FHL; Comm HL; FCC HL. Proxy: intervention experience.
(Soto Mas, Cordova et al., 2015)	Sample: Hispanic/Latino adults ≥ 18 years of age who	Delivery: in-person; elementary school (n = 19), large chain	TOFHLA.	None.	Direct: FHL. Proxy: N/A.

	were able to read/write in Spanish. America (Baseline n = 49). Study aim: explore feasibility of different community settings for improving adult HL via an English language programme.	hotel (n = 16) or community church (n = 14). Type: education. Material: HL and ESL education curriculum at sample sites. Dialogue, role-play and interactive skill-development activities; encouraged to engage in healthy extracurricular activities. Int. aim: improve English language proficiency and HL in Spanish-speaking Hispanic adults.			
(Soto Mas, Jacobson & Olivárez, 2017)	Sample: US-Mexico border college students enrolled in High School Equivalency/Migrant Access Programme, able to read and write in Spanish and ≥ 21 years of age (baseline n = 156). Study aim: explore whether basic adult instruction improves	Delivery: in-person (local community college). Type: education. Material: connected life science content with health and disease; discussed disease-specific/general health information.	TOFHLA.	None.	Direct: FHL. Proxy: N/A.

	HL in Spanish-speaking immigrants.	Int. aim: improve HL in Spanish-speaking immigrants.			
(Soto Mas, Ji et al., 2015)	Sample: adults ≥ 21 years from the local community (Texas area) with no intervention experience, low-to-intermediate English proficiency, able to read/write/speak basic English and read/write Spanish (baseline n = 181). Study aim: test feasibility of ESL instruction for improving HL in Spanish-speaking adults.	Delivery: in-person (community colleges) Type: education. Material: HL/ESL education curriculum. Health behaviour theory, HL research and practice, sociocultural literacy and communication theories. Guided by 'Health for Heart' programme. Int. aim: familiarise low-to-moderate English proficiency Spanish-speaking adults with literacy demands in health settings.	TOFHLA.	None.	Direct: FHL. Proxy: N/A.
(Soto Mas, Schmitt, Jacobson & Myers, 2018)	Sample: American Spanish-speaking Hispanic adults ≥ 21 years, able to read/write in Spanish, no prior relevant intervention experience, and had low-to-intermediate	Delivery: in-person. Type: education. Material: HL and ESL education curriculum. Focused on personal skills, health-related vocabulary and how	TOFHLA.	Spanish cardiovascular health questionnaire; CELSA.	Direct: FHL. Proxy: cardiovascular health behaviours; English proficiency.

	English proficiency (baseline n = 181). Study aim: explore HL curriculum on cardiovascular health behaviours in Spanish-speaking adults.	lifestyle can impact chronic disease. Int. aim: improve English proficiency and develop HL and cardiovascular disease preventive knowledge/skills.			
(Stassen et al., 2020)	Sample: students aged 18-25 with project agreements between a German university and vocational schools (Baseline n = 495). Study aim: understand whether web-based int. in schools improves structural HL model competencies.	Delivery: online and/or in-person (vocational schools). Type: education. Material: general health information, clarifying misinformation, nutrition, check-ups, quizzes, quick recipes and motivation topics, focusing on everyday vocational student working life. School health day for in-person segment. Int. aim: strengthen competencies regarding a healthy lifestyle.	Lenartz's German HL questionnaire.	None.	Direct: other HL. Proxy: N/A.
(Tsai, Lee, & Yu, 2018)	Sample: Southeast Asian women who immigrated to Taiwan due to marriage to a	Delivery: in-person. Type: education. Material: PBL HL education, with structured problem	Non-specific communicative and critical HL questionnaire.	Non-specific health empowerment questionnaire; 10-item five-point scale navigation self-efficacy	Direct: Comm and Crit HL. Proxy: health empowerment;

	Taiwanese man (baseline n = 223). Study aim: describe and evaluate a PBL HL int. for Southeast Asian immigrant women.	group learning facilitated by faculty tutor/coach (experienced PBL health educator) with a co-coach (medical translation immigrant women). Int. aim: promote competencies regarding access, comprehension and use of health information, empowerment, and use of health services.		scale; non-specific healthcare utilisation questionnaire.	navigation efficacy; healthcare utilisation.
(Zhuang et al., 2016)	Sample: community residents in Shenzhen, China ≥ 18 years of age, and lived in Shenzhen for a minimum of six months (baseline n = 6,413). Study aim: explore SMS health education for improving HL.	Delivery: in-person/instant messaging-based. Type: education. Material: conventional health education via bulletin boards, posters and lectures. Int. aim: improve adult HL.	Rapid assessment of HL questionnaire.	None.	Direct: other HL. Proxy: N/A.

Note. The contents of this table is based on a publication which was made available online during the third year of this PhD (Sawyers et al., 2022). Under the sub-heading *Delivery*, within the wider *Intervention* column, we reported the location of the intervention being conducted where possible. We reported this information when available to provide further context, with the inconsistent presentation being due to studies failing to report study location information. The sample values were also reported as baseline values under the *Sample* sub-heading of the wider *Sample and Sample Size* column (and inferred when not directly reported in the studies), as more studies reported baseline values than during/post-intervention sample values, and as such baseline values were reported to ensure consistency within the table presentation. The presentation order for direct and proxy outcomes reflects the order in which direct and proxy instruments are presented.

Abbreviations: ASQ-3, Ages and Stages Questionnaire; ASQ:SE, Ages and Stages Questionnaire: Social-Emotional; CCHLS, Communicative and Critical HL Scale; CELSA, Combined English Language Skills Assessment; Comm HL, Communicative Health Literacy; Crit HL, Critical Health Literacy; Ctrl., Control; ESL, English as a Second Language; FCC, Functional, Communicative and Critical; FHL, Functional Health Literacy; GAD-7, Generalised Anxiety Disorder Questionnaire; HELIA, Health Literacy for Iranian Adults; HL, Health Literacy; HLQ, Health Literacy Questionnaire; HLSAC, Health Literacy for School-Aged Children; HLS-APP-Q14, Health Literacy App Questionnaire; HLSBS-II, HLS-EU-Q16, European HL Short Scale; Healthy Lifestyle Behaviour Scale-II; HPLP-II, Health-Promoting Lifestyle Profile-II; Int., Intervention; N/A, Not Applicable; NVS, Newest Vital Sign; PACT, Parents and Communities Together; PAM, Patient Activation Measure; PBL, Problem-Based Learning; PHQ-9, Patient Health Questionnaire; PHS, Perception of Health Scale; SF-12, Short Form-12 Questionnaire of Life Quality; SMS, Short Message Service; SS, Study-Specific; S-TOFHLA, Short-form Test of Functional Health Literacy in Adults; TOFHLA, Test of Functional Health Literacy in Adults; TPB, Theory of Planned Behaviour; VARK, Visual, Aural, Read/write and Kinesthetic.

[a] Austvoll-Dahlgren et al (2012) originally listed the PAM as a measure of civic and science literacy, however we categorised instruments based on their intended use, which led to the categorisation of the PAM as a proxy measure of patient activation rather than of science and civic literacy identified in the original article.

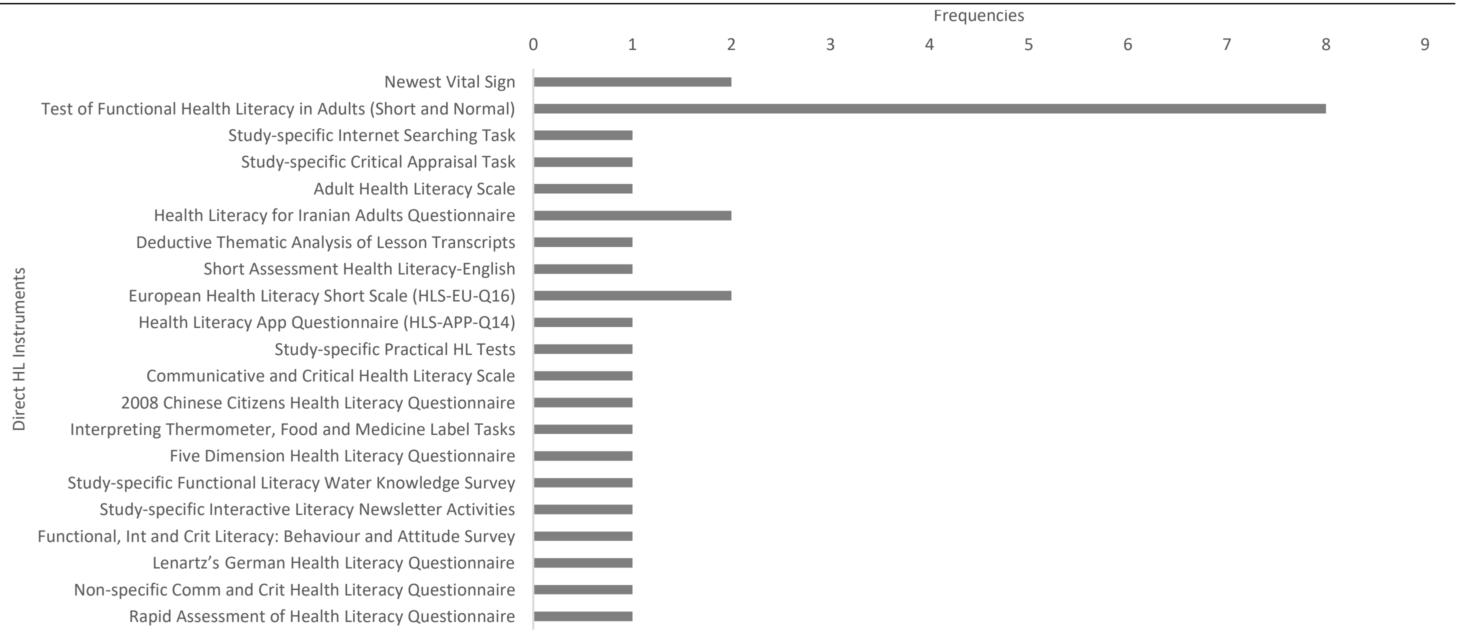
[b] The Adult Health Literacy Scale was described in minimal detail, and the original instrument development paper was used to support the categorisation of the measure as a direct or proxy measurement. However, the original paper was non-English, and subsequently uninterpretable (Sezer & Kadioglu, 2014). The instrument was therefore identified as an unknown direct health literacy measurement.

[c] We were unable to gain access to the Fernández-Gutiérrez et al. (2019) full-text paper, and were unable to categorise the outcomes assessed for the HLS-APP-Q14, which appears to be a study-specific intervention knowledge measurement. Given our lack of confidence in the categorisation, we categorised the HLS-APP-Q14 as an unknown direct HL measurement.

Direct Health Literacy Outcome and Instrument Frequencies

A total of 21 unique direct HL measures were extracted, including measures which assessed outcomes pertaining to Nutbeam's (2000) model of HL and measures which utilised different HL models (see Figure 7).

Figure 7. Frequencies for Direct Health Literacy Instruments Reported.



Abbreviations: Comm, Communicative; Int, Interactive; Crit, Critical; HL, Health Literacy; HLS-EU-Q16, European Health Literacy Short Scale.

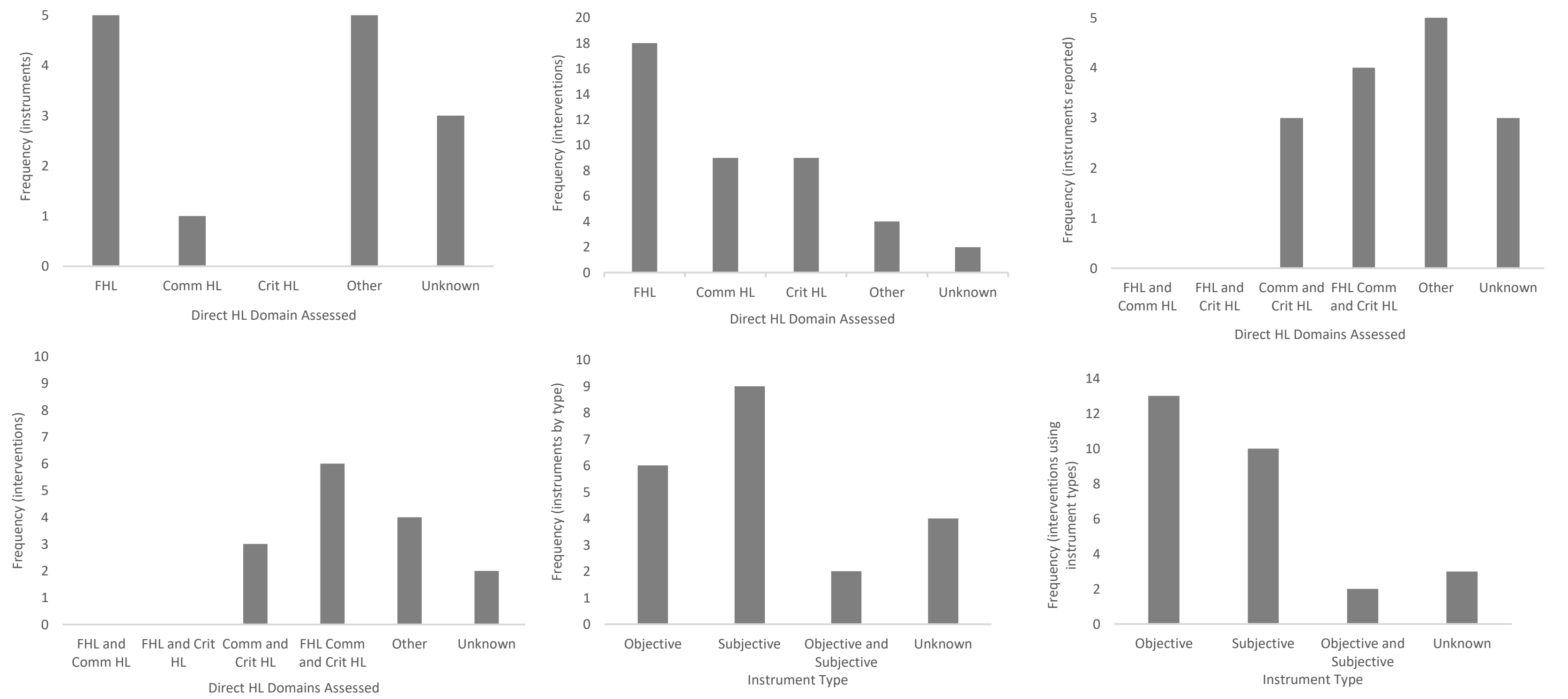
The Test of Functional HL in Adults (TOFHLA) was the most frequently extracted direct HL instrument, with short-form (n = 3 (Ayaz-Alkaya et al., 2020; Chervin et al., 2012; Grebner, 2014)) and normal variants (n = 5 (Khaleghi et al., 2019; Soto Mas, Cordova et al., 2015; Soto Mas et al., 2017; Soto Mas, Ji et al., 2015; Soto Mas et al., 2018)) identified. Four direct HL instruments were used multiple times, with the Newest

Vital Sign NVS; (n = 2 (Bolton et al., 2020; Carolyn et al., 2019)), HL for Iranian Adults Questionnaire HELIA; (n = 2 (Bayati et al., 2018; Panahi et al., 2018)) and European HL Short Scale HLS-EU-Q16; (n = 2 (Buhr et al., 2020; Fernández-Gutiérrez et al., 2019)) identified.

Categorised Direct Health Literacy Outcome and Instrument Frequencies.

Frequencies were charted across 6 formats (see Figure 8).

Figure 8. Frequencies of Interventions and Instruments by Direct Health Literacy Domains Assessed and Instrument Type.



Note. From left to right. Top row: Bar chart frequencies showing: Individual direct health literacy domain outcomes for instruments; individual direct health literacy domain outcomes for interventions; and combined direct health literacy outcomes for instruments. Bottom row: Bar chart frequencies showing: combined direct health literacy outcomes for interventions; instrument types identified from instruments extracted; and instrument types reported across interventions.

Individual Domains Extracted

The majority of individual domain direct HL outcome instruments assessed functional HL (n = 5: NVS; TOFHLA; Short Assessment HL-English; Interpreting Thermometer, Food and Medicine Label Tasks; Study-specific Functional Literacy Survey: Water-related Basic Knowledge). One instrument assessed communicative HL alone (n = 1; Study-specific Interactive Literacy – Sharing with Family: Newsletter Activities), and no instruments assessed critical HL in isolation.

At the individual level, functional HL was assessed substantially more (n = 18 (Ayaz-Alkaya et al., 2020; Bayati et al., 2018; Bolton et al., 2020; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Carolyn et al., 2019; Chervin et al., 2012; Cook, 2021; Fernández-Gutiérrez et al., 2019; Grebner, 2014; Khaleghi et al., 2019; McCaffery et al., 2019; Panahi et al., 2018; Simonds et al., 2019; Soto Mas, Cordova et al., 2015; Soto Mas et al., 2017; Soto Mas, Ji et al., 2015; Soto Mas et al., 2018)) than communicative (n = 9 (Bayati et al., 2018; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Fernández-Gutiérrez et al., 2019; Ishikawa et al., 2018; McCaffery et al., 2019; Panahi et al., 2018; Simonds et al., 2019; Tsai et al., 2018)) or critical HL (n = 9 (Bayati et al., 2018; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Fernández-Gutiérrez et al., 2019; Ishikawa et al., 2018; McCaffery et al., 2019; Panahi et al., 2018; Simonds et al., 2019; Tsai et al., 2018)) across the studies sampled.

Combined Domains Extracted

For combined direct HL domains, communicative and critical HL (n = 3: Communicative and Critical HL Scale; Five Dimension HLQ; Non-specific Communicative and Critical HL Questionnaire), were the most prevalent direct HL instruments from Nutbeam's (2000) model domains.

No instruments assessed functional and communicative HL or functional and critical HL in combination.

The most frequent combined domain measures across the studies were functional, communicative and critical HL evaluations (n = 6 (Bayati et al., 2018; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Fernández-Gutiérrez et al., 2019; Panahi et al., 2018; Simonds et al., 2019)). Alternative combined Nutbeam (2000) domain measures in the studies were communicative and critical HL measures (n = 3 (Ishikawa et al., 2018; McCaffery et al., 2019; Tsai et al., 2018)). No investigations implemented measures assessing functional and communicative HL or functional and critical HL.

Direct Assessment Instrument Type Frequencies

The majority of direct HL instruments were subjective (n = 9: HELIA; Deductive Thematic Analysis of Lesson Transcripts; HLS-EU-Q16; Communicative and Critical HL Scale; Five Dimension HLQ; Study-specific Functional Literacy Survey: Water-Related Basic Knowledge; Functional, Interactive and Critical Literacy: Behaviour and Attitude Survey; Lenartz's German HL Questionnaire [LGHLQ]; Rapid Assessment of HL Questionnaire [RAHL]), with objective instruments second in frequency (n = 6: NVS; TOFHLA, , Study-specific Internet Searching Task; Study-specific Critical Appraisal Task; Short Assessment HL-English; and Interpreting Thermometer, Food and Medicine Label Tasks). A subset of instruments were objective and subjective (n = 2: 2008 CCHLQ; Study-specific Interactive Literacy – Sharing with Family: Newsletter Activities).

Objective instruments were the most commonly used in the studies (n = 13 (Austvoll-Dahlgren et al., 2012; Ayaz-Alkaya et al., 2020; Bolton et al., 2020; Carolyn et al., 2019; Chervin et al., 2012; Cook, 2021; Grebner, 2014; Khaleghi et al., 2019; McCaffery et al., 2019; Soto Mas, Cordova et al., 2015; Soto Mas et al., 2017; Soto Mas, Ji et al., 2015; Soto Mas et al., 2018)), with subjective instruments less frequently used across the studies retrieved (n = 10 (Bayati et al., 2018; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Fernández-Gutiérrez et al., 2019; Ishikawa et al., 2018; McCaffery et al., 2019; Panahi et al., 2018; Simonds et al., 2019; Stassen et al., 2020; Zhuang et al., 2016)). Few objective and subjective instruments were used (n = 2 (Liu et al., 2018; Simonds et al., 2019)).

Other and Unidentified Frequencies

In total, 5 direct instruments were categorised as 'other' due to the measures being based on models not utilising Nutbeam's (2000) three-domain model of HL (Study-specific Internet Searching Task; Study-specific Critical Appraisal Task; 2008 CCHLQ; LGHLQ; RAHL). In total, 4 studies used 'other' direct instruments as HL outcome measures (Austvoll-Dahlgren, Bjørndal, Odgaard-Jensen, & Helseth, 2012; Liu et al., 2018; Stassen et al., 2020; Zhuang et al., 2016). Alternative models were: the Zarcadoolas et al model (Zarcadoolas et al., 2005), utilised once (Austvoll-Dahlgren et al., 2012); the knowledge-attitude-practice model, used once (Liu et al., 2018); the structural model of HL (Soellner et al., 2017), implemented once (Stassen et al., 2020); and systems theory, used once (Zhuang et al., 2016). For the 'other' direct HL measures, 11 specific domains comprised the factors assessed: Science literacy; knowledge; beliefs; behaviours; skills; self-perception; proactive approach to health; dealing with health information; self-control; self-regulation; and communication and cooperation.

For instruments assessing direct HL with individual or combined outcomes (i.e. functional HL alone or functional, communicative and critical HL in conjunction), a small proportion of instruments assessed unidentifiable outcomes (n = 3: AHLS; Health Literacy App Questionnaire [HLS-APP-Q14]; Study-specific Practical HL Tests), and a subset of studies used these unidentifiable outcome measures (n = 2 (Ayaz-Alkaya et al., 2020; Fernández-Gutiérrez et al., 2019)). Four instruments were categorised as unknown instrument types (n = 4: AHLS; HLS-APP-Q14; Study-specific Practical HL Tests; Non-specific Communicative and Critical HL Questionnaire) compared to those categorised as subjective, objective or objective and subjective instrument types, and three studies used instruments with unidentifiable types (n = 3 (Ayaz-Alkaya et al., 2020; Fernández-Gutiérrez et al., 2019; Tsai et al., 2018)).

Proxy Health Literacy Outcomes

Proxy Instrument Frequency Analysis

In summary, 38 unique proxy HL instruments were extracted, with thematic analysis retrieving the following measurement themes: anthropometric, developmental and physiological characteristics; perceived health, knowledge, behaviours and health intentions; perceptions of healthcare, usage and patient experiences; intervention experience-based evaluations; psychosocial, general and non-health factors; and miscellaneous.

One proxy HL outcome tested the capacity to teach HL for education centre directors, but this was not tested in the primary sample within which HL improvement was sought (Chervin et al., 2012). The measure was not an assessment of active participants in the intervention, and was listed separately – forming the miscellaneous group – and did not feature in further data representations.

Figure 9. Bar Chart of Frequencies for Proxy HL Outcome Instruments Extracted.

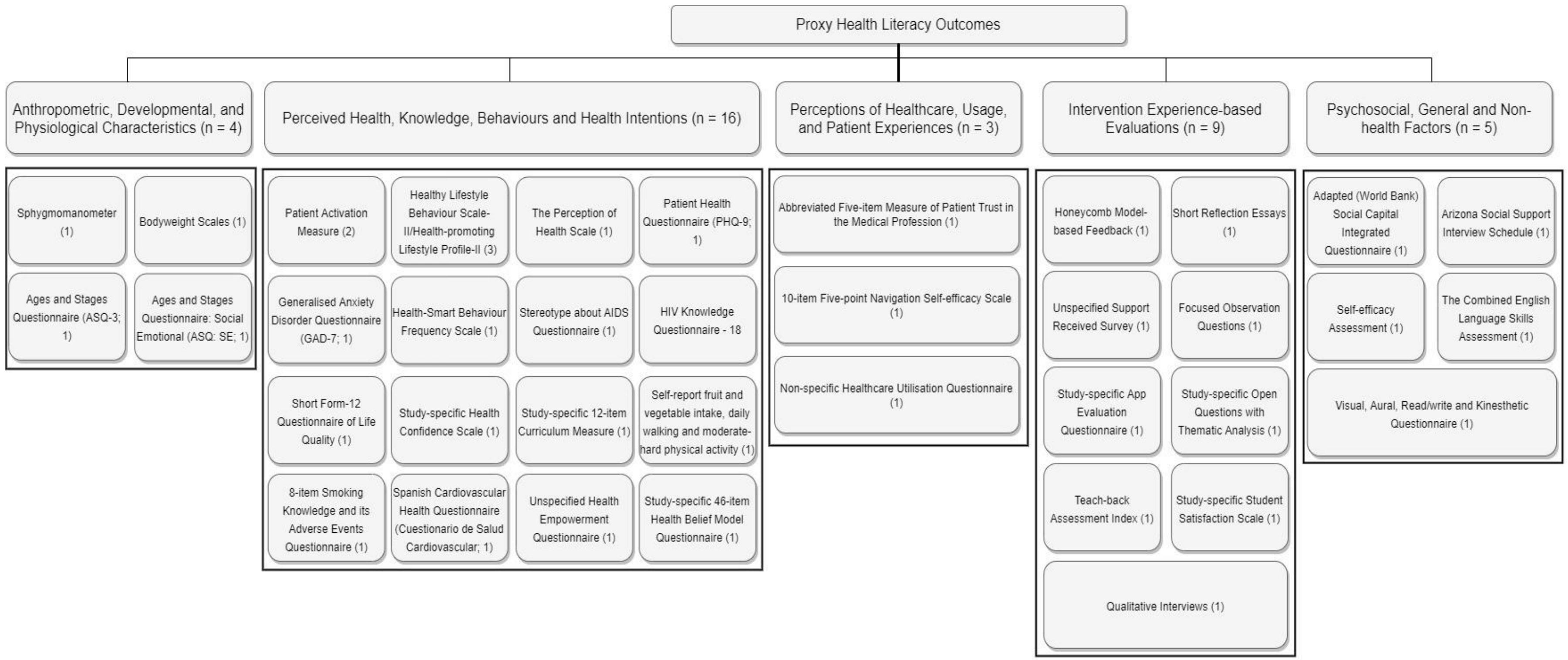
Abbreviations: HPLP-II, Health-Promoting Lifestyle Profile-II; AIDS, Acquired Immune Deficiency Syndrome; HIV, Human Immunodeficiency Virus; PA, Physical Activity; VARK, Visual, Aural, Read/write and Kinesthetic.

The Healthy Lifestyle Behaviour Scale-II (HLSBS-II)/Health-Promoting Lifestyle Profile-II (HPLP-II) was the most common proxy HL instrument utilised across community HL interventions (n = 3 (Ayaz-Alkaya et al., 2020; Bayati et al., 2018; Carolyn et al., 2019)). The second most frequently implemented instrument was the PAM (n = 2 (Austvoll-Dahlgren et al., 2012; McCaffery et al., 2019)), and the remaining 36 instruments were utilised once.

Proxy Outcome Categorisation

Proxy measures were categorised into one of five measurement categories (see Figure 10).

Figure 10. Proxy Health Literacy Outcome Categories.



Note. From top to bottom: the figure topic, proxy measurement categories and instruments. The miscellaneous domain (n = 1) was excluded from the figure due to the instrument not assessing the primary intervention sample of interest. Bracketed numbers represent the frequency each instrument was extracted. Abbreviations: AIDS, Acquired Immune Deficiency Syndrome; HIV, Human Immunodeficiency Virus; n, Sample Size.

Combined Direct and Proxy Measures

Two instruments measured direct and proxy HL simultaneously. The study-specific theory of planned behaviour questionnaire (n = 1 (Austvoll-Dahlgren et al., 2012)) considered ‘other’ HL components like civic and science literacy at the direct level, and beliefs about behavioural intentions at the proxy level. The HL for school-aged children questionnaire (n = 1 (Buhr et al., 2020)), which assessed ‘other’ HL components (theoretical knowledge, practical knowledge, critical thinking, self-awareness and citizenship), measured health behaviours at the proxy level. Both measures were subjective instrument types.

Discussion

Key Findings

Our study (Sawyers et al., 2022) identified a myriad of direct and proxy HL outcome instruments, with 21 unique direct and 38 unique proxy measures identified from the community interventions sampled. The sampled research studies frequently incorporated functional measures (18/25) rather than communicative (9/25) and critical (9/25) measures. Not all studies incorporated measures which evaluated Nutbeam’s (2000) model domains (4/25), with conceptual variance in the measurement of HL observed. The instruments retrieved followed a similar trend, with functional HL instruments more prevalent (5/21) than communicative (1/21) and critical (0/21) instruments when considered as individual direct HL domains. For combined direct HL instruments, although no functional and communicative (0/21) or functional and critical (0/21) instruments were extracted, several communicative and critical (3/21) and functional, communicative and critical (4/21) instruments were present. Similar to the intervention frequencies, a range of instruments measured domains not included in Nutbeam's (2000) HL model (5/21), but a unidimensional trend towards functional measurement was nevertheless apparent, with the TOFHLA, a prevalent instrument measuring functional HL, being the most frequently extracted direct HL instrument (8/21) overall (Sawyers et al., 2022).

A notable gap in frequency was observed between the TOFHLA and the next most prevalent direct instrument, with the HELIA and HLS-EU-Q16 used 2 times, respectively. The frequency gap indicated no such convergence towards holistic HL measurement at the direct level – that is, measurement practice appears to be more unidimensional as opposed to being holistic, which is the opposite of prior discourse (Altin et al., 2014). This is evidenced from observational findings from this review, which indicate that, from the 18 studies assessing functional HL, only 6 measured communicative and critical HL simultaneously or sequentially, with 3 assessing communicative and critical HL alone. The direct HL outcome practices of current community HL interventions appear to indicate that, while a degree of holistic instruments are available and are actively being used, the preference for measurement across present-day community interventions remains one-dimensional. A contrast in the perceived expectation of HL measurement previously (Altin et al., 2014) versus the ongoing reality of practices is present, and identifying inconsistent treatments of HL as a variable subsequently yields preliminary evidence for the need to clarify HL measurement in community populations.

At the proxy level, 38 unique instruments were extracted, which were categorised into the following measurement categories: anthropometric, developmental and physiological characteristics (n = 4); perceived health, knowledge, behaviours and health intentions (n = 16); perceptions of healthcare, usage and patient experiences (n = 3); intervention experience-based evaluations (n = 9); and psychosocial, general and non-health factors (n = 5). The majority of proxy instruments were utilised individually across the studies, with the exception of the PAM and the HLSBS-II/HPLP-II, which were utilised 3 and 2 times, respectively.

Across both direct and proxy HL measures, a significant degree of variation in measurement trends were observed, demonstrating disparities and potential disagreement towards outcome measurement at the domain, instrument, direct and proxy level of present-day community HL intervention research.

Functional Domain Frequency

The prioritisation of functional HL over communicative and critical HL is expected, and reflects existing evidence across the field. Around one in every three HL instruments were previously suggested to be based on prevalent functional measures (Altin et al., 2014), with a functional preference noted across adult (Guzys, Kenny, Dickson-Swift, & Threlkeld, 2015) and child (Guo et al., 2018) populations. The preference for functional measurement in community HL interventions appears to form standard practice, despite previous indications of a convergence towards all-encompassing HL measurement[5]. While this practice is not problematic if interventions intend to focus exclusively on FHL, evidence from this review indicates that, while a large portion of studies incorporate FHL-specific outcomes reflecting the proposed intervention aims (Grebner, 2014; McCaffery et al., 2019; Simonds et al., 2019; Soto Mas, Cordova et al., 2015; Soto Mas et al., 2017; Soto Mas, Ji et al., 2015; Soto Mas et al., 2018), others utilised interventions with aims relating to the improvement of 'HL' in general – implying an intended improvement across multiple HL levels – but only incorporated direct outcomes targeting FHL (Carolyn et al., 2019; Chervin et al., 2012; Cook, 2021). These practices indicate that, while a good proportion of community HL intervention studies are successfully applying FHL outcomes in reference to the developed intervention aims, research may struggle to identify appropriate direct HL evaluations beyond the functional level, potentially ignoring the assessment of further skills potentially relevant to interventions within the construct. Enabling a conceptually consistent, but multidimensional, series of HL measurement practices is essential for understanding HL problems facing community populations (Batterham, Hawkins, Collins, Buchbinder, & Osborne, 2016), which in-turn can influence the development of HL-promoting strategies to be tested across intervention designs. The preference for FHL assessment may therefore hamper the development of multidimensional HL strategies, and limit subsequent health promotion advancements in the field.

Given the frequent use of the HL term in titles and key word sections of many intervention publications, these unidimensional HL practices infer that HL may be seen as a label for established interventions and outcomes (Nutbeam et al., 2018) rather than as the multidimensional, skills-based construct that it is (Hibbard, 2017), as communicative and critical components are frequently overlooked. When the studies from the current review are considered with respect to the label argument, this may explain why the investigations referring to HL as a general concept only assessed FHL, as they indirectly attributed HL as more of a description for the intervention rather than as a construct guiding the intervention. An individual's skill in one HL domain does not represent their overall HL, yet this approach infers that the opposite is true, which may potentially lead to an inaccurate representation of public HL.

While the treatment of HL as a fashionable label for community HL interventions is one potential explanation for the conceptually limiting outcomes applied, this does not explain the preference for functional HL outcomes observed as only a subset of studies did not successfully match FHL outcomes with their intervention goals. The preference for functional HL outcomes at the direct level may be a consequence of the hierarchical nature of Nutbeam's (2000) model. In order to build upon an individual's communicative or critical HL, they must first possess adequate FHL, and because of this interventions may attempt to focus exclusively on functional HL to understand, identify and improve a person's foundational HL skills before they can target higher levels of the construct. In this regard, functional HL acts as an important catalyst to enable access to higher order HL skills in the public, and is a fundamental level required for people to self-manage their health. Given the hierarchical location of FHL within Nutbeam's (2000) model of HL, the scope for public HL change may be most opportune at the functional level, and may contribute to the long-standing FHL prioritisation at both the domain and instrument level. To bolster the prevalence of health interventions, researchers may label an intervention with a HL focus, but the prioritisation of unidimensional, functional HL measurement may also be a consequence of the hierarchical nature of the most prevalent conceptualisation of HL, despite frequent calls to operationalise HL in a multidimensional manner (Pleasant et al., 2016).

Although a functional prioritisation for direct HL outcomes within community HL interventions is appropriate when the intervention aims are concerned with FHL, this current review demonstrates that there is a problem with HL measurement practices when considered with respect to the intervention intent. More specifically, some studies incorporated HL measurements which did not evaluate the proposed HL goals of the intervention (Carolyn et al., 2019; Chervin et al., 2012; Cook, 2021), which is indicative of a misrepresentation with the construct rather than a preference for targeting and evaluating HL at the fundamental level. Although the majority of studies considered in this review were able to appropriately consider direct HL outcome measurement in reference to their intervention aims, not all were able to, and as a consequence there may be scope for an expert-led framework to clarify HL measurement at the direct level to simplify the process and provide both added rigour and comparability for the findings.

Such a framework may consider the direct HL outcomes most important for community HL assessment, and could potentially benefit not only the outcomes applied to community HL interventions but the instruments used to conduct the evaluations. Currently, the functionally-focused TOFHLA was identified as the most frequently implemented direct HL instrument, with more holistic direct HL assessments like the HELIA and HLS-EU-Q16 being incorporated substantially less. Given that prevalent functional instruments like the TOFHLA and NVS are relatively simple to administer, have multiple methods of administration (Russell et al., 2019) or have short-form variants available (Baker et al., 1999), functional measures may be more appealing to implement for already complex interventional research. Alternatively, this may be because the TOFHLA/NVS and associated variants most appropriately assess the intervention goals at the direct level of HL measurement. While this was the case for the majority of investigations sampled (Grebner, 2014; Soto Mas, Cordova et al., 2015; Soto Mas et al., 2017; Soto Mas, Ji et al., 2015; Soto Mas et al., 2018), one study utilised the NVS which did not evaluate the intervention aims as effectively as other all-encompassing, psychometrically validated measures available (Carolyn et al., 2019). In this instance, the All Aspects of Health Literacy Scale (AAHLS (Chinn & McCarthy, 2013)) may have been more appropriate due to the wider scope for HL assessment – measuring FHL, communicative HL and critical HL – compared to the unidimensional NVS and the similar length of administration able to be achieved across both instruments. The AAHLS has been available for several years and indicates that, while FHL is an important domain to consider, there may be instances where all-encompassing instruments like the AAHLS are more appropriate for the assessment of general HL-focused interventions.

The development of a measurement framework considering direct HL measurement, while predominantly indicating the most appropriate domains to consider for community HL assessment, would potentially reduce confusion surrounding direct HL assessment for general population HL research, and may subsequently enable more informed FHL measurement decisions to be made in future community HL interventions. Such a development may lead to reductions in any unnecessary unidimensional functional prioritisation in the measurement phase of community HL interventions, allowing for further insight into public HL when study designs warrant more all-encompassing data generation. The FHL review findings subsequently demonstrate a need in additional guidance for community population HL measurement to ensure future HL assessments provide valid functional evaluations moving forward.

Communicative and Critical Health Literacy Omission

While communicative and critical HL were measured more consistently than previous evidence suggests (Nutbeam et al., 2018), they were assessed less than the functional domain. Prior suggestions for the disparity point towards the lack of comprehensive HL instruments available, with the AAHLS, the HLQ (Osborne et al., 2013), the Functional, Communicative and Critical Health Literacy Scale (FCCHLS (Finbråten et al., 2018)) and the European Health Literacy Scale (EU-HLS) being unavailable to investigations identified at the time of previous work (Nutbeam et al., 2018). While this may have been the case in the past, the majority of sampled interventions in the current study were able to access these measures, yet only 3 incorporated the HLQ (McCaffery et al., 2019) and EU-HLS (Buhr et al., 2020; Fernández-Gutiérrez et al., 2019). Given that only 3 studies utilised communicative and critical HL measures (Ishikawa et al., 2018; McCaffery et al., 2019; Tsai et al., 2018), and 6 studies assessed functional, communicative and critical domains (Bayati et al., 2018; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Fernández-Gutiérrez et al., 2019; Panahi et al., 2018; Simonds et al., 2019), the aforementioned instruments were likely seldom implemented in the sampled studies because the interventions intended to target functional HL more than communicative and/or critical HL. While there were studies which did not comprehensively investigate HL for interventions which may have benefitted from communicative and/or critical evaluations (Carolyn et al., 2019; Chervin et al., 2012; Cook, 2021), the majority of studies utilising interventions aiming to target communicative and/or critical HL domains successfully applied instruments evaluating these components. However, one study proposing an intervention to improve elements of functional, communicative and critical HL only included an assessment of communicative and critical HL, omitting functional HL (Tsai et al., 2018). When considering studies using interventions which aimed to target functional, communicative, and critical HL, while we observed a greater number of studies which failed to incorporate communicative and critical HL outcomes where general HL improvement was sought, studies did not exclusively omit the higher level these higher dimensions of HL, and demonstrated narrow conceptual measurement practices at the functional level as well. This was, however, less prevalent than the more common omission of hierarchically superior outcomes like communicative and critical HL.

Again, the preference for functional HL measures may stem from the ease of implementation, which prevalent functional instruments possess compared to their holistic counterparts. The TOFHLA, for instance, has a short-form variant readily available (Baker et al., 1999). However, the preference for functional-only measures cannot be explained in full by the ease of administration. The AAHLS, a recently recommended instrument for assessing all domains of Nutbeam's (2000) model (Nutbeam et al., 2018), takes approximately 7 minutes to administer (Chinn & McCarthy, 2013). The S-TOFHLA, however – being the most commonly implemented instrument in this review – can take around 12 minutes to administer, assessing functional HL alone (Baker et al., 1999). Given that 5 of the 8 studies which used the TOFHLA applied the original version, which can take approximately 22 minutes to administer (Parker et al., 1995), the prioritisation towards functional HL measures may not be a consequence of the ease of implementation which functional HL assessments are traditionally associated with. A lack of awareness regarding holistic instruments like the AAHLS may contribute to the regular emphasis placed on prevalent functional measures like the TOFHLA and NVS. However, while this suggestion is neither supported nor disputed by this review, unpacking the observable trends concerning instrument type may explain the functional preference for measurement frequently observed in the HL literature.

Instrument Type and Functional Trend

The focus towards applying common functional instruments like the TOFHLA may be a consequence of community HL intervention research prioritising the instrument type in addition to the domain assessed. While less unique objective instruments were identified (n = 6) compared to subjective instruments (n = 9), the frequency by which interventions used objective instruments was greater than that of subjective variants, with 13 interventions using direct HL instruments (Austvoll-Dahlgren et al., 2012; Ayaz-Alkaya et al., 2020; Bolton et al., 2020; Carolyn et al., 2019; Chervin et al., 2012; Cook, 2021; Grebner, 2014; Khaleghi et al., 2019; McCaffery et al., 2019; Soto Mas, Cordova et al., 2015; Soto Mas et al., 2017; Soto Mas, Ji et al., 2015; Soto Mas et al., 2018) versus the 10 interventions incorporating subjective instruments (Bayati et al., 2018; Bruselius-Jensen et al., 2017; Buhr et al., 2020; Fernández-Gutiérrez et al., 2019; Ishikawa et al., 2018; McCaffery et al., 2019; Panahi et al., 2018; Simonds et al., 2019; Stassen et al., 2020; Zhuang et al., 2016). Though the difference between these frequencies was minimal, a preference emerged for interventions using objective instruments.

Instrument type can have a strong impact on the information retrieved, and as such should be used in their appropriate context. Objective measures, for example, provide appropriate estimates for an individual's true HL skills, as their performance-based nature acts in a test-like manner, providing empirically grounded information. Contexts investigating how a person's true HL skill is associated with others factors frequently employs a narrowed, objective approach to measurement, with one such example exploring how a person's true HL impacts their use of, and trust in, health information (Chen et al., 2018). Subjective measures, on the other hand, can prove useful for determining population needs, including whether the current healthcare system is supporting the population appropriately, and are simpler to undertake for the participant due to their low cognitive demand (Nguyen et al., 2017). However, both objective and subjective HL measures come with inherent limitations, with objective instruments using a test-based, potentially stigma-inducing approach and subjective instruments being unable to accurately determine whether a person's response denotes their true HL skill (Nguyen et al., 2017).

While this review does not dispute that objective instruments, like the TOFHLA, may contribute to a true measurement of public HL, subjective instruments could act as more holistic evaluations of community HL interventions because of their wide-ranging profiles. This is particularly important to consider, as objective instruments tend to assess direct HL domains in a singular fashion, with none of the 6 objective instruments extracted investigating functional, communicative and critical HL. Prioritising functional HL may therefore unintentionally restrict the scope for measurement, given that functional HL is most frequently assessed with objective instrument types. While providing an objective reality for community HL intervention evaluations is important, future research should be cautious when implementing objective instruments in isolation due to their unidimensional focus, as HL remains a multidimensional construct, and should only be used in the intervention context when functional HL skills form part of the key evaluation criteria.

‘Other’ Direct Health Literacy Measures

Considerations to HL outcome measurement stemmed beyond the functional, communicative and critical levels of measurement in this review, with 5 instruments across 4 interventions assessing alternative model or theory-driven domains. Different approaches to direct HL measurement included: the Zarcadoolas et al model of HL (Austvoll-Dahlgren et al., 2012; Zarcadoolas et al., 2005); an applied variation of the Knowledge-Attitude-Practice model (Liu et al., 2018); the structural model of HL (Soellner et al., 2017; Stassen et al., 2020); and an interpretation of systems theory (Zhuang et al., 2016). Variation across the HL continuum regarding measurement is an expected consequence of the myriad interpretations of HL as a construct, with evidence suggesting up to 250 different definitions of HL having co-existed in recent times (Malloy-Weir et al., 2016).

While unique attributes like science literacy from the Zarcadoolas et al (2005) model and the clusters forming the structural model may contribute to a well-rounded understanding of HL, knowledge-based outcomes provide a limited interpretation of HL as a construct. Although they can be useful for determining the retention of intervention-specific information, knowledge is an ever-present requirement of the three direct domains of HL, thus using knowledge as a HL intervention outcome in isolation makes for a challenging interpretation of the domains in which HL change can occur. Using functional, communicative, critical, science literacy or other non-overlapping dimensions subsequently adds clarity to the intervention evaluation process when HL is concerned. HL interventions intend to improve HL by understanding mechanisms inducing HL skill changes, and knowledge instruments alone may not be suitable evaluations of this in isolation, and may instead be an important adjunct to complement intervention evaluations.

Proxy Measurement Inconsistency

At the proxy level, substantial variation at both the instrument and domain level were observed, with 38 unique proxy HL instruments extracted and five broad outcome measurement categories identified. Although perceived health, knowledge, behaviours and health intentions was the most frequently extracted proxy HL category (n = 16), a range of outcome measures were retrieved. While the fluctuation of proxy measurements were expected due to the wide conceptual scope for HL as a construct, the lack of consistency surrounding the frequency by which instruments were utilised for similar measurement domains suggests greater consensus may be achievable at the proxy level.

Only two proxy instruments were implemented across multiple interventions: the HLSBS-II/HPLP-II and the PAM, reported 3 (Ayaz-Alkaya et al., 2020; Bayati et al., 2018; Carolyn et al., 2019) and 2 times (Austvoll-Dahlgren et al., 2012; McCaffery et al., 2019) respectively. This suggests that, while various proxy measurements were retrieved, only a fraction of domains utilised the same instruments. Moreover, many factors have demonstrated a shared association with HL, including physical activity (Geboers, de Winter, Luten, Jansen, & Reijneveld, 2014), dietary quality (Chari et al., 2014), medical treatment adherence (Miller, 2016), medical service usage (Jessica et al., 2016) and cognitive functioning (Geboers et al., 2018), to name a few. However, although some of these variables were considered in a subset of interventions sampled (Ayaz-Alkaya et al., 2020; Bayati et al., 2018; Carolyn et al., 2019; McCaffery et al., 2019; Tsai et al., 2018), others were not, including adherence and cognitive functioning.

While we do not propose that all variables should utilise the same instruments, and that all interventions should use the same proxy domains, there may be scope for a framework to guide direct and proxy outcome measurement in the community HL intervention context. For example, one education intervention extracted assessed functional HL alone, but utilised an education intervention with 12 units of study – one being medication management – to improve HL in adult Spanish-speaking citizens. Although at the direct HL level the functional domain was considered, at the proxy level no further variables were assessed (Soto Mas, Cordova et al., 2015). Improvements to the proxy level of HL measurement in this instance could have been to incorporate an adherence measure to provide a proxy indication of the impact HL improvement at the functional level had on adherence, suggesting more comprehensive proxy HL measurement may be plausible. Alternatively, the implementation of an instrument to assess a person's self-efficacy towards medications in this instance – such as the Self-Efficacy for Appropriate Medication Use Scale (Cameron et al., 2010) – may also have improved the proxy HL evaluation process in this instance.

The low frequencies extracted from the 38 unique proxy instruments identified, with only 2 instruments implemented across multiple interventions, further supports the notion of an outcomes framework to foster greater depth of HL-related measurement for community interventions. While direct HL measures have model-based frameworks providing a rough overview of the relevant HL dimensions, proxy HL measures have no such guiding mechanism. This review subsequently highlights that current outcome practices for community HL interventions may benefit from a framework guiding community HL outcome measurement at the direct and proxy level.

Combined Direct and Proxy Measurement

Interestingly, two instruments were extracted which considered both direct and proxy measurement domains: the Study-specific Theory of Planned Behaviour Questionnaire (S-TPBQ), assessing civic and science literacy at the direct level (Austvoll-Dahlgren et al., 2012); and the Health Literacy for School-Aged Children (HLSAC) questionnaire, measuring theoretical knowledge, practical knowledge, critical thinking, self-awareness and citizenship (Buhr et al., 2020). At the proxy level, the S-TPBQ considered beliefs about behavioural intentions, while the HLSAC assessed health behaviours more generally. Both instruments were also subjective instrument types. When taken collectively, both instruments utilised ‘other’ direct HL domains, considered behaviour as their proxy foci, and were subjective instrument types. This trend is likely a consequence of the unidimensional nature of objective instruments, with a unidimensional preference observed in performance-based instruments like the TOFHLA and NVS. Subjective instruments appear to be more holistic, with 6 out of 9 direct subjective HL instruments assessing multiple HL dimensions. This may explain why the S-TPBQ and HLSAC had holistic measurement profiles, given their subjective profiles. The added confusion of accessible instruments which incorporate both direct and proxy HL elements further emphasises the need for a framework to guide community HL outcome measurement.

Future Research Recommendations and Research Limitations

This review identified a unidimensional focus towards HL outcome measurement, and outlines the importance of defining HL as a multifaceted construct, recommending unidimensional direct HL measurement only where a unidimensional component of HL is of interest, and not the construct as a whole. Determining the use of objective, subjective or objective and subjective instruments for HL measurement is another important consideration, and should be decided by reflection upon the intervention design and intent, with objective tools providing true, unidimensional evaluations and subjective instruments providing broader self-reports of direct HL. Secondly, while the proxy level of HL remains unclear, future research should consider adopting proxy measures via guidance from existing association-based HL research while awaiting the development of an expert-led conceptual outcomes framework.

Although this review provides a fruitful, informative overview of HL measurement practices for community HL interventions on a broad scale, some limitations emerged. Firstly, the findings do not evaluate the quality of HL interventions, primarily due to scoping reviews typically not including quality or appraisal elements (Grant & Booth, 2009). Ensuring that interventions are being evaluated appropriately is arguably a greater consideration in the short-term, and understanding existing community HL intervention outcome practices will foster an efficient and knowledgeable appraisal moving forward. Additionally, only English-text studies were included, leading to potentially relevant intervention omissions.

Study Conclusion

This scoping review provides important evidence regarding the trends in HL outcome measurement across current community HL interventions (Sawyers et al., 2022). While other HL reviews exist and provide important insight into HL measurement practices (Haun et al., 2014) and community HL (Nutbeam et al., 2018), they are either dated, have restrictive inclusion criteria, and/or do not capture instruments developed in the last decade. This review addresses these gaps in the field, providing a broad view of peer-reviewed and grey literature to identify community HL measurement practices. Despite previous suggestions of a potential convergence towards more holistic HL measurement practice (Altin et al., 2014), the functional prioritisation of direct HL outcomes remains prevalent. Recommendations to consider HL as more of a functional skill (Guzys et al., 2015; Hibbard, 2017) have subsequently done little to elicit meaningful change in outcome practices over the years. Although multidimensional direct HL instruments exist, such as the AAHLS (Chinn & McCarthy, 2013), which can be implemented faster than the most frequently extracted instrument from this review (TOFHLA/S-TOFHLA), interventions continue to implement unidimensional HL measures frequently. One explanation for the continued use of unidimensional functional HL measures may pertain to the preference for objectivity, with objective HL instruments more prevalent than their subjective counterparts. While this could explain the high TOFHLA/S-TOFHLA frequency, a combination of instrument types may yield more holistic direct HL measurement processes and more informed intervention evaluations, without the sacrifice in objectivity.

At the proxy level of HL measurement, a preference for self-reported health, health behaviours, health knowledge and intervention experience measurements emerged. The generation of 38 unique proxy HL instruments, of which only 2 were applied across multiple interventions, suggests that community HL interventions could benefit from in-depth literature consult to guide proxy level HL association measurement inclusions presently. However, the lack of homogeneity surrounding community HL intervention measurement at the direct and proxy level indicates potential for an expert-led outcomes framework to be developed. Such an advancement may help alleviate confusion regarding the most appropriate dimensions to consider when planning the measurement phase of community HL interventions. In providing a framework, a more consistent, all-encompassing, rigorous and reliable practice of outcome measurement may be in reach, promoting the standard for community HL intervention evaluations moving forward.

This review subsequently addresses the first key objective of my PhD: ***to synthesise and understand current HL measurement practices across community HL interventions.*** In synthesising current practices from grey and traditional literature, inconsistency in the measurement of public HL at the direct and proxy level is apparent. While direct measurement practices have improved in recent years, the incorporation of proxy HL measurement requires optimisation, which in-turn enables a multidimensional approach to HL measurement and more robust evaluations of HL-promoting strategies. Developing a framework led by HL experts achieves an important outcome which is necessary for catalysing growth in the field: consensus. The second study forming my PhD aimed to yield consensus, both at the direct and proxy level of HL measurement for community population research. Given the almost exclusive focus towards adult HL measurement in community populations noted from this Chapter's scoping review, Chapter 3 will spotlight the need for achieving consensus on community adult **and** child HL measurement consensus, the method to achieve this, and the general findings and HL measurement framework proposed. Chapter 2 subsequently informs the reader of current trends in community HL measurement across the intervention context, and identifies the potential need for consensus on community measurement practices moving forward.

Study Highlights

- HL is generally regarded as a multidimensional construct, with many instruments available.
- Evidence suggests the field may be converging towards measuring HL in a holistic manner, but there is no up-to-date review evaluating whether this is true.
- A scoping review was conducted to identify patterns and trends in community HL measurement across recent interventions.
- A lack of consensus at the direct (model-based) and proxy (non-model) level of HL measurement was reported.

- An expert-led framework may help reduce inconsistent measurement practices and improve the rigour of HL data moving forward.

Chapter 3 – The Second Study: Achieving Consensus on Community Health Literacy Measurement

Introduction

As evidenced from the previous Chapter, the multidimensional development of HL as a construct has led to a range of varying measurement practices across community interventions in the last 10 years (Sawyers et al., 2022). From both an instrument and outcome perspective, practices are either inconsistent, do not fall in line with the view that HL is a multifaceted construct, are misaligned with the proposed study agenda, or all of the above. Recent developments in the field has led to a range of evidence demonstrating the efficacy of both unidimensional and multidimensional HL measurement, with the HLQ (Osborne et al., 2013; Slatyer, Toye, Burton, Jacinto, & Hill, 2022), the AAHLS (Chinn & McCarthy, 2013), the TOFHLA (Náfrádi, Papp-Zipernovszky, Schulz, & Csabai, 2019) and the NVS (Linnebur & Linnebur, 2018) representing a few of the well-established, psychometrically validated instruments in circulation. Even performance-based measures of HL, those traditionally known to reflect unidimensional overviews, appear to be transitioning towards multidimensionality, with a recent checklist for the development of these tools being developed by leading researchers in the field (Muscat, Costa, Nutbeam, McCaffery, & Ayre, 2021).

A comprehensive array of instruments are available for contemporary HL researchers, with 361 studies reporting on an instrument in a recent systematic review covering 1993 to 2021 (Tavousi et al., 2022). Though the practicality of having HL instruments available for a plethora of research scenarios is appealing, Chapter 2 demonstrated the negative implications of this on current measurement practices.

Given that many community HL research practices appeared to default towards unidimensional instruments like the TOFHLA (Khaleghi et al., 2019; Soto Mas et al., 2017), the direct level of HL measurement could benefit from clarity, particularly given the myriad HL models in circulation across both adult (Malloy-Weir et al., 2016) and child populations (Bröder et al., 2017). Understanding which operationalisation of HL to incorporate within community HL research can be challenging, as many instruments are able to be implemented into a given research design. The problem lies with the outcomes attained, and not all instruments in circulation will attain outcomes appropriate to the underlying research questions being investigated, leading to inadequate findings and difficulty drawing conclusions and eliciting comparability of findings across the field. Developing consensus on direct HL measurement in community populations subsequently enables this, allowing for greater clarity during the research design and evaluation process.

From a proxy measurement perspective, there is an urgent need to identify HL outcomes which complement community HL population research (Sawyers et al., 2022). Direct measures provide clear outcomes pertaining to community research projects, but proxy evaluations are indicative of widespread affect, and demonstrate how potential HL-related mechanisms of change impact the individual and their environment holistically. Achieving consensus around HL measurement in community populations cannot be achieved in a unidimensional manner, as considerations within contemporary academia (HL model components) must also be considered alongside those which seldom are (components outside the remit of inclusion – non-model components). The development of a HL measurement framework therefore must consist of both model-based components prevalent across the field, and non-model components identified from novel expert opinion and contemporary HL resources.

The need for consensus is clear – the abundance of instruments and subsequent conceptualisations of HL makes for a challenging interpretations of how to evaluate community HL research. Direct HL is an important consideration as they provide immediate overviews of a person's HL, and proxy HL provides a broader overview of how a person's direct HL is interconnected. The final key consideration is the community. As mentioned in Chapter 1 (sub-section *deviation in health literacy measurement*), HL was initially conceived with adults in mind. Children were often considered as relatively inactive from a health information perspective, with parents and carers taking precedent. This view has changed in recent years, with calls to begin considering children as active health practitioners (Fairbrother et al., 2016) forming the status quo presently. Enthusiasm towards child HL has, however, generated a number of problems from a measurement perspective. Models of HL were formed with adult populations, and did not consider the unique HL needs of children (Baker, 2006; Nutbeam, 2000; Zarcadoolas et al., 2005). Given that prominent HL models from the early 2000s guide prevalent instruments of HL like the TOFHLA, prevalent HL instruments may provide a misleading interpretation of a child's true HL. Attaining consensus on both adult and child HL is therefore essential to clarify priorities for the assessment of HL in adults and children, and further research across both groups as a whole.

With recent attempts to understand current child HL model perspectives (Bröder et al., 2017) and instruments in circulation (Guo et al., 2018; Okan et al., 2018), HL measurement is a timely consideration. In order to provide consistent foundations for HL measurement in community populations, a framework of important HL outcomes for community adult and child populations must be ascertained. An expert-led Delphi study was subsequently proposed, forming the second study within this PhD, with the aim being to investigate the conceptual nature of HL in community adult and child populations. To do this, the focus was to develop an expert-led outcomes framework to stabilise the inconsistent and unclear measurement practices in the field. Both adult and child community populations were considered, as the lack of consensus in adult HL measurement and the lack of child HL assessments overall (see Chapter 2, sub-section *results*) demonstrate a need in clarifying measurement practices for these populations moving forward. Though the field is complex, with many conceptual interpretations of HL in existence, many share the same core elements (Nutbeam & Lloyd, 2021). This Chapter subsequently intends to foster consensus on the measurement through a pragmatic lens. The second objective proposed within this thesis – to develop an expert-led consensus on the HL measurement outcomes important to consider at the direct and proxy level for adult and child community populations – is subsequently targeted within this study.

Methodology

The Decision to Conduct a Delphi Study

Given that the primary aim of this study was to develop expert-led consensus towards community HL measurement outcomes, Consensus Development Methods (CDMs) were the primary research methods considered for the study design. In general, CDMs refer to a systematic method for the measurement and development of consensus (Humphrey-Murto, Varpio, Gonsalves, & Wood, 2017), and a number of consensus methods exist. Across the literature, the Delphi Method and Nominal Group Technique (NGT) are prevalent, but other methods exist, including the Consensus Development Conference (CDCo) and the RAND/UCLA Appropriateness Method (RAM), with all differing in terms of anonymity, the use of in-person vs online formats, time scale to completion, and sample size (Arakawa & Bader, 2022). The impact of the Covid-19 pandemic played a significant role in the method chosen. Nevertheless, all CDMs were initially considered, and decisions were made on their use from a practical and theoretical standpoint relative to the study objective and Covid-19 restrictions at the time.

The Delphi method was initially described by the RAND Corporation, and is the most prevalent CDM type, with roughly 75% of papers in the medical education field using either Delphi or modified Delphi CDMs (Humphrey-Murto et al., 2017). Six key stages form the Delphi methodology including identifying the problem of interest; determining the participants; creating a survey of statements; conducting iterative, anonymous, postal or email survey rounds; collate individual and group feedback across rounds; and providing a summary of the findings (Humphrey-Murto et al., 2017). As a CDM, the Delphi method acts as a flexible approach for gathering expert perspectives on a complex topic, with the anonymity promoting honesty and reducing the likelihood of particular member perspectives dominating throughout the process (Barrett & Heale, 2020). Delphi studies provide a more objective way of exploring issues requiring judgement, but can be particularly time consuming due to the rounds taking an extensive amount of time due to the significant preparation and analysis time per round (Gordon, 2009). The Delphi method can include a combination of question types, including open-ended or structured questions, and often undergoes descriptive statistical analyses which are then used as feedback for participants. When taken collectively, the Delphi method can be particularly useful where subjective information from experts is required to address the topic of interest (McPherson, Reese, & Wendler, 2018).

The Delphi method has been modified across a number of applications, ranging from a two-round, online and in-person approach to aid a rapid review study (Tricco et al., 2016) to a three-round email panel to identify global health education course objectives (Covvey & Ryan, 2018). Adjustments to the general Delphi method structure – referencing the six stages of conducting a Delphi study (Humphrey-Murto et al., 2017) – are frequently referred to as the modified Delphi, having no standard criteria (Nasa et al., 2021). Depending on the modification for each Delphi method, the advantages and disadvantages of the approach may differ. For example, using an in-person Delphi round may facilitate greater engagement than an online round at the cost of anonymity and the presence of domineering perspectives. This may not be applicable where an online format is taken.

Another frequently applied CDM is the NGT, referring to a structured in-person group approach with the intention of achieving consensus and subsequent action planning on a topic of interest (Harvey & Holmes, 2012). With a key focus on individual input and not interactions between the group, four stages are typically used: an introduction by the NGT facilitator; individual responses via a 'silent generation' phase; clarifying and consolidating – implementing a verbal feedback phase for each participant to clarify, and subsequent merging of similar responses; ranking responses, asking participants to respond with their five most valued responses; and closing of the session (Varga-Atkins, Bunyan, Fewtrell, & McIsaac, 2011). Prevalent in its application, the NGT has been used across a broad range of contexts, such as in the identification of community health priorities (Makundi et al., 2006), improvement areas for pain management in hospitals (Peña, Estrada, Soniat, Taylor, & Burton, 2012), and important outcomes for chronic patient populations (Cho et al., 2019; Manera et al., 2019), to name a few. The NGT has a number of benefits, including an explicitly structured approach, delivery in a time-efficient manner to busy experts, and knowledge of the outcome of the study for participants on the same day of participation (Maguire, Garvey, Ryan, Olasoji, & Willets, 2022). On the other hand, the NGT is prone to targeting a single question or idea, relying on the effectiveness of the facilitator for success, and being time and resource intensive (Manera et al., 2019).

The RAM acts as a variation of the Delphi method, using a two-round rating process with a combination of independent rating in the initial round and an in-person session in the second round, with the opportunity for reviewing the initial round ratings in the second round (Sparks et al., 2022). More specifically, a literature review and list of specific clinical scenarios – known as indications – are produced, which experts rate across the two rounds. Unlike the Delphi method, participants rate the indications with three categories: appropriate, inappropriate, and uncertain. From here, the final ratings are established for the indications according to median responses and the level of disagreement provided by the panel (Fitch et al., 2000). Seen as a hybrid between the Delphi method and NGT (Arakawa & Bader, 2022), the RAM is frequently used in the absence of clinical trial evidence to develop clinical practice guidance (Broder, 2022) and has been successfully employed to develop guidelines for various clinical scenarios, including aphasia rehabilitation (Power et al., 2015) and peripherally inserted central catheters (Chopra et al., 2015). As a method, RAM allows for a transparent and systematic approach, supporting in-depth quantitative analysis through the use of interpercentile range, both as a standalone and adjusted for symmetry, allowing the identification of disagreement while considering variation in panel size (Arakawa & Bader, 2022). The in-person format does, however, restrict the panel size (Basger, Chen, & Moles, 2012).

Lastly, the CDCo acts as an exclusive in-person format with panel members from a public forum, applying with a less formal approach taken compared with other CDMs. Frequently used to assess how medical technology is used (McGlynn, 1990), the CDCo uses a small group of participants who are presented with a range of different evidence types on a given topic, in which a meeting is chaired and discussions take place. The endpoint of the CDCo is typically a consensus statement, though members in the audience within the public forum can also contribute to the discussions (James & Warren-Forward, 2015). The central advantage of a CDCo is that the method fosters in-depth discussions and debate on the topic (James & Warren-Forward, 2015), but typically suffers from expensive running costs given the running of the CDCo in a public forum, and time limitations when hearing evidence on the topic matter (Arakawa & Bader, 2022). Prevalent examples can be seen within the National Institute of Health (NIH), who have devised several joint statements using CDCo methods on coeliac disease (NIH, 2005) and the diagnosis and scoring of chronic graft-versus-host disease (Jagasia et al., 2015). Other implementations of CDCo methods also exist, with another conference achieving consensus on engaging young adults with type one diabetes with health services they use and how to improve their management of diabetes (O'Hara et al., 2017).

When considering the different types of CDMs available with the study aim, some methods appeared more appropriate. For example, given the timing of this project, the Covid pandemic made conducting in-person research impossible, and subsequently all CDMs with in-person requirements were unable to be conducted. This meant that the CDCo and NGT were unable to be considered. The RAM, while typically employing an in-person second round, has previously demonstrated efficacy when used in a modified online format (Claire et al., 2015), and was thus considered alongside the Delphi method for this study. When the design of the study was considered, an initial four-round approach was proposed to incorporate questions assessing content relevant to the study aim (see Appendix 7**).** This was subsequently reduced to three rounds (see Figure 11), but was deemed unable to be reduced further. Given that a RAM is typically conducted with two rounds, and is generally conducted in the context of clinical guideline development (Broder, 2022), the decision was made to use a modified Delphi method, using email recruitment and online survey rounds throughout. Covid-19 had a significant impact on the decision to continue with a modified Delphi method, as both CDCO and NGT approaches were unable to be considered. As the Delphi method provides flexibility in its approach (Barrett & Heale, 2020), this solidified the decision to use a modified Delphi given the actively changing Covid-19 research landscape and the other CDMs being unfeasible as discussed above.

Three rounds were determined to be most appropriate because this enabled the generation of consensus on areas directly relevant to the study aim, while maintaining a relatively low completion time per round. As two rounds would omit an important feedback round and four rounds may create a more drawn out Delphi method and impact panel retention, three rounds was decided to maintain the panel's interest while covering the main topic content relevant to the study aim.

Survey Development

The items participants were asked to rate in round 1 likert scales were guided by the findings from a recent scoping review, which identified recent HL measurement practices for community HL intervention research and categorised them into direct or proxy outcomes. This provided an appropriate starting point for currently used HL measures for experts to rate, both at the direct and proxy level, and were incorporated as items to rate in the opening round matrix tables. The open questions for each round 1 HL measurement context succeeding the matrix tables enabled participants to generate additional items not accounted for in the scoping review, providing both a literature and expert-led basis for the HL items rated in the survey.

All members of the research team provided feedback on the initial draft, supporting an iterative process of refinement to improve the survey structure, clarity, and determine whether any additional survey components were needed. Two members of the research team (P.A and G.D – HL experts) checked the HL content to ensure the survey material reflected the Delphi aims, and the remaining members (C.A and L.S.T) ensured the clarity and structure was appropriate. Feedback from the team which was implemented included the addition of survey headings to break-up the content within all three Delphi rounds, an explanation of the age ranges presented for each of the four study contexts, changing key instructions to bold format, and rephrasing of the questions to be more direct and succinct. All feedback was incorporated and provided to the team for approval via email.

Study Design

The Delphi method was utilised, which refers to a round-based consensus gathering approach aiming to find general agreement on a specific topic requiring expert input. An expert panel was formed, who were provided several iteratively managed survey rounds in the hope of achieving consensus. For this study, HL experts formed the sample, and the complex topic requiring discussion and consensus was identifying important outcomes for community HL measurement in adults and children. The Delphi method supports rational academic debate (Fink-Hafner, Dagen, Doušak, Novak, & Hafner-Fink, 2019) while reducing the opportunity for participants to conform to dominant viewpoints, promoting a balanced consideration of ideas and reducing group dynamic influences(Donohoe & Needham, 2009).

Three rounds were conducted, with each round asking questions on HL measurement across four community HL contexts: adult direct, adult proxy, child direct and child proxy HL (see Table 7).

Table 7. Definitions for each health literacy context used in the Delphi study

HL Context	How they were defined
Adult Direct	• Adult defined via WHO definition of Young People (10-24; (WHO, #596), proposing adulthood succeeds this. • Direct HL defined as any domains extracted from HL models or models applied to HL.
Adult Proxy	• Adult defined via WHO definition of Young People (10-24; (WHO, #596), proposing adulthood succeeds this. • Proxy HL defined as domains not directly attributable to known HL models or domains which may be useful adjunctive outcomes to determine a person's HL.
Child Direct	• Child defined via UNICEF and wider literature. Lower 10-year threshold defined in line with UNICEF definition of early adolescence (UNICEF, 2015). Upper threshold determined via literature recommendation (Salmela-Aro, 2011) and the suggestion that later-stage adolescence may require standalone HL measurement considerations due to the development of advanced cognitive skills taking place (UNICEF, 2015). • Direct HL considers any domains extracted from HL models or models applied to HL.
Child Proxy	• Child defined via UNICEF and wider literature. Lower 10-year threshold defined in line with UNICEF definition of early adolescence (UNICEF, 2015). Upper threshold determined via literature recommendation (Salmela-Aro, 2011) and the proposal that later-stage adolescence may require standalone HL measurement considerations due to the development of advanced cognitive skills taking place (UNICEF, 2015). • Proxy HL defined as domains not directly attributable to known HL models or domains which may be useful adjunctive outcomes to determine a person's HL.

Note. Abbreviations: HL, Health Literacy; WHO, World Health Organisation; UNICEF, the United Nations International Children's Emergency Fund.

In round 1, participants were asked to independently rate the importance of HL measurement items retrieved from a previous scoping review on a scale of 1-5 (where 1 = not important and 5 = very important). Likert scales were used throughout the Delphi rounds as they are a convenient approach supporting fast data collection, while also providing simple data comparisons (Nemoto & Beglar, 2014). Participants were provided with definitions for each HL item in the form of a tooltip to aid with clarity, and the question was formatted as a matrix table to allow participants to respond to all items via the same response scale. The Likert scale was repeated across each of the four HL contexts (adult direct, adult proxy, child direct, child proxy). An open-ended question was provided as a follow-up for each Likert scale question across all contexts, asking participants to identify any additional measurement items they perceived as important for the relevant context that were not listed as response options in the matrix table. Open question response formats allowed the panel to implement additional items which were not considered from the initial literature consultation, supporting active participant involvement and enabling a broader view of the topic area which likert scales alone may omit. Participants were asked to provide their full name at the onset of the round for data management purposes.

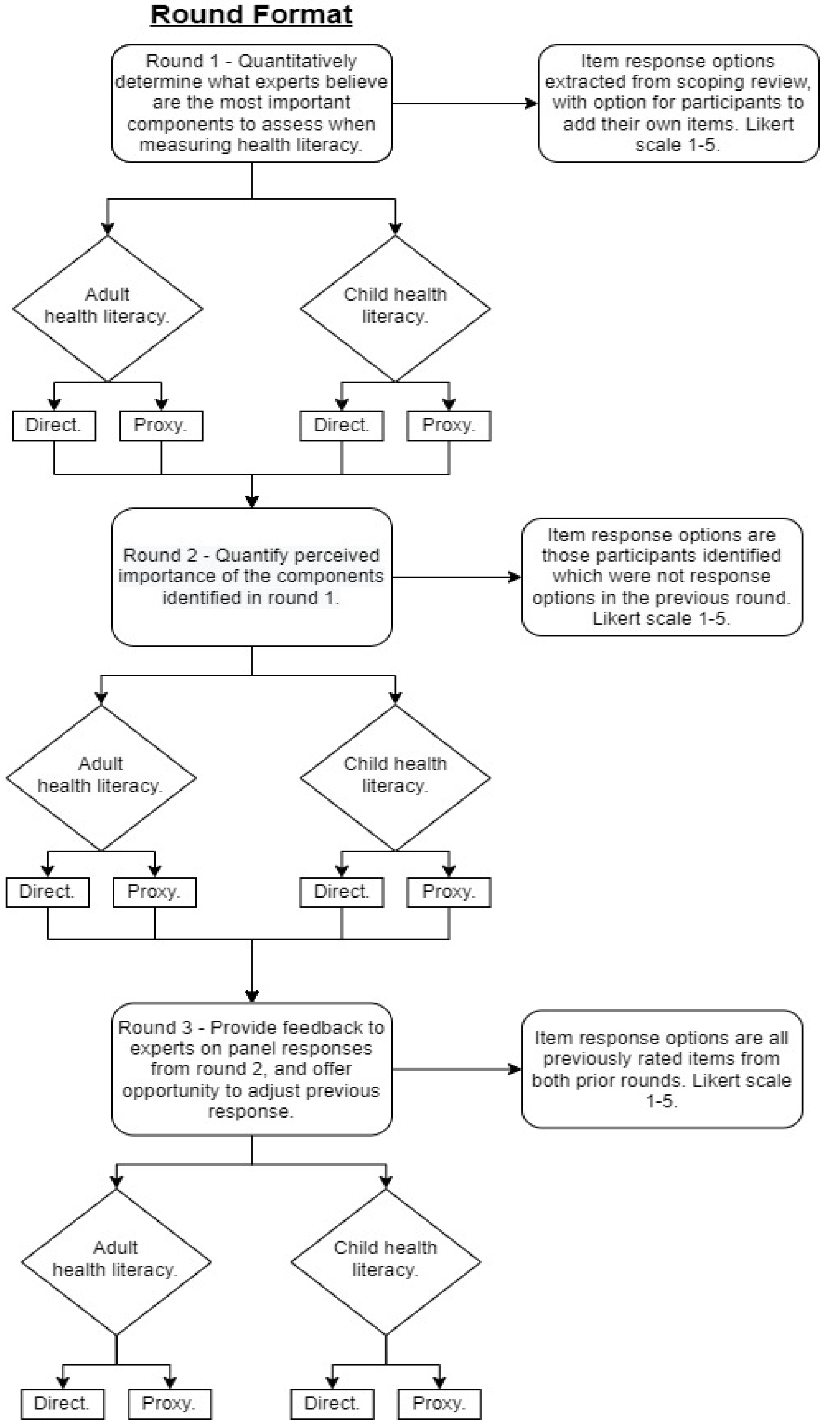
For round 2, the same likert scale question format was provided to participants as in round 1. The key difference were the items participants were asked to rate, which considered items participants identified in round 1 via the open question provided per each context. Items to rate for the likert scale were subsequently determined by expert input in round 2. A series of new items for each context were therefore provided for experts to rate. In addition to the likert scale question, participants were also asked two closed questions about the sufficiency of existing HL instruments for assessing HL. The questions were asked across two formats – adults and children, providing perspectives on the sufficiency of community adult and child HL instruments in circulation. These groups were defined in the same manner as the adult and child HL contexts noted across all rounds. Participants were given four response options to select from (Yes, No, Don't know, Other [free-text response option]), with a free-text option provided for one choice. Two closed questions of this format were provided to participants, with one considering adult HL instruments and the other focusing on child HL instruments. Closed questions benefit from being simple to respond to and analyse, though the restrictive nature of the question format means important data can be missed (Pate, 2012). Both questions were subsequently followed by an open-ended question to address the boundaries imposed by closed questions, asking participants to expand upon their response if they responded with one of two options (Yes or No) to the initial closed questions.

In round 3, participants were provided with four likert scale matrix tables, with one provided for each study context. Four columns were listed in the matrix tables for participants to see: Panel Rating Mean; Panel Rating Standard Deviation; Your Previous Rating; Your New Rating. Two columns were pre-filled with the same data for all participants (Panel Rating Mean and Panel Rating Standard Deviation), and one column (Your Previous Rating) was personalised to each participant's own previous response to a corresponding item from round 1 or 2. The final column (Your New Rating) was left blank, and participants were asked to look at the information provided across all the pre-filled columns before inputting their final rating via the same weighted values used previously. The items participants were asked to respond to were determined by a pre-existing mean panel threshold (≥ 3.50 being indicative of consensus on a HL item deemed important). Participants were provided with one Likert scale matrix table utilising this design across each of the four study contexts. The use of likert scale response options was again employed for a combination of convenience to the participant and comparability of the findings – key strengths attributed to likert scale formats (Nemoto & Beglar, 2014).

Two closed questions were also used to enquire about how participants would categorise self-efficacy as a HL item (due to the variable being identified as both a direct and proxy outcome throughout the Delphi survey rounds – see sub-section *results*). Each question represented a different HL measurement context (adult, child), and four response options were provided (Direct; Proxy; Direct and Proxy; Other [free-text response option]) with a free-text option provided for one choice. Both questions were followed by an open-ended question, asking participants to expand upon their response to the initial closed question. The closed-preceding open question format was employed for the same reasons listed in round 2 (see the above paragraph).

All surveys were developed, administered and managed via Qualtrics software. The survey flow can be seen below:

Figure 11. Delphi Rounds Flow Chart.



Expert Panel Recruitment

Participants forming the expert panel were initially identified from a combination of search engine enquiries and personal and professional networks. Participants who were not known to the research team were identified as potential participants of interest from searching Google and Google Scholar for HL-related publications. Authors of the HL-relevant publications were then identified and listed as potential HL experts to contact regarding their participation as a member of the expert panel. For personal networks, potential HL experts were identified through available links from members of the research team. Lastly, professional networks involved a variety of HL groups and organisations, who were approached to disseminate information via Twitter or their own web pages.

Through these methods, 67 HL experts were identified and invited to participate through email (See Appendix 8), Twitter (See Appendix 9), or their personal web page contact section (See Appendix 9). Evidence regarding the ideal sample size for a Delphi panel is variable, (Atkins, Tolson, & Cole, 2005; Okoli & Pawlowski, 2004; Trevelyan & Robinson, 2015) and suggestions propose greater dependence on group dynamics for achieving consensus rather than statistical power (Slade, Dionne, Underwood, & Buchbinder, 2014). Consequently, we placed greater emphasis on how we characterised HL expertise within our panel as opposed to a pre-specified sample size range. We did, however, wish to achieve a minimum a priori sample of 12 respondents per Delphi round, in line with the view that this is generally viewed as sufficient to enable consensus (Vogel et al., 2019).

The HL experts were defined as any individual who has been engaged in the development of a HL-related work and/or self-identified as a HL expert. To account for this, participants were requested to provide their self-reported area of expertise and any recent engagements – within the last five years – relevant to the field of HL (including conferences attended/keynotes given, involvement with relevant committees, publications, books, chapters, interviews, teaching, reviewer duties, or any other experiences). Previous Delphi research has used criteria to further characterise the term 'expert', given the variability of the term across expertise areas (Trevelyan & Robinson, 2015). To further vet the quality of the panel, the aforementioned requests were implemented in the consent form, allowing an understanding of active involvement and expertise of the HL panel members. Participants were required to sign a consent form (see Appendix 10) and participant information sheet (see Appendix 11), the former of which included the above-mentioned section to identify self-reported area of expertise and recent involvement in the field of HL.

The sampling was purposive to subsequently ensure participants were able to meet this criteria, though snowball sampling was also used when contacting potential participants to identify additional HL experts who may have been overlooked during the expert identification process. Participants were required to be over 18 years of age, which was expected given the experience-based nature of being a HL expert. Additionally, given that the identification of HL experts was dependent on self-reported expertise, experts did not have to be from a research-dominant background to participate, such as in an educator-focused role, so long as they identified as being involved in the field and could demonstrate this through their recent HL involvement and perceived expertise. To count as a Delphi panellist, participants were required to respond for all 3 Delphi rounds, and participants who did not respond to a given round were thus not invited to participate in the succeeding round(s).

Given the purposive nature of sampling HL experts for this Delphi study, the potential for bias is possible. The benefit of an anonymous approach within a Delphi study is the mitigation of bias that may result from participants being viewed negatively for their perspectives. The problem with this approach is the induction of cognitive bias in the form of the bandwagon effect, wherein participants may alter their responses to comply with the majority view presented during feedback (Barrett & Heale, 2020; Winkler & Moser, 2016). While confirmation bias may also arise from including only participants who respond to all three rounds in the final framework, this supports the consensus provided by the experts and allows participant responses to form the HL measurement framework directly, and in accordance with the pre-defined cut-offs for inclusion. Though it cannot be guaranteed that biases do not exist in this Delphi method, the approach presented centres on the panel's responses to act as the guiding mechanism for developing a community HL measurement framework. Nevertheless, the risk of bias may be present in the study design.

Ethics

The research was approved by the University of Nottingham's School of Pharmacy Research Ethics Committee (reference number 014-2021).

Analysis

Descriptive statistics were used to represent panel responses to the matrix table likert scales, which formed the HL measurement items with which consensus was being sought. As consensus within Delphi studies can be defined anywhere from 51-80%, and is frequently informed by pre-defined mean or median cut-off points (Chuenjitwongsa, 2017), literature was consulted to define this further.

Various methods of operationalising consensus exist in the literature, ranging from the use of measures of central tendency across Likert and nominal scale responses, the average percent from majority perspectives, the coefficient of variation, and post-Delphi group consensus questions (Gracht, 2012). From a brief view, health-related Delphi studies appear to define consensus as >70% of participants demonstrating agreement on a particular item or statement (Nicolson et al., 2014; Vogel et al., 2019). As the mean panel response of ≥3.50 (transformed to represent ≥70% of the scale response) signifies the cut-off point frequently used in the literature, this was employed to identify the HL measures deemed important across each of the four HL contexts. A standard deviation of 1.50 (representing 30% of variation across responses – representing the maximum deviation to remain within the mean exclusion parameter) was also used alongside the mean response rate to determine agreement and subsequent consensus.

Collectively using the mean and standard deviation is a common method for defining agreement in Delphi studies (Gracht, 2012), and has previously been used when assessments of the importance of variables are presented to experts (Giannarou & Zervas, 2014). Given that this Delphi study intended to ask experts the perceived importance of a range of HL outcomes, both mean and standard deviation parameters were set to determine agreement amongst the Delphi panel and items included per each round. Items below the mean or standard deviation thresholds were excluded from further rounds, and items matching or above the mean and standard deviation thresholds were included into further rounds or the final measurement framework.

Though the mean threshold has previously been used to reflect ≥4.00 where five-point likert scales are used in Delphi research (Cascella et al., 2021), it was desirable to consider all participant responses when determining panel consensus, and not just those which responded at the four and five point answer options. Items which achieved the mean panel response threshold of ≥3.50 were subsequently carried into the succeeding round for further input, and items with a mean panel response of <3.50 were excluded from further rounds, assuming both yielded standard deviation values of ≤1.50.

Descriptive statistics in the form of frequencies were generated for all closed question responses, and Braun and Clarke's thematic analysis was used to identify patterns and trends for all open question responses (Braun & Clarke, 2006). There were two exceptions to this, with the first being that conventional qualitative content analysis was performed on the open questions in round 1, with content analysis referring to a technique for producing valid and replicable inferences from text (White & Marsh, 2006) and conducted via an 8-step process: preparation of data; defining the unit of analysis; develop the coding scheme and categories; testing the coding scheme on a sample of text; code the full dataset; assess consistency of the coding; draw conclusions from the coded data; and report the methods and findings (Zhang & Wildemuth, 2005).

The second exception was in qualitative data gathered through the closed questions with an optional open-ended response option, where the number of responses was minimal and thematic or content analysis provided no further information. In this instance, answers were considered without a guiding analytical framework and reported in their raw state. Where data was of sufficient quality, either thematic analysis or content analysis was performed depending on the depth of response retrieved. For both thematic analysis and content analysis, participant responses were analysed separately for the adult and child variants of the question.

The final agreed-upon framework of HL outcomes was developed with the items exceeding the ≥3.50 threshold after round 3, and Braun and Clarke's thematic analysis was deployed to refine and further categorise items across each HL context studied (Braun & Clarke, 2006). Two members of the team, one being a trained qualitative researcher with a background in health psychology (L.S), and the other an experienced qualitative researcher with a pharmacy practice background (L.S.T), independently conducted thematic analysis on the HL items generated from round 3. Both researchers then came together to discuss their decisions and produced the categories forming the HL measurement framework. A third researcher (C.A) was on stand-by to resolve any disagreements that arose during the process. Feedback was obtained from the research team to ensure the final HL measurement framework was comprehensible, fit for purpose and retained the Delphi panel's perspectives.

SPSS Statistics (Version 27) was used to generate all descriptive statistics, and thematic analysis was conducted through Microsoft Word.

Results

Delphi Panel Characteristics

From the 67 experts who were invited to participate in the Delphi study, 18 completed round 1 (26.87%). The primary reason cited by participants who declined the invitation was being at capacity with regards to workload. For the remaining rounds, 16 experts participated in round 2 (88.89%) and 15 completed round 3 (93.75%). In total, a small drop-out rate was observed (16.67%). All participants were academics with experience in conducting HL research, with various subjectively reported areas of HL-related expertise identified (see Table 8). Participants provided their recent experiences in the field of HL, including, but not being limited to:

publishing HL works; attending and presenting at conferences; supervision duties; peer review; and HL committee, working and special interest groups. While geographical demographics were not collected, European, North American and Australian HL experts formed the Delphi panel, in line with the general view of HL research globally (Qi et al., 2021).

Table 8. Self-reported Delphi Panel Expertise.[a]

Area of Expertise	Frequency Reported[b]
Adult HL	2
HL interventions	4
General HL	5
Behaviour change	1
Diabetes	1
Parental HL	1
HL skills training	1
Written patient education materials	1
Child HL	5
Adolescent HL	4
Psychometrics	5
HL assessment	2
HL of people with intellectual disabilities	1
Online/E-health literacy	4
Maternal HL	1

Abbreviation: HL, Health Literacy.

[a]Frequency values do not match the baseline sample size (n = 18) due to participants providing multiple areas of expertise.

[b]A subset of participants did not respond to the question surrounding their expertise.

Round 1 Findings

Likert Scale Responses – Review Item Ratings

Overall, 25/76 items gathered from the initial scoping review were determined by the panel as important for measuring HL, differing across each study context: adult direct (n = 6 important; n = 10 not); adult proxy (n = 8 important; n = 14 not); child direct (n = 6 important, n = 10 not); child proxy (n = 5 important, n = 17 not).

Descriptive statistics for the Delphi panel were identified for each item rated across the four HL contexts (see Table 9).

Table 9. Round 1 Likert Scale Items Included and Excluded Across Each Study Context.

Adult direct items identified as important (n = 6)		
Item	Mean	Standard Deviation
Communicative HL	4.72	0.45
Critical HL	4.44	1.12
Dealing with health information	4.39	0.76
Functional HL	4.17	1.17
Proactive approach to health	3.82	1.10
Practical knowledge	3.61	1.25
Adult direct items excluded (n = 10)		
Item	Mean	Standard Deviation
Self-awareness	3.39	0.89
Self-perception	3.33	1.20
Communication and cooperation	3.11	1.15
Science literacy	2.94	1.08
Civic literacy	2.89	1.10
Citizenship	2.83	1.07
Cultural literacy	2.78	0.97
Theoretical knowledge	2.67	1.20
Self-regulation	2.61	1.11
Self-control	2.44	0.83
Adult proxy items identified as important (n = 8)		
Item	Mean	Standard Deviation
Healthcare navigation self-efficacy	4.28	0.80
Perceived control over health decisions	4.28	0.73
Self-efficacy	4.17	0.69
Health behaviours	3.83	1.26
Perceived control over health	3.72	1.10
General health knowledge	3.72	0.99
Perceptions about health	3.72	0.99
Health-related quality of life	3.50	1.17
Adult proxy items excluded (n = 14)		
Item	Mean	Standard Deviation
Social capital	3.39	1.16
Health confidence	3.33	0.82
Patient activation	3.28	1.45
Intent to search for health information	3.28	1.45
Social support	3.11	1.05
Trust in the medical profession	3.06	0.91

Satisfaction	2.67	1.20
English proficiency	2.50	1.46
Learning styles	2.44	1.12
Child development	2.28	1.19
Learning throughout the research	2.11	0.94
Participant research experience	1.83	0.90
Blood pressure	1.83	1.17
Weight	1.83	1.17
Child direct items identified as important (n = 6)		
Item	Mean	Standard Deviation
Communicative HL	4.44	0.76
Functional HL	4.39	1.25
Critical HL	4.06	1.13
Dealing with health information	3.78	1.08
Practical knowledge	3.72	1.04
Communication and cooperation	3.61	0.89
Child direct items excluded (n = 10)		
Item	Mean	Standard Deviation
Self-awareness	3.44	0.96
Self-regulation	3.11	0.87
Proactive approach to health	3.11	1.20
Self-perception	3.11	1.05
Theoretical knowledge	3.06	1.27
Science literacy	2.72	1.28
Self-control	2.67	0.88
Cultural literacy	2.39	1.01
Civic literacy	2.39	1.21
Citizenship	2.33	1.00
Child proxy items identified as important (n = 5)		
Item	Mean	Standard Deviation
Self-efficacy	4.17	0.96
Perceptions about health	3.89	0.74
Health behaviours	3.83	1.01
General health knowledge	3.72	0.99
Perceived control over health decisions	3.67	1.05
Child proxy items excluded (n = 17)		
Item	Mean	Standard Deviation
Health confidence	3.44	1.17
Social support	3.44	1.07
Perceived control over health	3.41	1.09
Health-related quality of life	3.28	1.24
Intent to search for health information	3.28	1.48
Child development	3.22	1.23
Healthcare navigation self-efficacy	3.17	1.54

Social capital	3.11	1.29
Satisfaction	2.94	1.30
Learning styles	2.83	1.46
Patient activation	2.72	1.04
English proficiency	2.61	1.50
Trust in the medical profession	2.41	1.09
Learning throughout the research	1.89	0.99
Weight	1.83	1.17
Participant research experience	1.78	0.92
Blood pressure	1.78	1.18

Abbreviations: HL, Health Literacy; n, Sample Size.

Open Questions – Items Generated

The open question response rate for round 1 was greater for adult direct (n = 9; 50%) and adult proxy (n = 8; 44.44%) contexts when compared to the child direct (n = 6; 33.33%) and child proxy (n = 4; 22.22%) contexts. A myriad of additional HL items were generated by the expert panel across each of the four HL contexts (total n = 44). Content analysis identified a range of new HL measurement items to be rated in round 2 (see Table 10).

Table 10. Round 1 Additional Health Literacy Items Generated From Open Questions.

Adult direct (n = 11)	
Items generated	Frequency
Digital HL	5
Health beliefs	1
Media literacy	2
Navigation healthcare literacy	1
Self-belief	1
Self-efficacy	1
Information seeking	1
Information appraisal	1
Information use	1
Accessing health information	1
Public health advocacy and engagement	1
Adult proxy (n = 15)	
Items generated	Frequency
Physical activity level	1

Food safety skills	1
HL friendliness of institutions and organisations	1
Education level	1
Literacy level (first language)	1
Familiarity with healthcare system	1
Recall of written information	1
Recall of verbal information	1
Ability to ask questions	1
Ability to seek new information	1
Use of medical terminology	1
Drug knowledge	1
Informed health choices	1
Making decisions relative to a person's own health goals	1
HL of institutions and organisations	1
Child direct (n = 11)	
Item generated	Frequency
Channels of information – how circles of influence impact a child's HL	1
Self-efficacy	1
Digital HL	4
Empowerment	1
Numeracy	1
Reading comprehension	1
Media literacy	2
Self-belief	1
Information seeking	1
Information appraisal	1
Information use	1
Child proxy (n = 7)	
Item generated	Frequency
Child's position relative to disempowering or overprotective members of society	1
Recall of written information	1
Recall of verbal information	1
Ability to ask questions	1
Ability to seek new information	1
Use of medical terminology	1
Informed health choices	1

Abbreviations: HL, Health Literacy; n, Sample Size.

Round 2 Findings

Likert Scale Responses – Expert-generated Item Ratings

From the items generated by experts in round 1, 31/44 (70.45%) achieved or exceeded the mean threshold for inclusion into round 3, differing across each context: adult direct (n = 8 important, n = 3 not); adult proxy (n = 9 important, n = 6 not); child direct (n = 9 important, n = 2 not); child proxy (n = 5 important, n = 2 not).

Table 11. Round 2 Likert Scale Items Included and Excluded Across Each Study Context.

Adult direct items identified as important (n = 8)		
Item	Mean	Standard Deviation
Information appraisal	4.69	0.68
Information use	4.56	0.70
Accessing health information	4.31	1.04
Digital HL	4.31	0.97
Information seeking	4.25	0.97
Navigation healthcare literacy	4.00	0.94
Public health advocacy and engagement	3.75	1.03
Media literacy	3.63	0.93
Adult direct items excluded (n = 3)		
Item	Mean	Standard Deviation
Self-efficacy	3.44	1.06
Health-related self-belief	3.06	1.09
Health beliefs	2.88	1.17
Adult proxy items identified as important (n = 9)		
Item	Mean	Standard Deviation
Ability to seek new information	4.63	0.60
Ability to ask questions	4.56	0.61
Making decisions relative to a person's own health goals	4.25	1.03
Familiarity with healthcare system	3.94	0.75
Informed health choices	3.88	1.11
Literacy level (first language)	3.63	1.11
HL of institutions and organisations	3.56	1.46
Recall of verbal information	3.50	1.12
Recall of written information	3.50	1.12
Adult proxy items excluded (n = 6)		

Adult proxy items excluded (n = 6)		
Item	Mean	Standard Deviation
HL friendliness of institutions and organisations	3.44	1.50
Education level	3.38	1.17
Use of medical terminology	3.13	0.86
Food safety skills	2.81	1.24
Drug knowledge	2.75	1.15
Physical activity level	2.38	1.27
Child direct items identified as important (n = 9)		
Item	Mean	Standard Deviation
Information use	4.56	0.61
Information appraisal	4.56	0.61
Information seeking	4.50	0.71
Digital HL	4.19	1.01
Numeracy	4.13	0.81
Reading comprehension	4.00	0.94
Media literacy	3.88	1.05
Empowerment	3.60	0.95
Self-efficacy	3.50	0.94
Child direct items excluded (n = 2)		
Item	Mean	Standard Deviation
Channels of information	3.31	1.21
Self-belief	3.25	1.09
Child proxy items identified as important (n = 5)		
Item	Mean	Standard Deviation
Ability to seek new information	4.63	0.48
Ability to ask questions	4.50	0.61
Informed health choices	3.94	1.09
Recall of verbal information	3.88	0.99
Recall of written information	3.81	1.01
Child proxy items excluded (n = 2)		
Item	Mean	Standard Deviation
Child's position relative to disempowering or overprotective members of society	3.13	1.11
Use of medical terminology	2.67	0.79

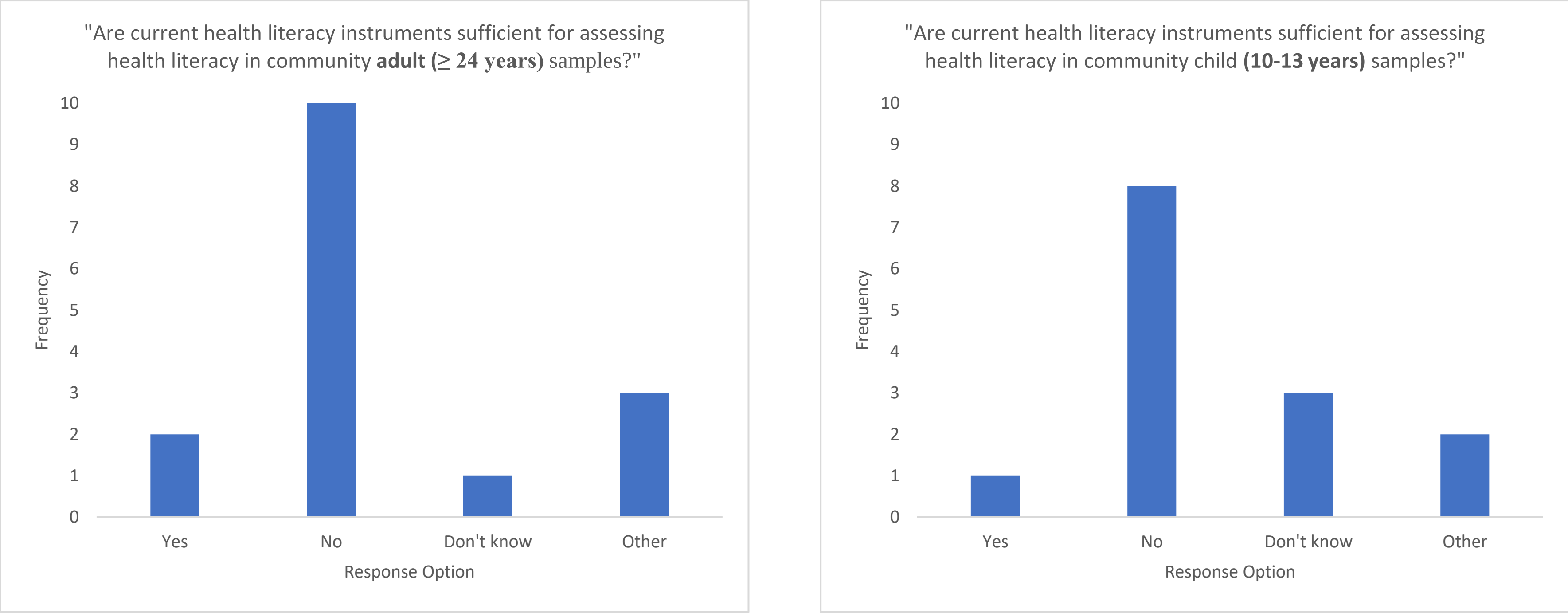
Abbreviations: HL, Health Literacy; n, Sample Size.

Closed Questions – Sufficiency of Current Measures

Descriptive Statistics

The closed question response rate varied across the adult (n = 16) and child (n = 14) closed questions, and the majority of participants responded with the ‘No’ option across the adult and child question variants (see Figure 12).

Figure 12. Response Frequencies for Round 2 Closed Questions.



Qualitative Outputs

Participants used the 'other' additional text space for the adult (n = 3) and child (n = 2) question variations.

Open Questions – Current Health Literacy Instrument Sufficiency

The majority of participants elaborated on their response in the succeeding open-ended question, with response rates differing across the adult (n = 12; 75% response rate) and child (n = 11; 68.75% response rate) follow-up open questions. Two separate sets of themes were generated: one for the adult-focused question and another for the child variation (see Table 12).

Table 12. Themes Generated.

Adult Instrument Sufficiency Question		Child Instrument Sufficiency Question	
Theme	Code(s)	Theme	Code(s)
Conceptual measurement	Omission of important HL elements	Narrow conceptual view	Individual focus
Suitability problems	Universal application Research-oriented utility	Instrument availability	Lack of child HL instruments.

Abbreviation: HL, Health Literacy.

Adult Question – Conceptual Measurement

Participants generally agreed that there are conceptual issues with HL measurement, suggesting that important considerations are omitted from existing adult HL instruments.

> *"I think that they cover only certain aspects of health literacy, while omitting others."* (Participant S2-18).

Others suggested that adult HL instruments provide great emphasis on individual HL factors, and subsequently do not consider environmental considerations which may be important to measure in adults.

> *"Most instruments focus on individual health literacy (e.g., HLQ, HLS-EU-47), few focus on health literacy environment (i.e. organizational HL)."* (Participant S2-05).

When asked whether current adult HL instruments sufficiently assess HL, some participants proposed that this depends on which HL elements are of interest.

> *"Depends upon the particular HL competencies you are trying to assess."* (Participant S2-11).

One participant further elaborated, stating that instruments taking a more general approach have a tendency to elicit views of a person's self-efficacy, rather than their HL.

> *"It depends on the topic … for example, the HLS-EU is not a good instrument because the questions are too general and answering depends more on self-efficacy."* (Participant S2-03).

Adult Question – Suitability Problems

The second dominant viewpoint on the sufficiency of current adult HL instruments reflected the applicability of current tools. One participant pointed to the Westernised and high-income focus for adult HL instruments.

> *"There are some useful HL tools in circulation eg Newest Vital Sign. I believe that they were formulated with adults in mind. They are embedded in a Western/High income context, however, so they may not be universally applicable."* (Participant S2-09).

Alternate views discussed the utility of HL instruments as being for research purposes, with another participant suggesting that existing adult HL instruments are unsuitable for clinical practice.

> *"Most [HL] assessments are formal tests of an individual's ability and are not suited for a non-research setting. They are also too time consuming to be used in practice."* (Participant S2-08).

Child Question – Narrow Conceptual View

Participants' perspectives on the sufficiency of HL instruments for children were similar, with several participants suggesting that current tools focus on the individual.

> *"Current health literacy tools in my opinion for children are quite narrow and very individually focussed as opposed to examining the broader constraining and facilitating factors on a child's health literacy."* (Participant S2-12).

Broader social elements of a child's HL were suggested to receive less attention than HL components focusing on the individual, indicating that current child HL instruments are insufficient due to the narrow focus on individual factors.

> *"While there is an increasing number of child and adolescent HL instruments, they also focus on children or adolescents themselves, ignoring the broader social environments."* (Participant S2-05).

Child Question – Instrument Availability

Other participants highlighted that existing child HL instruments are scarce, indicating the need for more tools to be developed for younger populations.

"I believe that there are relatively few tools available that are aimed at children/young people." (Participant S2-09).

One participant provided an in-depth example of an existing gap in child HL measurement, suggesting that population-specific considerations and modern HL concepts are required for sufficient child HL measures to be taken with current instruments.

" … there are almost no tools to measure children 11-13, I mean such tools that a) were developed only for this subgroup and b) based on modern health literacy concepts … focussing on finding, understanding, appraising and applying health information." (Participant S2-14).

Another participant, however, indicated instruments are available for measuring child HL, stating that a HL instrument does exist, but requires further validation. Instruments to measure child HL may be available, but require further work before they are deemed sufficient.

"There is an instrument developed … but it is not validated." (Participant S2-03).

Round 3 Findings

Likert Scale Responses – Review Item Ratings

From the items generated in rounds 1 and 2, the final framework of outcomes were identified across the four contexts. Marginal variance in the number of outcomes were noted across all community measurement contexts, and less exclusions were made in round 3. Expert ratings across all contexts led to the exclusion of several adult direct and proxy items, but no items for the child direct and proxy groups (see Table 13).

Table 13. Round 3 Likert Scale Items Included and Excluded Across Each Study Context.

Adult direct items identified as important (n = 12)		
Item	Mean	Standard Deviation
Functional HL	3.97	1.23
Communicative HL	4.70	0.46
Critical HL	4.30	0.88
Digital HL	4.00	1.04
Media literacy	3.60	0.91
Information appraisal	4.73	0.70
Information use	4.67	0.62
Accessing health information	4.37	0.90
Dealing with health information	4.43	0.62
Information seeking	4.40	0.74
Navigation healthcare literacy	4.00	0.66
Proactive approach to health	3.93	0.59
Adult direct items excluded (n = 2)		
Item	Mean	Standard Deviation
Practical knowledge	3.27	1.10
Public health advocacy and engagement	3.47	0.74
Adult proxy items identified as important (n = 12)		
Item	Mean	Standard Deviation
Ability to ask questions	4.63	0.55
Self-efficacy	4.10	0.47
Healthcare navigation self-efficacy	4.20	0.78
Perceived control over health decisions	4.20	0.56
Making decisions relative to one’s own health goals	4.47	0.52
HL of institutes and organisations	3.50	1.21
Familiarity with healthcare system	3.80	0.56
Informed health choices	3.80	0.56
Health behaviours	3.80	1.15
Ability to seek new information	4.60	0.63
Perceptions about health	3.57	0.82
Perceived control over health	3.73	0.80
Adult proxy items excluded (n = 5)		
Item	Mean	Standard Deviation
Health-related quality of life	3.27	0.70
Recall of written information	3.23	0.98
Recall of verbal information	3.30	0.10
Literacy level (first language)	3.47	1.06
General health knowledge	3.40	0.74
Child direct items identified as important (n = 15)		
Item	Mean	Standard Deviation
Information seeking	4.53	0.64

Information appraisal	4.53	0.64
Information use	4.53	0.64
Communicative HL	4.43	0.56
Functional HL	4.18	1.41
Critical HL	4.10	1.07
Digital HL	4.03	0.86
Reading comprehension	4.00	0.66
Numeracy	4.00	1.07
Media literacy	3.67	0.90
Dealing with health information	3.63	0.72
Communication and cooperation	3.60	0.74
Practical knowledge	3.53	0.99
Self-efficacy	3.53	1.06
Empowerment	3.53	1.19
Child direct items excluded (n = 0)		
Child proxy items identified as important (n = 10)		
Item	Mean	Standard Deviation
Ability to ask questions	4.63	0.48
Ability to seek new information	4.60	0.51
Self-efficacy	4.13	0.83
Informed health choices	4.00	1.00
Perceptions about health	3.80	0.68
Recall of verbal information	3.73	0.96
Health behaviours	3.73	1.03
Recall of written information	3.70	0.96
General health knowledge	3.60	0.91
Perceived control over health decisions	3.60	0.99
Child proxy items excluded (n = 0)		

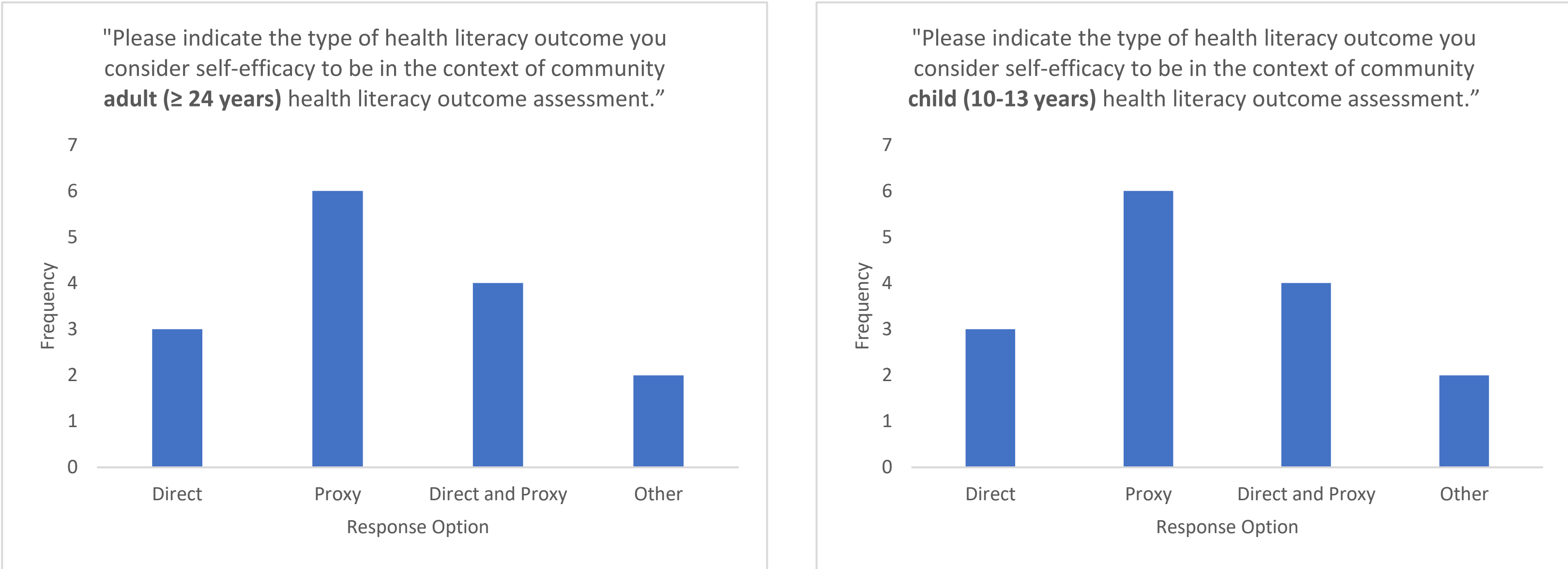
Abbreviations: HL, Health Literacy; n, Sample Size.

Closed Questions – Self-efficacy Categorisation

Descriptive Statistics

Self-efficacy was identified as both a direct and proxy HL outcome during the process, and the round 3 closed questions aimed to identify whether the expert panel could agree on a final interpretation of self-efficacy as a HL item. The closed question response rate was the same across both the adult (n = 15) and child (n = 15) question contexts, with no change in panel response noted (see Figure 13). The most common categorisation of self-efficacy across both contexts (proxy: n = 6; 40%) was too minimal to demonstrate consensus across the panel.

Figure 13. Response Frequencies for Round 3 Closed Questions on Self-efficacy Categorisation.



Qualitative Outputs

No panel members used the 'other' additional text space for the adult (n = 0) and child (n = 0) self-efficacy categorisation questions.

Open Questions – Categorisation of Self-efficacy as a Health Literacy Item

Several participants elaborated on their responses to the closed questions through the open questions provided for the adult (n = 7; 47% response rate) and child (n = 5; 33% response rate) contexts.

Table 14. Themes Generated for Self-efficacy Categorisation

Theme	Code
Confidence determines categorisation	None
Conceptualisation of HL	None
Population dependence	None

Abbreviation: HL, Health Literacy.
Note. Due to participants repeating the same responses across both the adult and child question variations, one theme set was generated for both question types. Additionally, the qualitative data collected was minimal, and a rich structure of sub-themes and themes was difficult to attain. As a means to prioritise clarity in the data reporting process and reduce repetition, no sub-themes were identified.

Confidence Determines Categorisation

Several participants highlighted the importance of self-efficacy denoting confidence, suggesting that a person's confidence does not directly relate to a skill assessment and thus cannot be a direct assessments of a person's HL.

> *"Confidence in health literacy skills is related to how much exposure people have had to the health system/how high their informational/health service needs were. As such, self-efficacy is not a direct measure of ones' skills."* (Participant S2-01; stated self-efficacy as a proxy HL outcome).

Other participants suggested confidence to be an important determinant of how self-efficacy is categorised as a HL outcome, but instead proposed that a person's HL directly contributes to their confidence, indicating self-efficacy as a direct assessment of HL.

> *"Health literacy directly contributes to confidence, which facilitates health behavior"* (Participant S2-07; stated self-efficacy as a direct HL outcome).

The same participant further highlighted that the relationship between HL and confidence may not be bi-directional, but nevertheless identified self-efficacy as a direct HL outcome for community adult and child groups.

> *"Not sure confidence may be indicative of health literacy, people may be confident in doing wrong behaviors or actions believing they are right."* (Participant S2-07; stated self-efficacy as a direct HL outcome).

Conceptualisation of Health Literacy

Many participants who elaborated on their initial categorisation of self-efficacy highlighted the importance of how HL is conceptualised in guiding their final decision. One participant further explained how a person's conceptualisation of HL can influence the categorisation of self-efficacy as a HL measurement.

> *"Depends on your understanding of health literacy, really. If you define HL as people's perceived difficulty of dealing with health information, it's very much self-efficacy. However, when you understand HL as being people's motivation, knowledge, and competence to access, understand, appraise, and apply health information, self-efficacy is not part of that."* (Participant S2-02; stated self-efficacy as a proxy HL outcome).

Others held stronger beliefs around how HL is conceptualised, which guided how they categorised self-efficacy as a HL outcome.

"I understand health literacy to be knowledge, skills and competencies." (Participant S2-15; stated self-efficacy as a proxy HL outcome).

Population Dependence

One participant highlighted the influence of the target population in determining how self-efficacy can be categorised as a HL outcome. Public and patient HL may be regarded differently where self-efficacy is an outcome of interest.

"Personal self-efficacy could be an antecedent of health literacy among the general population. There are some frameworks supporting this such as Manganello's adolescent health literacy framework. However, in a population of people with chronic diseases, their health literacy could affect their self-efficacy. There are some literature supporting this." (Participant S2-05; stated self-efficacy as a direct and proxy HL outcome).

More general self-efficacy perspectives emerged with respect to its categorisation as a HL outcome. Differences emerged in how self-efficacy is conceptualised as a HL outcome, with one participant proposing that the subjective nature of self-efficacy warrants proxy outcome categorisation.

"The subjective nature of this measure is more suitable as a proxy measure." (Participant S2-08; stated self-efficacy as a proxy HL outcome).

An alternate view was proposed by another participant, indicating self-efficacy as an initial input variable rather than a HL-related outcome.

"I believe Self-efficacy is an input variable, a proxy and moderator, not so much an outcome." (Participant S2-14; stated self-efficacy as a 'other' HL outcome).

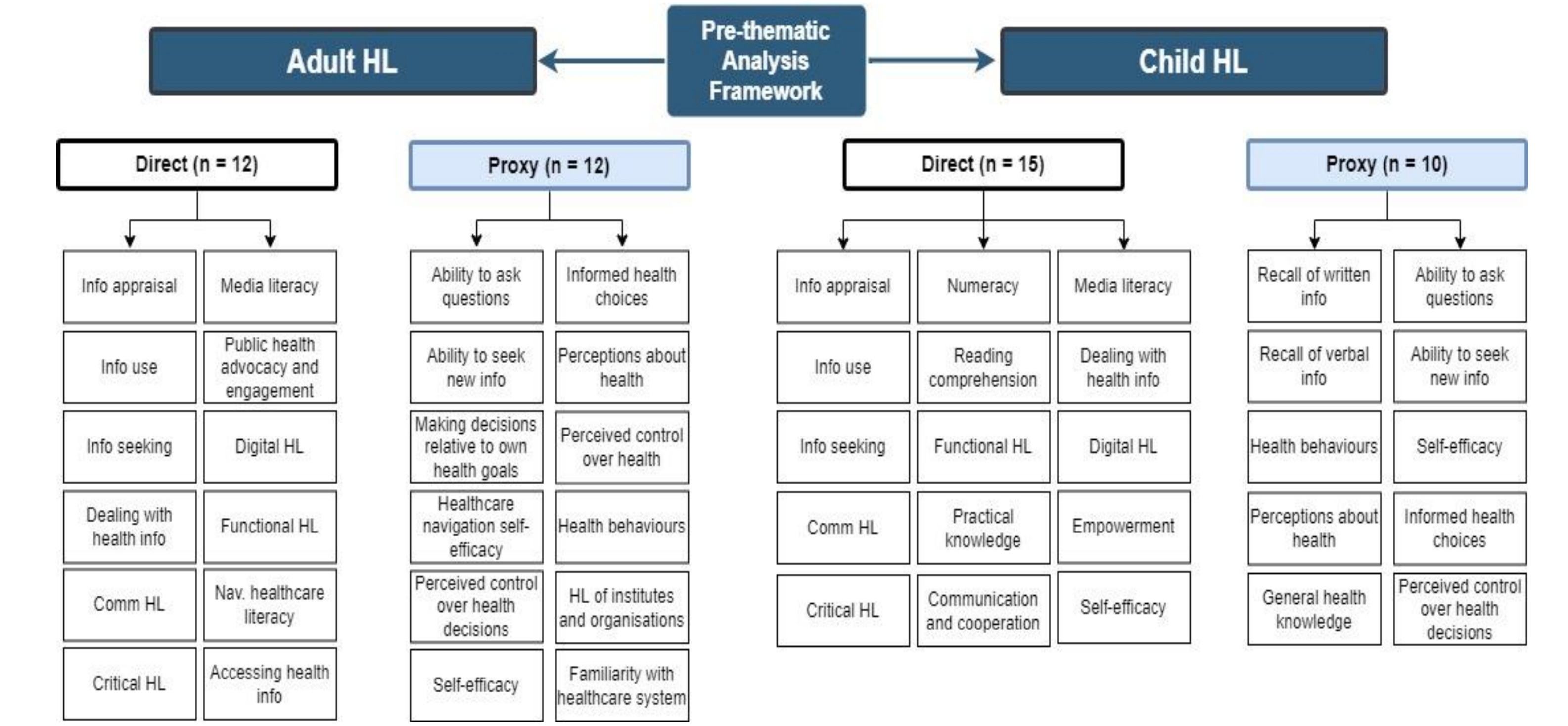
The range of perspectives identified through the open-ended questions further substantiate the closed question responses in that a number of beliefs impact how researchers interpret self-efficacy as a HL outcome.

Post-Delphi Study: Health Literacy Measurement Framework Development

Two HL outcome frameworks were generated: an initial framework based on the original round 3 Delphi findings (see Figure 14), and a revised framework founded through independent thematic analysis by two researchers (see Figure 15).

All experts were emailed a copy of the initial and revised frameworks, and provided an opportunity to feedback on the post-thematic analysis version (n = 1/15 (6.67%; see Figure 15). The response led to changes in the phrasing of the framework, with a preference for “HL Measurement Framework” as opposed to “HL Outcomes Framework”, and the use of the “domain” term rather than the “n” symbol.

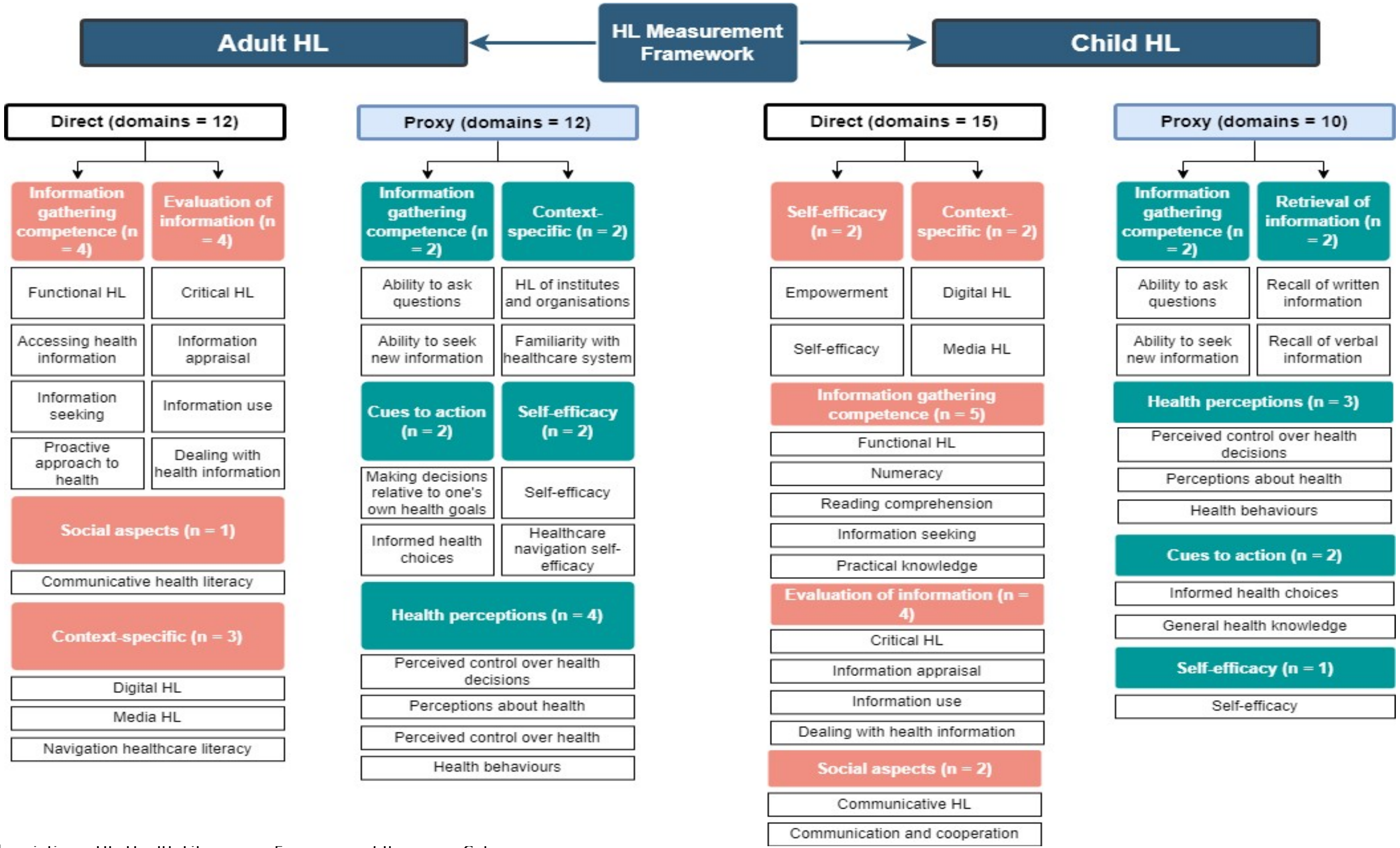
Figure 14. The Pre-thematic Analysis Outcomes Framework Retrieved from the Final Delphi Round.



Abbreviations: HL, Health Literacy; n, Frequency of Items per Category.

The initial framework captured all components the HL experts perceived as important HL outcomes. The research team identified various points of overlap across the outcomes generated, and thematic analysis was performed to enable a HL measurement framework with discrete outcome categories.

Figure 15. The Final Post-thematic Analysis Health Literacy Outcomes Framework.



Abbreviations: HL, Health Literacy; n, Frequency of Items per Category.

The final framework captured all components generated by experts. Thematic analysis was used to categorise outcomes into discrete measurement outcome classifications, with items reflecting HL measurement properties designated into analogous groups.

Discussion

Overview of Study Findings

Consensus on items to measure HL with across four key adult and child contexts were achieved, with global expert perspectives superimposed to create a HL measurement framework for community populations (see Figure 15). This initial development phase provides much needed stimulation towards measuring HL consistently in adult community populations, and importantly provides an expert-led indication of deviations in HL measurement across child populations. With the expansion of HL as a multidimensional construct in recent decades, child HL measurement has been seldom addressed and adult HL measurement has remained conceptually inconsistent. With the generation of an expert-led measurement framework, this study provides a stable platform for HL measurement in the general public, demonstrating important areas to consider for future HL research designs. By outlining important HL model components and previously dismissed proxy aspects, this Delphi study contributes to a more well-rounded overview of HL needs for adult and child community research moving forward.

The initial Delphi round provided an important centralisation opportunity for the many direct and proxy HL outcome perspectives in circulation, using mechanisms to elicit scholarly literature recommendations to experts across each HL context, while enabling additional feedback for items not considered. The second Delphi round provided an opportunity for experts to rate items generated from the first round which were attained from open feedback per each context. The final round subsequently provided an opportunity for the panel to retrieve feedback on their ratings provided. From here, experts were provided with a final opportunity to adjust their rating for each item achieving the threshold for inclusion. Through this process, an expert-led HL measurement framework was generated, informed by model and non-model based perspectives for adult and child community populations. The end product is a framework generated through expert consensus, which may be used to inform HL researchers which items to consider when measuring community adult and child HL research. Researchers can subsequently view the framework at their convenience and understand important HL outcomes which can be used across a range of community population study designs.

The Process of Developing Adult Health Literacy Consensus

Adult HL measurement has been a consistent point of debate since the conceptualisation of HL. As mentioned previously (see Chapter 1, sub-section *historical roots of health literacy*), early interpretations of HL were functionally-oriented (AMA, 1999), and ensuing debate as to the multidimensionality of HL led to varying conceptualisations and subsequent measurement perspectives in circulation. Evidence suggesting this also noted that a handful of conceptualisations are more frequently considered than the myriad of interpretations in circulation (Malloy-Weir et al., 2016). Given that the majority of conceptualisations were developed with adult HL in mind, attaining direct adult HL consensus appeared immediately feasible from concept development. This was primarily a consequence of the evidence-base indicating some consensus already existed. The refinement of existing interpretations of direct adult HL subsequently appeared plausible, and initial round design transpired. In line with this view, attaining the direct adult HL items to posit to HL experts was achieved through the implementation of recent scoping review findings.

The scoping review provided an array of community HL measurement practices for use in adults, identifying the Nutbeam model of HL (Nutbeam, 2000), the Zarcadoolas et al expanded model of HL (Zarcadoolas et al., 2005), the knowledge-attitude-practice model (Liu et al., 2018), the structural model of HL (Soellner et al., 2017) and applied systems theory (Zhuang et al., 2016) as common model guides in circulation (Sawyers et al., 2022). These were subsequently presented to HL experts in the initial Delphi round. Given that a range of HL models were unexpectedly not retrieved from the initial review (Baker, 2006; Chin et al., 2011; Sørensen et al., 2012), open-ended response options were provided during the initial round for experts to add additional outcomes important for HL measurement not retrieved from the initial review.

This process enabled a holistic synthesis of perspectives on measures identified through two sources: the HL literature and experts' perspectives. Mirroring this, the same approach was taken across the adult proxy HL context, which provided a broad overview of adjunctive HL outcomes used alongside direct HL outcomes. This is seldom discussed in the field, and HL measurement conversations have frequently converged on model-based dimensions in contemporary research (Abel & McQueen, 2020; Maragno et al., 2019; Rowlands et al., 2013). For proxy HL outcomes, the scoping review yielded an array of proxy HL outcomes which were presented to the Delphi panel in the opening round, with the panel having the opportunity to list additional proxy HL outcomes once more. These initial round designs provided a multi-tiered approach to the generation of initial HL-relevant items for inclusion into a guiding framework, taking into consideration the wider literature and expert perspectives to formulate a foundation for future measurement consensus across community adult population research. This in-turn enabled a less biased consensus building Delphi process on a subject matter with divergent perspectives, limiting the scope for researcher bias, which can be present during Delphi study designs (Hasson, Keeney, & McKenna, 2000). Acknowledging the presence of such bias enabled a triangulated approach to generating the initial Delphi items. In doing so, a more credible account of important adult HL items at the direct and proxy level could be achieved.

Adult Health Literacy Measurement: The Findings

In reference to round 1, more items were excluded (direct n = 10; proxy n = 14) than included (direct n = 6; proxy n = 8) for the adult HL measurement contexts. Communicative HL being the highest regarded direct HL outcome with minimal deviance reflects the multidimensional nature of HL. As a construct, HL is no longer viewed as a unidimensional applied literacy assessment, with recent tools including an array of direct HL domains, like communicative HL, in conjunction (Lee, Lee, Lee, Nam & Kim, 2018; Liu et al., 2018; Zegers et al., 2020). Other direct HL items only just achieved the threshold for inclusion, with panel responses demonstrating greater deviations in individual ratings, like practical knowledge. Members of the Delphi panel held a preference for items extracted from certain models of HL, with the Nutbeam model domains (Nutbeam, 2000) surpassing the threshold for inclusion into round 3 and the Zarcadoolas expanded model all excluded in round 1 (Zarcadoolas et al., 2005). Items from alternative models were also dropped during round 1, with items reflecting the structural model of HL (Soellner et al., 2017) not achieving the threshold for inclusion into round 2. The identification of Nutbeam direct HL components as most important for measuring adult HL may be a consequence of these dimensions being prevalent across many frequently used HL instruments (Chinn & McCarthy, 2013; Ishikawa, Takeuchi, & Yano, 2008; Osborne et al., 2013; Weiss et al., 2005; Zegers et al., 2020). Experts active in the field may therefore perceive the most appropriate adult direct HL measurement practices as those reflecting contemporary approaches.

The adult proxy context in round 1, however, reflected a novel take in the field, indicating healthcare navigation self-efficacy, perceived control over health decisions, and general self-efficacy as the most important considerations from the review items. Health-related quality of life, an item frequently associated with HL research (Jayasinghe et al., 2016; Khaleghi et al., 2019), tethered the inclusion-exclusion parameter, and a broad range of items were excluded. Standard deviations were greater in the items excluded (patient activation, intent to search for health information, and English proficiency), and may be a consequence of limited prior discussions in the literature around proxy HL components when compared with direct HL measures. Anthropometric assessments like weight and blood pressure were strong cases for exclusion, with the lowest mean scores of any items rated during the Delphi process. This may be due to the items being deemed inappropriate for community population HL assessments, in addition to the lack of probing into underlying cognitive processes and experiences around health information management. More well-regarded items, such as those considering health decisions and confidence, may be more attuned to assessing these elements, and subsequently be rated higher by the experts.

An array of novel items were generated in round 1 by the panel for adult direct (n = 11) and adult proxy HL (n = 15), with digital HL being the most prevalent response (n = 5). When these items were further collated and rated in round 2, many of the panel-generated HL items achieved the threshold for inclusion into round 3 (direct n = 8, proxy n = 9). The most well-regarded round 2 direct HL item was information appraisal, which reflects the Delphi panel's perspectives on critical HL in round 1 and the perceived importance of information appraisal in the literature more broadly (Diviani, 2019). In contrast, health beliefs was identified as the least important expert-generated item, and was excluded from further investigation. Given prior evidence suggesting a potential relationship between HL and health beliefs (Soones et al., 2017), this was an unexpected exclusion. However, experts nevertheless prioritised alternative adult direct HL measures as more important, indicating health beliefs as either less important or better suited as a proxy measure of HL.

From a proxy HL perspective, experts identified a person's ability to ask questions, seek new information, and decision-making relative to their health goals as the most important adult proxy HL attributes. This echoes the recent drive across the field to further develop measurement practices to evaluate a person's abilities as they relate to a common conception of HL – to find, understand, use, and communicate health information (Champlin, Mackert, Glowacki & Donovan, 2017). When the inverse is considered, proxy HL items identified as least important were primarily targeting specific areas of knowledge or health behaviours, including food safety skills, physical activity levels and drug knowledge, rather than HL-oriented abilities that are usable across multiple contexts. Though these findings indicate context-limiting measures were less favoured by the expert panel, and falls in line with recent suggestions to prioritise transferable skills development within HL interventions (Nutbeam & Lloyd, 2021), the findings are not indicative of an exclusion towards context-specific proxy HL measures. One such item, the HL of institutions and organisations, was also regarded as an important proxy HL adult measure by experts, which also supports the Healthy People 2030 view (Santana et al., 2021) and encompasses both individual and organisation-specific proxy HL measures throughout the process. This came despite the Delphi study focusing on community population HL, positioning proxy HL value on transferable skills for health information and context-specific considerations.

On the investigation of panel perspectives around the sufficiency of current HL instruments for community adult HL measurement in round 2, the majority of panel members responded stating that existing instruments are insufficient. A common justification for this view pertained to current HL instruments focusing on individual HL, with many assessments omitting environmental HL. Other views discussed existing tools as too unreliable, outlining their dependence on self-efficacy or their development for research, rather than practice, purposes as contributory factors. Though HL measures do exist for clinical purposes (Dumenci et al., 2014; Sand-Jecklin & Coyle, 2014), they often consider communicative HL and seldom consider prose, numeracy, and critical HL (Duell, Wright, Renzaho, & Bhattacharya, 2015), and their poorly optimised nature may explain the reliability concerns identified here. For HL instruments which do assess a myriad of components, a defining limitation is their dependence on self-efficacy. This falls back to the previous discussion around objective and subjective HL, where objective HL measures provide more rigorous findings with limited scope, but subjective HL tools provide broader reach at the cost of reliability. Recent findings suggest objective HL has greater potential to prevent individuals becoming susceptible to health misinformation (Schulz et al., 2021). Taking this into consideration, panel suggestions of self-efficacy limiting the efficacy of HL instruments may reflect ongoing limitations of subjective HL instruments, which tend to be the more well-regarded, all-encompassing measures in circulation. Other participants did, however, believe some HL instruments were useful for assessing HL in adults, but may be limited to Western and high-income contexts.

These perspectives represent various long-standing concerns in the field, and in recent years there has been work conducted to address these barriers. A range of HL instruments have been conducted through adaptations of common HL assessments across several Eastern and low-income countries (Nair, Satish, Sreedharan & Ibrahim, 2016; Nakayama et al., 2015; Zhang et al., 2016), and though more HL research is conducted in Western and high-income countries (Qi et al., 2021), progress is being made. On the view that greater focus is placed on individual HL, HL stems from a focus towards the individual, and as a consequence has previously focused on the person predominantly. In recent times, however, greater attention has been placed on the development of instruments to consider environmental HL influences, including organisational HL (Trezona et al., 2020; Trezona et al., 2018), though there remains a stark contrast in preference for individual HL assessments, and antecedents to a person's HL are seldom pondered. Through an expert lens, a range of ongoing HL assessment considerations were identified for adult HL in round 2.

The final items generated from feedback in round 3 remained similar to previous rounds, with information use, information appraisal and communicative HL identified as the most important direct adult HL outcomes (n = 12). From the items excluded (n = 2), public health advocacy and engagement and practical knowledge yielded the lowest adult direct HL mean responses. Adult proxy HL considerations (n = 12) were retained from prior rounds, with seek new information, make decisions relative to one's own health, and the ability to ask questions all attributed to be the most important proxy components. The evidence from round 3 thus echoes prior sentiments from round 2, as items focusing on the ability to identify and utilise health information were viewed as more important in community adults.

The generation of a final HL measurement framework for community adult populations therefore reflects general trends within the contemporary literature. Items identified by experts typically related directly to a contemporary definition of HL from both an individual and systems perspective: to obtain and translate knowledge and information to maintain and improve health (Liu et al., 2020). These clear preferences nevertheless emerged across the framework generated, and the final framework yields measurement indicators from a direct and proxy perspective which fall in line with a multidimensional, ability-oriented conceptualisation.

The Process of Developing Child Health Literacy Consensus

Though discourse on inconsistency in HL measurement in adults has long been present in the field (Berkman et al., 2010; Haun, Luther, Dodd, & Donaldson, 2012), only in recent years has child HL measurement become a focal point for discussion (Lane & Aldoory, 2019). As a consequence, child HL has become a grey area, particularly from a conceptualisation and subsequent measurement perspective. From a recent systematic review of available definitions and models of children and young people's HL, a surprising number were identified. However, many are considered from a developmental and cognitive perspective, excluding important child and youth needs, susceptibilities and social elements (Bröder et al., 2017). Though instruments have recently been made available for the assessment of child HL and have been recommended for use (Guo et al., 2018), evidence suggests a need for conceptual clarity within child HL instruments and the development of a more standardised approach (Okan et al., 2018). In recent years, notable disagreement around the assessment of child HL has emerged, and given that the conceptual clarity of child HL has been largely unclear, these issues formed the rationale for considering child direct HL in the Delphi design. Through this approach, the Delphi study could inform the standardisation of child HL measurement practices at the direct level; an important and currently unmet consideration across the field.

Child proxy HL was also considered in the Delphi process to provide a holistic overview of a subject area which has only recently been considered. Evidence around best practice proxy HL measurement is minimal in children, with association studies providing a rough indication as to variables closely linked with child HL which may be appropriate (Fretian et al., 2020; Ran et al., 2018). This Delphi study subsequently synthesised child HL perspectives from both a direct a proxy perspective, with the aim of providing a well-rounded view of child HL measurement. Two child HL contexts were therefore formed, allowing for perspectives to be generated which were broader than current those currently present in the scholarly literature. This, in-turn, provided a broad pool of proxy measurement items for the development of a standardised, and conceptually clear, approach to child HL measurement.

Child Health Literacy Measurement: The Findings

During round 1, an array of exclusions were made to the child direct (n = 10) and child proxy (n = 17) contexts, with only a subset of outcomes surpassing the criteria for inclusion (direct n = 6; proxy n = 5). In a similar manner to the adult direct HL findings, experts identified all three Nutbeam domains as important when measuring community child direct HL (Nutbeam, 2000). Exclusions were, however, made to the proactive approach to health item, contrasting the initial round findings for the adult direct HL context and instead favouring communication and cooperation. One explanation for this preference may be the non-autonomous and rather dependent nature of child health, hence the lack of prioritisation over proactivity-related items. However, the recent proposition regarding children as active, and critical, health practitioners (Fairbrother et al., 2016) is reflected in the child direct HL context, with all three Nutbeam dimensions noted as important (Nutbeam, 2000). Citizenship was identified as the least important indicator of child direct HL by experts in the initial round. Children are not frequently involved in or exposed to information regarding their citizenship which may relate to their health at a young age, and this may explain the item being eliminated in the initial round.

A small number of child proxy HL items achieved the threshold for inclusion, with self-efficacy rated as the most important consideration. Self-efficacy has been identified as a key indicator of a range of healthy lifestyle behaviours (Bektas, Kudubeş, Ayar & Bektas, 2021), and is associated with HL scores across both adult and child populations previously (Dominick, Dunsiger, Pekmezi & Marcus, 2013; Fretian et al., 2020). Given experts likely being familiar with the literature, this may have influenced their valuation of self-efficacy as an important child proxy item. Anthropometric items were poorly regarded, and strong cases for exclusions. Research-specific participant experience items were deemed not important, which may be due to these outcomes not employing the underlying skill-based mechanisms forming a person's HL.

When offered the opportunity to generate additional items, a range of child direct (n = 11) and proxy (n = 7) HL outcomes were generated from round 1 by the panel and reviewed in round 2. Information appraisal, information seeking, and information use were viewed as the most important child direct HL items from those proposed by the panel experts, once more reflecting a similar item composition identified in the adult direct HL context. These views further support the notion that experts value children as active health practitioners (Fairbrother et al., 2016), as their high regard for information management skills in children suggests active cognitive and literacy involvement. Child direct exclusions like self-belief were viewed as less important than self-efficacy and empowerment attributes. Unexpectedly, channels of information was excluded, which refers to how circles of influence impact a child's HL, particularly given the recently emerging view to consider HL from an environmental perspective (Jafari, Sany, & Peyman, 2021). In equal fashion, another environmental child HL consideration was excluded from the child proxy context during round 2, with the child's position relative to disempowering or overprotective members of society less valued than other items. The child proxy items determined as most important were the same in the adult direct context during round 2, with both of the highest rated items reflecting skills to attain health information (ability to seek new information; ability to ask questions). Experts within the Delphi panel appeared to prefer skill-based HL outcomes for the adult and child proxy contexts, providing insight into the potential applications of proxy HL outcomes by round 2.

When questioned around current HL instruments, the panel generally agreed that current HL instruments are insufficient for measuring community child HL at 10-13 years. Evidence in recent years suggests child HL assessments lack conceptual clarity (Okan et al., 2018) and methodological study rigour (Guo et al., 2018), with a range of disagreements on the measurement of child HL being prevalent (Driessnack et al., 2014; Howe et al., 2019; Howe et al., 2018; Weiss, 2019). Further elaborations on the insufficiency of child HL instruments by the panel attribute the availability of instruments and inadequate conceptual scope as determinants of this, with the latter reflecting recent academic rhetoric in the field (Guo et al., 2018; Okan et al., 2018). Though not all experts believed this, with one expert perceiving current child HL instruments as sufficient, and referring to said sufficiency as dependent on the HL conceptualisation being followed. Nevertheless, the benefit of a standardised child HL measurement framework is evident, as identified model components forming child HL can be established and provide a more universal conceptualisation to guide measurement moving forward.

The third Delphi round yielded similar child HL findings to the previous rounds, with child direct HL considering all three Nutbeam domains of HL (Nutbeam, 2000), and communicative HL valued as the most important component overall. Recent COVID-19 discussions highlight child communication strategies as essential for addressing their HL needs (Bray et al., 2021), and as such the Delphi panel may have placed greater emphasis on communicative features when measuring child HL. Other items generated in round 2 remained, with information appraisal, seeking and use all equally viewed as important items to measure in children at the direct level, supporting the active nature of children in reference to health information (Fairbrother et al., 2016). From a proxy perspective, child HL skills relating to attaining health information, like the ability to seek new information and ability to ask questions, were once more considered the most important proxy measurement items. High value was subsequently placed on information-gathering behaviours in reference to child HL measurement in the general population. No items were excluded across both child direct and proxy contexts, suggesting consensus on the proxy HL items forming the final child HL framework were primarily identified in round 2.

The final framework condensed the direct and proxy child HL items agreed upon into a clear overview of HL outcomes identified by experts as important for the measurement of community child (10-13 years) HL. This provides the first international consensus-generated structure of components important for the assessment of child HL, with direct HL reflecting a preference for the Nutbeam model of HL (Nutbeam, 2000) and a range of applied settings, and proxy HL valuing a myriad of cognitive, behavioural, general and skill-specific outcomes to consider for future community child HL measurement scenarios. The framework identifies a range of access, interpretation, appraisal, and engagement skills from an individual and environment-specific viewpoint, falling in line with recent indications to consider child HL from a more sociological perspective (Bröder et al., 2019). The broad scope of outcomes comprising the framework reflects the narrative that children are active health practitioners, and should not be viewed as passive recipients of health information. As a consequence, the portion of the framework for child HL corroborates the view that children actively engage with health information, while providing novel insight into important HL outcomes to consider in future HL research using community child populations.

Study Implications and Limitations

This study provides the first expert consensus on important items to consider when measuring community adult and child HL. The collaborative development of a HL measurement framework yields an initial structure to a field frequently marred with inconsistent measurement practices (Liu et al., 2018). While the framework provides clarity on the myriad models and proxy HL indicators to consider in community adult populations, initial insight into the components to consider from a direct and proxy perspective are presented for community child HL. Though prior attempts have been largely built through the perspective of a subset of researcher perspectives (Bröder et al., 2019), this study presents a view gathered from a diverse panel of HL experts, and may provide the foundations for future child HL assessments. Future researchers are subsequently encouraged to use the HL measurement framework presented herein (see Figure 15) to guide the study design phase of adult and child community HL research including, but not being limited to, cross-sectional, intervention, retrospective, prospective, and qualitative approaches.

There are, however, some important limitations to acknowledge. Mainly, this study did not explore the situational influences which may alter the importance of measuring direct and proxy HL outcomes across adult and child community populations. Though this was an interest at the study conceptualisation (see Appendix 7), the round was removed for pragmatic reasons, such as in ensuring the number of rounds did not dissuade experts from participating across the full process. Another limitation rests in the community populations studied, where adolescent HL was not considered. Adolescents pass through numerous biological, psychological, and social development stages, where normative and maladaptive health behaviours can be developed which may impact the life course (Peralta, Rowling, Samdal, Hipkins, & Dudley, 2017). Given the substantive changes during this time, HL dimensions viewed as important may differ in community adolescents when compared with adults and children. As such, researchers are encouraged to add to this framework and provide a direct and proxy overview of community adolescent HL needs. Lastly, experts forming the panel were predominantly from Europe, North America, and Australia, and community adult and child cross-cultural HL values may have been missed beyond these regions.

Nevertheless, an important step in the form of the HL measurement framework has been taken, within which researchers are encouraged to use to guide intervention development, population assessments, and broader community adult and child HL work. Researchers are also recommended to iteratively review and add to, or adjust, the HL framework to improve upon the limitations of this study. By providing a HL measurement framework and iteratively adjusting as appropriate, more consistent and comparable HL research can be conducted, increasing progression in the field and improving public health outcomes as a consequence.

Conclusion

Understanding the measurement of HL has been of interest since the conceptualisation of HL. Though the primary focus has been on adult HL, neither adult or child HL conceptualisations have been considered separately, nor have they achieved consistency of measurement. The Delphi study herein provides a unique, independent overview of adult and child HL, as guided by expert consensus rather than researcher-generated narrative – a common practice to date (Nutbeam, 2000; Zarcadoolas et al., 2005). The study presented herein subsequently supports the second aim of this thesis: to clarify the conceptual nature of HL in community adult and child populations. Developing a measurement perspective guided by a select few scholars provides little to this aim, as disagreement and alternative proposals will be made from a range of individual narratives. With the approach detailed so far, the HL measurement framework supports a well-rounded scholarly discourse and end product, consequently providing the first conceptual mapping of child HL at the direct and proxy level, and a clarified view of adult direct HL with novel proxy insight.

Chapter 3 subsequently presents a consensus-driven process for achieving clarity on adult and child HL measurement practices in the general community. The second objective, ***to determine expert-led consensus around the HL outcomes important to consider at the direct and proxy level for adult and child community populations***, has therefore been achieved. Though adult HL has demonstrated feasible measurement practices in recent years with the items forming the framework, child HL has been assessed less frequently, particularly with the items retrieved from the Delphi study. In order to verify the feasibility of the framework for guiding child HL measurement practices, the final study Chapter will attempt to identify the feasibility of measuring child HL as guided by the framework developed so far.

Study Highlights

- HL suffers from inconsistent and polarising measurement practices, particularly at the proxy level.
- A three-round Delphi process was employed across adult direct, adult proxy, child direct, and child proxy HL to develop a measurement framework clarifying community HL measurement practices.
- A HL measurement framework was produced, predominantly encompassing the three Nutbeam (2000) dimensions of HL for adult and child populations, and a broad scope of information gathering, retrieval, perspective-driven, cue-based, evaluation, and context-specific proxy HL outcomes.
- Future study design and health policy may benefit from the framework to identify HL areas of interest for studies and policy initiatives centred around community adult and child populations.

Chapter 4 – The Third Study: A Child HL Pilot Test

Introduction

The development of a framework to guide measurement practices has led to conceptual clarity for numerous under-represented fields, including mental health help-seeking (Rickwood & Thomas, 2012), community health worker performance (Agarwal et al., 2019) and e-health programme evaluations (Khoja, Durrani, Scott, Sajwani, & Piryani, 2013). Measurement frameworks typically follow principles from implementation science, and seek to implement innovations into contemporary practice (Moullin, Sabater-Hernández, Fernandez-Llimos, & Benrimoj, 2015). The development of conceptual frameworks may thus inform theoretical and empirical discussion, support the interpretation of evidence, and guide study design for the topic (Moullin et al., 2020).

Producing a HL measurement framework (see Figure 15) provides an important foundational stage for improving community adult and child HL practices. Importantly, implementation science recommendations suggest evaluating frameworks to advance knowledge exchange and aid successful implementation (Moullin et al., 2020). Though an evaluation of the full HL measurement framework requires resources beyond the scope of this thesis, an initial pilot evaluation of the feasibility of part of the framework may be both practical and beneficial for the field as a whole. Testing the HL framework provides an opportunity to assess the need for adjustments to the framework, having been implemented previously to refine health research methods (Pearson et al., 2020).

While evaluating the framework through implementation science guidelines is important, providing an initial, practical pilot assessment of the framework is equally important, particularly when both can be done in parallel. Though an initial pilot assessment would benefit both adult and child community populations, assessments do exist for adult HL (Bostock & Steptoe, 2012; Protheroe et al., 2017), with various HL instrument research conducted in the last few decades (Haun et al., 2014; Mancuso, 2009; O' Neill, Gonçalves, Ricci-Cabello, Ziebland, & Valderas, 2014). When compared with community child HL, the evidence base has only developed in recent years, with the literature primarily exploring instruments in circulation (Guo et al., 2018; Okan et al., 2018) and general recommendations to prioritise child HL development (Fairbrother et al., 2016; Otten, Kemp, Spencer, & Nash, 2022).

Testing the effectiveness of the framework in guiding community child HL measurement was thus considered as the primary focus via a pilot study. In doing this, an opportunity also exists to verify whether measuring the proxy HL outcomes forming the framework in community children was possible. As discussed previously (see Chapter 1; sub-section d*eviation in health literacy measurement*), the existence of proxy HL outcomes has been predominantly determined by research aiming to verify the interrelatedness of constructs with HL (Duplaga & Grysztar, 2021; Riiser et al., 2020; Sukys, Trinkuniene, & Tilindiene, 2019). With the HL framework, the outcomes have been identified through expert consensus. Given that the credibility of various HL instruments are unclear due to poor methodological quality or conceptual clarity (Guo et al., 2018; Okan et al., 2018), a pilot study may be appropriate to guide the measurement of direct and proxy HL and gauge the practicality of measuring child HL with available instruments measuring the dimensions. By doing this, the pilot study can both provide an initial view of child HL in England, while identifying HL dimensions where no appropriate instruments exist in community children. To summarise, the benefits of assessing the HL framework with a pilot assessment are centred around the identification of adjustments to the framework (Pearson et al., 2020). The findings may support a refinement of instruments used to assess components of the framework, and also provide practical insight into measuring child HL. In-turn, child community populations benefit from potential developments to the measurement of HL, which may also lead to discussions and developments to community adult HL.

In line with this, Chapter 4 seeks to address the second aim of this thesis: **To gather preliminary data on the state of child HL in England.** Given that feasibility testing is an important component for gathering a well-rounded overview of population suitability for existing assessments, the primary objective for Chapter 4 is **to pilot-test a child HL assessment in England.** In line with suggestions from the HL framework produced in Chapter 3, all direct HL dimensions – functional, communicative, and critical – will be assessed in 10-13 year old children. To test the feasibility of conducting proxy HL assessments in children, self-efficacy and health behaviours will be measured. As suggested through Social Cognitive Theory (SCT), self-efficacy – which refers to a person's judgement of their ability to execute an action – is a predictor of healthy behaviours (Sebastian, Rajkumar, Tejaswini, Lakshmi, & Romate, 2021). Given that literature indications (Guntzviller, King, Jensen, & Davis, 2017; Osborn, Cavanaugh, Wallston, & Rothman, 2010) and expert input on the Delphi study infer interrelatedness between self-efficacy and HL, understanding the feasibility of self-efficacy and HL assessments in community child populations is important. In doing so, a more well-rounded view of using self-efficacy as a proxy HL consideration will be provided – which forms a key component of the proxy branch forming the HL framework.

Furthermore, the pilot study provides an opportunity to assess the potential relationship between both deprivation and child health behaviours with HL scores. Deprivation scores can be calculated through postcode data, and have previously demonstrated a link with adult HL (Rowlands et al., 2015; Schaeffer et al., 2021; Vogt, Schaeffer, Messer, Berens, & Hurrelmann, 2018). Identifying whether this exists across child populations is important, as deprivation scores may be an important determinant of child HL in England. Assessing this in children provides knowledge of a potential marker in deprivation scores for HL concerns in children, allowing for the development of appropriate interventions and general initiatives to promote child health in the future. The same principle forms the rationale for identifying the potential relationship between health behaviours and HL in children. A number of associations have been presented between adult HL scores and their health behaviours (Friis, Vind, Simmons, & Maindal, 2016; Rueda-Medina et al., 2020; Vozikis, Drivas, & Milioris, 2014), however there remains minimal evidence on child HL in England relative to their health behaviours. For these reasons, deprivation scores and health behaviours were also measured alongside self-efficacy, child HL scores and general demographics.

Given that pilot studies focus on the evaluation of feasibility, recruitment, retention, study assessments, broader research implementation, and do not test hypotheses or yield effect size estimates (Leon, Davis, & Kraemer, 2011), no hypothesis was proposed for this study.

Methods

The survey methodology

Several observational methods were considered in the development of the child HL assessment, but before a specific study design was considered, the decision was made to implement a pilot study approach. A pilot study falls under the same defining criteria as a feasibility study, with both intending to ascertain whether a study should be done in an area, how this should be carried out, and whether there is value in proceeding with the research. The primary difference relates to the specific design of pilot studies compared with feasibility studies, with a pilot study utilising a future study, or part of a future study, with a smaller scale methodology (NIHR, 2023). Previously, literature suggestions indicate the term feasibility as an overarching term for preliminary studies (Whitehead, Sully, & Campbell, 2014), suggesting a pilot study can be viewed as a form of feasibility testing. Furthermore, given the lack of available evidence regarding community child HL assessments in England, and the various challenges of conducting research in school settings (Alibali & Nathan, 2010), a pilot study is appropriate to understand the feasibility of conducting HL assessments in community child populations.

In doing this, an inference of the practicality of the HL measurement framework in guiding the measurement selection phase for community children can be established. Using a pilot study design also supports knowledge exchange with regards to conducting HL assessments in primary and secondary schools across England. The design subsequently allows reflection on the practicality of the HL measurement framework in community child populations and reflection on conducting HL assessments in schools, which future HL researchers using the framework may benefit from.

In terms of a specific study design for the pilot study, three study designs were considered: cohort, case-control, and cross-sectional.

Cohort studies refer to an observational study design with a sample of participants who do not have a given outcome at baseline. Participants are typically selected based on their exposure status, and are followed over a period of time to assess the presence of the outcome (Setia, 2016). Frequently used in the field of epidemiology to understand a condition, disease, change in health, life event or death, cohort studies typically use >100 participants per group, and compare two groups differing by exposure status in a retrospective (past) or prospective (future) design (Alexander, 2013). Examples of cohort study applications can be seen across epidemiological studies of alopecia areata (Harries et al., 2022), COVID-19 (Bi et al., 2020), and cardiomyopathies (Brownrigg et al., 2022). Typically taking a clinical focus, cohort studies benefit from being able to assess the impact of multiple exposure variables on multiple study outcomes across one cohort, and can be a useful aid for generating hypotheses for researchers (Euser, Zoccali, Jager, & Dekker, 2009). On the other hand, cohort studies are susceptible to loss during follow-up compared with other study designs, and can be both time-consuming and expensive to conduct (Wang & Kattan, 2020). Though cohort studies are a useful method for assessing exposures in reference to the outcome variables of interest, this study did not have any exposures of interest, and was thus not considered for the pilot study design.

Case-control studies are another observational study design, identifying participants by outcome status at the onset of the study, such as participants who have experienced a surgical complication. From here, participants are categorised as cases, and then controls – participants without the outcome from the same population – are identified. From here, data is retrospectively collected around participant exposure to risk factors, which is typically done through interview techniques, surveys, or existing data records (Song & Chung, 2010). Similarly to cohort studies, case-control studies follow a predominantly clinical perspective, with recent applications in contextual factors surrounding severe acute respiratory syndrome coronavirus 2 transmission (Leite et al., 2021) and risk factors associated with candidaemia (Keighley et al., 2021). A key strength of a case-control study design is the efficiency of statistical analysis, with less data typically used to quantify associations when compared with cohort study designs. However, it can be challenging to limit bias during the selection of controls (Gamble, 2014). Though the case-control approach may be useful to retrospectively establish correlations between exposure and outcome variables (Tenny, Kerndt, & Hoffman, 2023), this study primarily intends to provide a baseline assessment of child HL and test the feasibility of using the HL measurement framework as a guide. Other methods were thus determined to be more appropriate than a case-control study design, particularly given that this study intends to test the practical nature of measuring HL in a present-day school environment. Case-control studies are frequently retrospective, and a study design exploring a present view of conducting a HL assessment in primary and secondary schools may be more relevant to the study intent.

A cross-sectional study was the final observational study design considered, where the exposure and outcome are determined simultaneously for the sample (Pandis, 2014). Often implemented to measure the impact of health outcomes, such as depression and anxiety levels (Chen et al., 2020) and vaccine acceptance (El-Elimat, Al-Samen, Almomani, Al-Sawalha, & Alali, 2021), cross-sectional studies are typically cheap and simple to conduct, and can be a useful method for gathering preliminary findings when planning future research (Wang & Cheng, 2020). Cross-sectional studies also benefit from not having to deal with loss during any follow-up, and can be useful for generating determining the prevalence of an outcome, but can be susceptible to non-response bias and can be difficult to gauge causation due to the minimal temporal evidence generated (Sedgwick, 2014).

When combined with the time and cost-efficient nature of cross-sectional studies, in addition to being able to gather data practically and generate population outcome estimates (Levin, 2006), the cross-sectional study design was selected for the pilot study design. From a pragmatic perspective, a cost and time-efficient process enabling an initial child HL assessment was valued for the final PhD study forming this thesis, particularly given the need for flexibility in school-based research (Alibali & Nathan, 2010). Though case-control and cohort studies may provide more rigorous quantitative assessments of HL in children, it was determined to be more appropriate to utilise a cross-sectional pilot study design to meet the study aim and promote reflection with regards to the utility of the HL measurement framework and conducting child HL assessments in the school context.

Study design

A cross-sectional pilot-test study design was proposed from July to November 2022 in the East Midlands and Yorkshire regions of England. These regions were selected for pragmatic reasons, namely the presence of research team networks to support recruitment efforts being based in the East Midlands and Yorkshire regions.

Cross-sectional study designs are useful for investigating current attitudes and knowledge, in addition to understanding the applicability of different measurement instruments for given populations (Kesmodel, 2018). As mentioned previously, this study design supports an investigation towards an initial view of community child HL measurement in the context of the HL measurement framework (see Figure 15), while allowing for multiple outcomes to be assessed at the same time (Setia, 2016).

Ethics

This study was approved by the University of Nottingham's Research Ethics Committee (Reference number 018-2021).

Instruments used and survey development

The instruments used were formulated with the view of providing assessments for the most important direct and proxy HL outcomes. In doing this, future researchers can proceed with the understanding that basic requirements are accounted for when measuring important framework-identified components of child HL. Table 15 provides an overview of the instruments implemented within the cross-sectional survey.

Table 15. Instruments Incorporated into Child Health Literacy Survey

Instrument	Direct/Proxy Measure	HL Framework Domain(s) Assessed
HLAT-8	Direct HL	Functional HL, Communicative HL, Critical HL, Information use, Information seeking, Information appraisal, Ability to ask questions, Ability to seek new information.
GSE-10	Proxy HL	Self-efficacy.
Modified LQSAC	Proxy HL	Health behaviours.

Abbreviations: HL, Health Literacy; HLAT-8, Health Literacy Assessment Tool – 8 Item; GSE-10, General Self-Efficacy Scale – 10 Item; LQSAC, Lifestyle Questionnaire for School-Aged Children.

With the HL measurement framework identifying functional, communicative and critical HL as the primary model for child direct HL, assessing the feasibility of an instrument able to assess these is essential. The HLAT-8 (Abel et al., 2015) has recently been recommended for the assessment of child HL (Guo et al., 2018), but minimal evidence exists regarding its feasibility in 10-13 year old community-dwelling children outside of the school environment. Given that the HLAT-8 covers many of the core dimensions recommended for child direct HL assessments in the HL measurement framework, the tool presents an opportunity to gauge the feasibility of measuring direct HL in the context of functional, communicative, and critical domains in community child populations. Though it would be preferable to develop and validate a novel tool for measuring HL in community child populations, this is beyond the scope of the current study given the time and resource constraints of the PhD at the time of this study.

The HLAT-8 is scored from 0-37, with the higher score reflecting better HL. The pooled scores across each of the eight Likert scale responses is used to calculate the total score. A combination of five and six-point Likert scale responses are used, with each response option yielding a value to be summed for a total HL score (disagree strongly = one, disagree = two, agree = three, agree strongly = four, I do not have experience with these issues = zero).

As the two items identified as most important in the HL measurement framework were measured through the HLAT-8 (ability to ask questions; ability to seek new information), the third most important component was considered – child self-efficacy. The GSE-10 was therefore used to provide a child self-efficacy estimate. Although initial development of the GSE-10 was designed for adolescents and adults, the survey has been successfully administered across community child populations

(Haraldstad, Kvarme, Christophersen, & Helseth, 2019; Kvarme, Haraldstad, Helseth, Sørum, & Natvig, 2009; Mikkelsen et al., 2021). The GSE was initially developed for use in populations ≥12 years of age, with the instrument taking approximately 4 minutes to complete in adults and using a simple survey format. When taken with the view that the original paper provides no rationale for the omission of children under 12 (Schwarzer & Jerusalem, 1995), testing the GSE-10 in 10-13 year old children is important, particularly given the long administration times of alternative child self-efficacy instruments (Panc, Mihalcea, & Panc, 2012). The GSE-10 is scored from 10-40, with a higher score representing greater self-efficacy. Each of the 10 four-point Likert scales are individually scored according to the response (one = not at all true, two = hardly true, three = moderately true, four = exactly true), and are summed to provide a total self-efficacy score. As the GSE-10 appeared to be a time-efficient and simple instrument for assessing child self-efficacy compared with other self-efficacy instruments like the Children's Self-Efficacy Scale (Martinelli, Bartholomeu, Caliatto, & Sassi, 2009) and Elementary Student Self-Efficacy Scale (Fertman & Primack, 2009), the GSE-10 was used given the potential time constraints associated with measuring child HL in schools.

Lastly, to capture a well-rounded overview of contemporary practices and overall value for future researchers, health behaviours was measured. Health behaviours are frequently investigated in relation to public HL (Friis et al., 2016; Rueda-Medina et al., 2020; Vozikis et al., 2014), but the focus is predominantly on adults. A modified version of the LQSAC was proposed (Van Antwerp, 1995), taking the items capturing health behaviours and omitting items not relevant to health behaviours or not appropriate for 10-13 year old children. As a modified version of the LQSAC was used, and no known instructions for the LQSAC are available, the decision was taken to use a similar approach to the HLAT-8 and GSE-10. The modified LQSAC was subsequently scored from 10-40, where a higher score represents better engagement in health behaviours. A total of 10 four-point Likert scale questions were used, with each scale scored individually according to the response and then summed to represent a total health behaviours score (one = never, two = sometimes, three = usually, four = always).

All direct and proxy components were selected on the basis of perceived importance from the HL measurement framework (see Figure 15). For direct HL, information seeking, information appraisal, information use, communicative HL, functional HL and critical HL were viewed as most important in children. Given that the HLAT-8 provides an assessment of all of these, this formed the direct HL approach, with the variables condensed as total HL – comprising of all six most important direct HL outcomes from the framework. For proxy HL, although two variables were rated above self-efficacy in perceived importance (ability to ask questions; ability to seek new information), the HLAT-8 is also designed to provide an assessment of these, and as such the third-most important proxy HL item – self-efficacy – was selected. Informed health choices and health perceptions were the next successive items when ordered by proxy HL importance in children according to the framework, but the lack of assessments retrieved for informed health choices and the long administration length of the Child Health and Illness Profile (CHIP) – an assessment of child health perceptions (Forrest, Riley, Patrick, Gordon, & Starfield, 2004), led to the sixth-most important item in health behaviours being used.

A range of additional information was gathered from participants, including general demographics like child age and gender. Postcode was also requested, which was used to calculate a participants' Index of Multiple Deprivation (IMD) scores through the Ministry of Housing, Communities and Local Government's online IMD tool

(MHCLG, 2019). The tool converts postcode data into IMD scores, providing an assessment of a participant's relative deprivation in England across a range of weighted domains (income; employment; health deprivation and disability; education, skills training; crime; barriers to housing and services; living environment). The postcode data is transformed into Lower Layer Super Output Areas (LSOAs), which refer to output areas – the lowest geographical area used in census data – which are grouped together, typically ranging between 400-1,200 households (ONS, 2021). The IMD as a measure ranges from 1-32,844, with the numbers referring to the number of LSOAs nationally. The data is then divided into deciles, with decile 1 denoting the 10% most deprived LSOAs, and decile 10 representing the least deprived 10% of LSOAs (NHS). Deprivation has shared various associations with HL, including financial deprivation (Schaeffer et al., 2021; Vogt et al., 2018) to more general socioeconomic deprivation (Rowlands et al., 2015). However, this has predominantly been explored relative to adult HL, and not child HL. Postcode data was subsequently sought in addition to general participant demographics from parents of participating children.

To better understand child stakeholder perspectives for any future HL-tailored education intervention content, an open-ended question on health learning was incorporated into the survey. The question asked children what they would like to learn regarding their health (see Appendix 19, question 11).

Qualtrics survey software (Provo, Utah; Version: July-November 2022) was used to develop and manage the survey, given the breadth of customisation and dissemination options, in addition to its demonstrated use in adult and child health research (Badr et al., 2020; Caldwell & Melton, 2020). The survey structure was comprised of two participant-defined sections: a parent-specific and a child-specific section. The parent section comprised the initial two pages of the survey, with the first page comprising general study information and both adult and child participant information sheets and consent, and the second page including parent-reported age, gender and postcode information (demographics). The child section included five pages: child consent; HL assessment (HLAT-8); self-efficacy (GSE-10); health behaviours (LQSAC); and health learning.

Sample and recruitment

A combination of convenience and snowball sampling was used to recruit parent-child dyads to participate in the survey. Given the time and resource-sensitive nature of this pilot-test, alongside the non-random focus on community child populations, only non-probability sampling methods were considered.

Convenience sampling refers to selecting a sample of participants based on their accessibility to the researcher, and is frequently used in pilot-test studies given the time-efficient and inexpensive nature of the approach (Bhardwaj, 2019). Though external validity is typically limited in convenience sampling (Andrade, 2021), the pilot nature of this study means the intent is not to generalise the findings of the study beyond the specific design proposed. Convenience sampling was thus employed to maximise recruitment across a short period of time.

Snowball sampling first involves identifying participants matching the eligibility criteria for the study. These participants are then approached to participate in the study and further asked to recommend other potentially relevant participants who meet the criteria for inclusion (Bhattacherjee, 2012). The process subsequently continues via a continuing referral process, eliciting a “snowball” effect of rolling recruitment (Kirchherr & Charles, 2018). Given the potential to network effectively and provide a flexible option for recruitment, snowball sampling benefits in being able to access difficult-to-reach populations, but can be susceptible to similar flaws to convenience sampling, like selection bias and subsequent external validity problems (Parker, Scott, & Geddes, 2019). Given the difficulty of accessing child populations for research, particularly in school contexts where access to appropriate contacts can be challenging (Simpson, 2019), snowball sampling was also employed to maximise recruitment efforts in a difficult to reach population.

Other non-probability sampling methods like quota sampling – referring to the process where specific population characteristics are represented to a pre-determined level (Acharya, Prakash, Saxena, & Nigam, 2013) – were also considered. Though quota sampling supports a simplified data stratification process, larger samples are typically required given the need to stratify the sample according to various characteristics, and similar issues with external validity also exist given the non-random process (Sharma, 2017). For these reasons, in addition to the pilot study prioritising access to participants over an equal distribution of characteristics, convenience and snowball sampling were preferred to quota sampling.

The following inclusion criteria was proposed:

1. Children are aged 10-13 years old.
2. Both the child and their parent/guardian/caregiver provide consent to participate.

Children participate in various health-related decision from a young age (Borzekowski, 2009), and additionally have been reported to engage in self-medicating behaviours around the sample age range proposed (Abel, Johnson, Waller, Abdalla, & Goldsmith, 2012; Abraham, Feathers, Mook, & Korenoski, 2019). Understanding the HL of an underrepresented population which engage in potentially detrimental health decisions is thus imperative, and ascertaining the feasibility of such an assessment is also a priority.

A two-step process was conducted to maximise recruitment efforts. Firstly, a range of school trusts comprising of both primary and secondary schools were approached via telephone and email for their support with recruiting eligible participants through their schools. Various primary schools were also individually approached via telephone and email to ask for their support with the project. All school trusts and primary schools were based in either Yorkshire or the East Midlands, and both public and private schools were identified and approached to participate.

Secondly, social media and word-of-mouth approaches were employed simultaneously to maximise recruitment opportunities. Study adverts were placed on Facebook through the researcher's personal page, and set to share to the public. Additional study adverts were placed on Twitter, LinkedIn, and Mumsnet via the lead researcher's personal and professional accounts. On Twitter, a range of HL-relevant organisations and study pages were also contacted to disseminate a brief study advert relating to the project, and special interest groups like Health Literacy UK were also contacted to disseminate study adverts (see Appendices 12 and 13) and aid the recruitment process. The following Outlook email groups were also used to disseminate study adverts to potentially relevant participants:

1. University of Nottingham School of Pharmacy Staff and Postgraduate Researcher Group.
2. University of Nottingham School of Health Sciences Staff and Postgraduate Researcher Group.

Personal networks to the lead researcher were also asked to distribute information verbally and virtually to potentially relevant participants within their personal network. No remuneration was provided to participants for their time.

Procedure

Initially, a combination of primary, secondary, and broader school trusts were approached to ask for their participation via a verbal and written invitation through email and/or over the phone (see Appendix 14). Where schools expressed an interest in participating, the gatekeeper for school participation (such as the headteacher, assistant head, senior leadership team, or appropriate member of staff) would be asked whether the school would prefer the survey to be completed through in-person or online formats completed either during or outside of class time. Participating schools would then receive the participant consent forms (see Appendix 15 for children and Appendix 16 for adults) and information sheets (see Appendix 17 for children and Appendix 18 for adults). During this time, the appropriate contact from the school would be requested to disseminate the consent forms and information sheets to parents/carers or children aged between 10-13 years old, and to explain to parents that they could return completed consent forms back to the school. The school contact would also be asked to communicate to the school to retain all signed consent forms from the parent/carer and child dyad for the researcher to collect at a later date. Where a school trust was approached, the school trust contact would be provided the same information from all appendices and requested to distribute the content to school contacts falling under the remit of the trust.

Depending on the preferred format of the school with regards to completing the survey, participating children were provided either an online or in-person survey (see Appendix 19) to complete either during or outside of school hours. The in-person survey would be distributed by teachers in a timeslot and classroom determined by the school, and would be provided as homework or as part of a class-based activity, depending on the preferred format selected. Where participants did not consent and an in-person, during school hours approach was used, the school would be provided with a health and wellness worksheet (see Appendix 20) to complete while participating children completed the study survey. In a situation where schools preferred an online format outside of schools hours, online surveys would be completed via an anonymous Qualtrics survey link disseminated by the school to parents of participating children. Parents/carers would be requested to supervise children to facilitate survey completion if the child requested further support, which would be communicated by schools when distributing the Qualtrics link. Where an online, during school hours approach was used, the Qualtrics survey would be completed on appropriate school devices during class time.

Simultaneously, an anonymous Qualtrics survey link was also disseminated across a range of personal and professional links through social media (see Appendices 12 and 13) and email (see Appendix 14). This approach followed the two-step process discussed in the *Sample and Recruitment* sub-section above. In contrast to the school survey, participants were not provided with separate consent forms and information sheets, with both of these embedded within the Qualtrics survey link on the initial page (see Appendix 19).

Participants who responded to the anonymous Qualtrics survey link were sent to the survey. Once complete, participants were thanked for their time and their participation was complete.

Analysis

Survey data collected on Qualtrics was exported to IBM SPSS for the conduct of data cleaning and descriptive statistics. The primary aim of the analysis was to provide an indication of child HL across the East Midlands and Yorkshire regions of England.

Descriptive statistics in the form of frequencies and measures of central tendency were generated for all study variables (age, gender, deprivation, HL, self-efficacy, health behaviours), with additional descriptive statistics provided for survey completion time, with the latter used as an inference of initial feasibility for children completing the HL survey instruments. Depending on whether the variable data was interval/ratio, ordinal or categorical, either the mean or median were used as measures of central tendency. The data cleaning process removed outliers and incomplete responses for survey completion time data to provide a valid estimate, as Qualtrics survey tracking considers all time inactive and can lead to extreme values not representative of actual survey completion times. Initially, histogram and boxplot charting was used to determine potential outliers, and z-score conversions were used to follow-up on potential outliers and removed when z-score data values exceeded ±3.29 (Mowbray, Fox-Wasylyshyn, & El-Masri, 2019). As the HL, self-efficacy, and health behaviour data variables were ordinal data, the median was used as is recommended when handling ordinal data (Manikandan, 2011). A higher total median score for HL, self-efficacy, and health behaviours reflects a better score.

For the individual question medians, a higher score represents more points scored on the question, and directly relates to the response option selected.

The Interquartile Range (IQR) was selected for use with HL, self-efficacy and health behaviour variables due to ordinal data being used. The IQR uses the central 50% of datasets to gather dispersion estimates, whereas the standard deviation extracts from the mean position (Mishra, Pandey, Singh, & Gupta, 2018). The IQR was therefore determined as more appropriate where Likert scale data was used, so as to provide a central point of spread relative to the scales. All quantitative analysis was conducted on IBM SPSS version 27.

An inductive thematic analysis was conducted on the open-ended text responses to the health learning question, following the six-step process outlined by Braun and Clarke (Braun & Clarke, 2006). Where data was minimal and determined to not benefit from an inductive thematic analysis, a conventional content analysis would be conducted via the 8-step process outlined by Zhang and Wildemuth (2005).

Qualitative findings were exported from Qualtrics to SPSS with the quantitative data, and then participant responses for the health learning variable (HealthLearningOpenQ) were exported to Microsoft Word for analysis.

Results

Demographics

Taken collectively, 31 primary schools and 7 school trusts (including primary and secondary schools) were approached with an invitation to support recruitment for the study, with all schools and trusts either declining the invitation or not responding. For the social media and word of mouth recruitment process, 17 parent-child dyads responded to the survey invitation, and 15 participants provided complete survey responses. Survey completion times varied when tracked by Qualtrics, with participants taking between 5 – 16 minutes to complete the survey (M = 9.34; SD = 3.37). Participant demographics were presented below (see Table 16).

Table 16. Self-Reported Demographics of Responding Children by Parents and Survey Completion Time.

Participant characteristics	**n (%)**
Age	
10 years old	4 (23.5%)
11 years old	6 (35.3%)
12 years old	1 (5.9%)
13 years old	5 (29.4%)
Total	16
Gender	
Male	7 (41.2%)
Female	9 (52.9%)
Total	16
Deprivation (IMD scores)	
10% most deprived	1 (5.9%)
10%-20%	1 (5.9%)
20%-30%	1 (5.9%)
30%-40%	1 (5.9%)
40%-50%	1 (5.9%)
50%-60%	1 (5.9%)
60%-70%	1 (5.9%)
70%-80%	2 (11.8%)
80%-90%	2 (11.8%)
10% least deprived	4 (23.5%)
Total	14

Abbreviations: SD, Standard Deviation; IMD, Index of Multiple Deprivation; n, Sample Size.

Health Literacy Findings

HL scores for individual and total HLAT-8 values were presented below (see Table 17).

Table 17. Median HL Frequencies and Scores for the Health Literacy Assessment Tool-8-Item.

Question	n	Median ± IQR
HLAT-Q1: How well do you understand instruction leaflets for medication?	14	3.00 (±4)
HLAT-Q2: How well do you understand information brochures on health issues?	14	2.00 (±3)
HLAT-Q3: When I have questions on diseases or complaints, I know where I can find information on these issues.	14	2.00 (±3)
HLAT-Q4: When I want to do something for my health without being sick, I know where I can find information on these issues.	14	2.00 (±3)
HLAT-Q5: How often were you able to help your family members or a friend if they had questions concerning health issues?	14	2.50 (±3)
HLAT-Q6: When you came up with questions concerning health issues, how often were you able to get information and advice from others (family and friends)?	14	4.00 (±2)
HLAT-Q7: How well are you doing in choosing the advices and offers that fit with you the most?	14	3.00 (±3)
HLAT-Q8: Regarding information on health on the internet, I'm able to determine which sources are of high and which of poor quality.	14	2.50 (±2)
Total HLAT score	14	17.50 (±9.25)

Abbreviations: IQR, Interquartile Range; HLAT, Health Literacy Assessment Tool; n, Sample Size.

Self-efficacy Findings

Self-efficacy scores were also partitioned by individual and total GSE-10 values, and were presented below (see Table 18).

Table 18. Median HL Frequencies and Scores for the General Self-efficacy Scale-10-Item.

Question	n	Median ± IQR
GSE-Q1: I can always manage to solve difficult problems if I try hard enough	14	3.00 (±1)
GSE-Q2: If someone opposes me, I can find the means and ways to get what I want.	14	3.00 (±1)
GSE-Q3: It is easy for me to stick to my aims and accomplish my goals.	14	3.00 (±1)
GSE-Q4: I am confident that I could deal efficiently with unexpected events.	14	3.00 (±1)
GSE-Q5: Thanks to my resourcefulness, I know how to handle unforeseen situations.	14	3.00 (±1)

GSE-Q6: I can solve most problems if I invest the necessary effort.	14	3.00 (±0)
GSE-Q7: I can remain calm when facing difficulties because I can rely on my coping abilities.	14	3.00 (±1)
GSE-Q8: When I am confronted with a problem, I can usually find several solutions.	14	3.00 (±1)
GSE-Q9: If I am in trouble, I can usually think of a solution.	14	3.00 (±0)
GSE-Q10: I can usually handle whatever comes my way.	14	3.00 (±0)
Total GSE-10 score	14	26.5 (±5)

Abbreviations: IQR, Interquartile Range; GSE-10, General Self-efficacy Scale-10 item; n, Sample Size.

Health Behaviours Findings

Lastly, health behaviour values were presented as individual and total LQSAC scores, and were presented below (see Table 19).

Table 19. Median HL Frequencies and Scores for the Modified Lifestyle Questionnaire for School-Aged Children.

Question	**n**	**Median ± IQR**
LQSAC-Q1: I get between 7-9 hours of sleep every day.	15	3.00 (±2)
LQSAC-Q2: I brush my teeth twice a day.	15	3.00 (±2)
LQSAC-Q3: I visit the dentist every year.	15	4.00 (±2)
LQSAC-Q4: I watch less than 2 hours of TV every day.	15	2.00 (±2)
LQSAC-Q5: I eat fruit every day.	15	3.00 (±1)
LQSAC-Q6: I eat vegetables every day.	15	3.00 (±2)
LQSAC-Q7: I limit my intake of salty snacks and high-sugar snacks.	15	2.00 (±1)
LQSAC-Q8: I say *"no"* to smoking cigarettes.	15	4.00 (±0)
LQSAC-Q9: I stay away from alcohol.	15	3.00 (±0)
LQSAC-Q10: I exercise regularly (1 hour per day; can include PE lessons, active play/sports, walking, cycling).	15	3.00 (±2)
Total LQSAC-10 score	15	30.00 (±6)

Abbreviations: IQR, Interquartile Range; LQSAC, Modified Lifestyle Questionnaire for School-Aged Children; n, Sample Size.

Health Learning Findings

Content analysis revealed No health learning of interest as the most frequent code referenced when children were asked about health-related areas they were interested to learn more about (n = 9; 52.94% response rate; see Table 20).

Table 20. Health Learning Frequencies Identified.

Code	**Quotes**	**n (%)**
Dermatology and skincare	*"How to take care of your skin."* *"How to stop acne?"*	2
Nutrition education	*"About different vitamins that are good for my body"*	1
Body weight	*"… And abough (about) your weight"*	1
Maintenance of good health	*"How to stay healthy"*	1
Non-specific health	*"Just to be taught what's best for our tutors rather than an old syllabus of tired "education""*	
No health learning of interest	*"Nothing"* *"Nothing"* *"I don't know"* *"I don't think so as I am quite healthy"*	4

Abbreviations: n, Sample Size.

Discussion

To date, no assessment HL exists in children going beyond functional HL. This pilot study provides the first initial view of child HL in the East Midlands and Yorkshire regions of England, and although the study hypothesis was unable to be tested given the small sample, an initial pilot study was conducted and inferences of child HL were obtained. When taken collectively, the findings provide insight into the direct HL of children across two regions of England, while also highlighting potential concerns around the frequency of engagement in sedentary behaviours and salt/sugar intake – pending a full-scale assessment to confirm this. Though the findings of this pilot study are not generalisable to the wider population due to the lack of applicable inferential statistics applied, they may provide an inference as to future follow-up findings on HL, self-efficacy, and health behaviours in 10-13 year old children.

Direct HL Inferences made from the pilot study

Child HL has seldom been assessed in England, and thus national comparisons between the pilot data and broader population cannot be made. However, when put into context with international HLAT findings, the initial pilot findings indicate notable concern around child HL from the initial sample figures. From a recent HLAT assessment conducted in Chinese school-aged children, average HL scores were substantially higher (26.34 ±5.89) than reported in this pilot study (Guo, Yu, Davis, Armstrong, & Naccarella, 2022). This may be due to the higher mean age of the sample used in the HLAT survey conducted in China (13.42 ±1.01), however this does not explain the low median reported across functional and communicative dimensions in the pilot, with Q2, Q3 and Q4 yielding the lowest median values. This is because a higher mean age overlapping with a development process of key critical skills may lead to better HL scores across the critical HL questions on the HLAT. However, as participants in the pilot survey on average scored lower on questions exploring functional and critical dimensions of HL, the higher age reported in the HLAT assessment in China may not have played a role in the greater total HL score found. This may instead be a consequence of the low sample size tested in this pilot study.

When compared with other HLAT findings with higher age ranges, similar HL values to the cross-sectional study in China were reported, being viewed as an adequate scoring of a person’s HL (Gallè et al., 2020). This provides an unclear picture of child HL, as two separate literature HLAT assessments in children and adults yield similar total HL scores, with the latter finding being scored as adequate. What can be assumed, is that the HL of children in areas of England requires further clarification from a full-scale cross-sectional study. The findings from this pilot study can be used to both inform the methodology of – and be a point of comparison – for a large scale assessment of child and adult HL in England. Given that literature suggestions infer that the HL of 10-13 year old children may be higher than the pilot study reported (Gallè et al., 2020; Guo et al., 2022), there is a need for a full-scale cross-sectional study. This pilot does, however, demonstrate practicality for measuring HL in 10-13 year old children in the East Midlands and Yorkshire regions of England through the HLAT, while acknowledging the difficulty of recruiting the sample without support from primary and secondary school networks. Pilot studies provide a methodology to explore the feasibility of study protocols, the recruitment process, and provide key descriptive statistics for sample size calculations for central study outcomes (In, 2017). By running this pilot, these key elements can be used to inform the development of a full-scale assessment to provide an effective overview of child HL moving forward. Furthermore, the pilot study acts as the first initial feasibility test of the Delphi-proposed HL measurement framework, demonstrating efficacy in measuring direct HL in the form of the HLAT-8, and proxy HL through the GSE-10 and modified LQSAC-10.

HL is a key consideration for the promotion and maintenance of good health, and the prevention of bad health. By providing the foundations for a large scale assessment of 10-13 year old HL in England, future strategies to improve child HL can be developed. Further to this, future child-centred interventions can be considered and applied on the basis of evidence generated. While this pilot study provides an overview of potential health learning areas children may provide in a full-scale study, a complete overview can provide an outline of educational areas supported by children. This can, in-turn, be used to guide future HL interventions conducted in England, enabling more child-centred designs and more meaningful child interventions as a consequence (Velardo & Drummond, 2017).

Proxy HL inferences made from the pilot study

When considering the proxy HL dimensions, this pilot study provides the first initial assessment of key components of the HL measurement framework. Though self-efficacy has frequently been assessed in adult populations (McCleary-Jones, 2011; Peters, Potter, Kelly, & Fitzpatrick, 2019), few investigations assess self-efficacy in children directly (Kulik et al., 2019; Moschovi, Kapetanakis, Sfyridis, Rammos, & Mavrikaki, 2020), with minimal exploring this in the context of their HL. Although this pilot study did not retrieve a sufficient sample size to determine a potential association between child-reported self-efficacy and their HL, the feasibility of conducting a full-scale study can be confirmed – particularly with the support of primary and secondary school networks for the recruitment process. In providing this view, a more informed view of how self-efficacy impacts a child's HL can be gained, and adjustments can be made to future interventions to enable HL improvements relative to a child's self-efficacy.

An initial assessment of the frequency of a range of child health behaviours was also provided. Although once more the association between child health behaviours and their HL could not be ascertained in this pilot, children appeared able to effectively complete the modified LQSAC component of the survey. While studies exist across England (Gireesh, Das, & Viner, 2018; Porter, Ravaghi, Hill, & Watt, 2016) and internationally (McIsaac, Kirk, & Kuhle, 2015) exploring the frequency of child engagement with varying health behaviours, these investigations typically consider health behaviours and HL as unrelated. Though this pilot does not confirm the nature of a relationship between the two variables, 10-13 year old children appeared able to effectively respond to the LQSAC portion of the survey and reply in a timely manner. While these pilot findings do not represent the population well given the limited sample and lack of inferential statistics, responses to the LQSAC here echo similar observations in recent years. For instance, sedentary behaviour has been a notable concern given the recent COVID-19 pandemic, with increasing rates of sedentary behaviour observed in children (Owen & Bould, 2021). For Q4 responses across the modified LQSAC in this pilot study, median findings indicate that, on average, children appear to watch more than two hours of television a day, suggesting active engagement in a major contributor to sedentary behaviour. Given that findings have demonstrated a consistent association between television time and higher levels of obesity in children (Coombs & Stamatakis, 2015), further investigation through a full-scale study is required to determine the need for HL interventions targeting this.

In a similar sense, responses from children in this pilot study supports recent suggestions regarding the overconsumption of salt and sugar from food in childhood (PHE, 2018; Marrero, He, Whincup, & MacGregor, 2014). A child's HL could play a key role in improving dietary habits in children, and gaining a broader overview may support positive dietary health behaviours in children and provide topic areas for future HL interventions, or alternatively act as a guiding mechanism for their implementation. Further follow-up may therefore generate health behaviour evidence to support the development of future HL interventions for school-aged children in areas of England.

Although the findings from this pilot cannot provide a true overview of child HL in reference to their self-efficacy and health behaviours, similar literature narratives have been presented previously. Most importantly, this pilot does provide an initial feasibility assessment for measuring key direct and proxy HL outcomes – as guided by the HL measurement framework from Chapter 3 – in a survey format for 10-13 year old children. A follow-up using this pilot study for guidance may therefore be appropriate to provide a comprehensive investigation into the potential association between child HL scores and proxy HL outcomes in 10-13 year old children across England.

Challenges and recommendations for a full-scale study

Pilot studies are an important pre-study process for testing and providing necessary information for feasibility purposes, yielding information on participant recruitment and consent processes, the data analysis procedure, the questionnaire relative to the study intent, and the generation of descriptive statistics used in future sample size calculations for study outcomes (Hassan, Schattner, & Mazza, 2006; In, 2017). In addition to being able to identify an estimated survey completion time for a comprehensive assessment of child HL, a gauge of data management, and insight into retrieving parent/carer and child consent, conducting a pilot gives important insight for future work in the area. Though this study provides insight into various key areas, several challenges were nevertheless identified from conducting school-based pilot research on child HL.

The primary challenge from this pilot study concerned the logistics of using primary and secondary schools in the East Midlands and Yorkshire regions of England for HL research. Pilot findings from this study were collected through snowball sampling predominantly, using word of mouth and social media approaches. The initial plan to use professional school and researcher networks was unsuccessful, with minimal communication from school administrators and headteachers achieved. Support from headteachers and administrators is a fundamental component for effective recruitment in school research, as active involvement at an early stage of the research project from key stakeholders can yield clear communication across all levels of a school system (Mishna, Muskat, & Cook, 2012) with regards to the research project. Without support from school networks or experienced researchers in education, bypassing gatekeepers to reach the intended contacts to progress the research may be challenging (Simpson, 2019). Using schools to recruit eligible participants is essential for an efficient follow-up study, as school research yields improved retention rates, increased trust from parents and carers of the children participating towards the research, and additional cost savings due to participants already being present on the site (Manohar, MacMillan, Steiner, & Arora, 2018). Though various approaches to making contact with primary and secondary schools were used, including adjustments to the initial contact email and telephone approach, challenges to recruiting school to participate were evident.

Recommendations for future follow-up studies pertain largely to the need to develop collaborations with school partners early on in the research process, frequently, and through multiple modes, as this provides consistent information and an improved understanding of how, where, and when data collection occurs (Bartlett et al., 2017). Nurturing collaborative relationships between schools across multiple levels may therefore be a prerequisite for a successful follow-up study (Mishna et al., 2012).

Another key challenge pertained to the timing of the pilot study. The recruitment phase of this pilot study commenced in the latter half of 2021, with many schools in England adjusting to recent changes across face-to-face and virtual practices. This pilot study found contacting primary and secondary schools during this time increasingly difficult, with responses via email communication across reception, wider administration and headteacher levels difficult to attain. Though there was initial promise in getting a recruitment advertisement into an East Midlands-based primary school network newsletter, communications halted from the gatekeeper and this route was unable to be actioned.

These communication challenges may be due to the wider implications of the Covid-19 pandemic on the education sector. One PhD researcher proposed that participating in research may no longer be a key priority for schools than compared with the pre-pandemic timeline (Karimi, 2021). This may relate to the increasing workload facing teachers as a consequence of the Covid-19 pandemic (Kaden, 2020), the desire of teaching staff to focus on providing additional pastoral support to children (Lundie & Law, 2020) or the added focus towards implementing and maintaining complex health policy compared to pre-pandemic education. Given the continuous impact of the Covid-19 pandemic on learning deficits across schools long after the initial pandemic (Betthäuser, Bach-Mortensen, & Engzell, 2023), follow-up research may anticipate new challenges in lieu of the Covid-19 pandemic, including difficulty maintaining connections with various school levels. Recommendations to improve the research process – relative to the impact of Covid-19 – conducted in schools may reflect those echoed from a logistics perspective, including the use of a senior researcher in education and frequent check-ins across all school channels. Additional approaches which may improve the likelihood of successful research collaborations with schools may be in minimising the work required from teachers and providing regular validation to stakeholders (Mishna et al., 2012). Maintaining flexibility in the methodology to accommodate each school is also recommended, particularly in lieu of the pandemic where systematic change required both researchers and wider education stakeholders to respond accordingly. Tailoring the research to the needs of schools is thus imperative, particularly to yield successful school collaborations.

While this pilot study highlights a number of important challenges to address in future research and provides initial data on child HL in the East Midlands and Yorkshire regions of England, there are a number of important limitations to acknowledge. Firstly, this pilot study was unable to provide an overview of the feasibility of communication with schools beyond the initial recruitment request, and was unable to provide further information regarding communicating across the school system from a project management perspective. Though there are no specific guidelines for the conduct of HL research in English schools, recommendations have been proposed to improve the research process (Bartlett et al., 2017; Mishna et al., 2012)**,** citing early communication at the project conceptualisation phase, multi-level school communication, access to education networks, and a flexible research protocol as important considerations.

Secondly, this study was not able to control for independence of completion in survey responses. Although sections of the survey were highlighted for parents or children to complete independently, the questionnaire was provided to participants via an online survey platform (Qualtrics). Additionally, given that this pilot study was unable to conduct the survey on school sites, there is no means to ascertain whether participants conformed to the survey instructions and completed the survey independently. This may skew the findings from this pilot study, potentially presenting child HL as higher than a true independent survey response may be due to assistance not being controlled for. Future researchers may wish to opt for a self-declaration element being embedded at the end of the survey to mitigate the lack of control for independence where in-person sites are not used.

In addition, while the HLAT-8, GSE-10 and LQSAC are widely used across child populations and have undergone psychometric analyses (Guo et al., 2018; Luszczynska, Scholz, & Schwarzer, 2005), they have not undergone further testing when combined. Given that, when combined, the survey technically initiates a new instrument iteration, validity and reliability has not been analysed for the population studied. This study therefore cannot ascertain the collective validity and reliability of the survey. The combining of instruments was done in the interest of time, as recruiting children can be particularly challenging and maintaining a low completion time was preferred over ensuring the surveys were completed in a separated format. As schools have varied calendar constraints and may not be flexible in the provision of research timeslots (Plummer et al., 2014), the pragmatic approach was taken to maintain a simple assessment process with a low response time and resource demands. Where future research has the resources and school networks in place to facilitate the completion of these HL instruments separately, this approach may be more psychometrically rigorous than the pragmatic approach reported here, though a pragmatic lens should always be considered when working with schools given their limited time to host research. Nevertheless, future research should consider further psychometric testing where measuring community child HL according to the HL measurement framework components herein (see Figure 15).

Lastly, this pilot study did not collect information on the feasibility of completing the survey from the perspective of participating children. This was predominantly due to the HLAT being a recognised option for measuring child HL, but this was an oversight, and further information would be able to confirm whether all survey items are appropriate for 10-13 year old children from a perceived feasibility angle.

Nevertheless, though a number of limitations and challenges exist for a full-scale assessment of child HL via schools in England, this pilot study provides key recommendations for future follow-ups, and an estimation of survey completion time for children – the latter in which was brief, being rounded up to 10 minutes. When taken collectively, the findings from this pilot study inform an important future research project following on from this study. Child HL needs are investigated scarcely in the present tense, and providing a full assessment view of their HL is essential given that children are undergoing a transition towards health autonomy.

As described above, the findings from this study provide important information for future child HL research. The information gathered from the HL assessment conducted in children, and the study reflections and subsequent recommendations for conducting research in schools, can be used to inform the development of future studies of HL in children. The recommendations for school recruitment can be considered at the study conceptualisation phase and potentially improve recruitment efforts, and the initial findings may influence the implementation of cross-sectional research designs given that the assessment of multiple direct and proxy HL variables was practical herein. Important information regarding the recruitment is presented, and initial insight into the practical nature of conducting HL research in child populations is identified. As such, future studies of HL in children should consider this pilot study when conceptualising HL assessments in children.

If the pilot study recommendations presented herein are considered, future collaborations with schools in England for HL assessment research may be plausible moving forward. Given that this was identified as a major barrier to the success of a full-scale follow-up, this pilot subsequently provides transparency and guidance for future research conducted in the East Midlands and Yorkshire regions of England across schools moving forward, and insight into the practical nature of direct and proxy child HL measurement which may influence the study design of future studies guided by the HL measurement framework in their design.

Conclusion

Child HL is an essential area to investigate in England. Though this study initially was conceptualised with the presumption of support from primary and secondary schools in the East Midlands and Yorkshire, current affairs and schools not being involved at the study conceptualisation led to poor recruitment and the redesign of the study to a pilot. Nevertheless, the pilot provides insight into a number of challenges to address in a full-scale child HL assessment conducted with support from schools in England, and key recommendations for future research. Moving forward, engaging schools in the project at the conceptualisation phase and maintaining flexibility in the study protocol (Bartlett et al., 2017; Mishna et al., 2012) will be essential. In-turn, this can support the development of collaborations with schools across England and facilitate extensive recruitment efforts. Furthermore, schools provide a monitored environment for assessment completion allowing for confirmation on whether the assessment was completed independently by participants. Incorporating the recommendations to be prepared for future challenges in follow-up research is thus imperative for successfully assessing child HL.

This study addressed objective 3 of this thesis ***"to pilot-test a child HL assessment in England."***, presenting an early indication of child HL in the East Midlands and Yorkshire regions of England and providing the foundations for future research to explore the second aim of this thesis further: ***"to gather preliminary data on the state of child HL in England."***. Though the findings from this pilot study cannot be extrapolated to infer the HL of children across the East Midlands and Yorkshire, and recruitment may have been negatively impacted by COVID-19, this Chapter provides methodological clarity and key recommendations to enable further research on child HL in England, while successfully employing the HL measurement framework to guide child HL measurement.

Study Highlights

- Children engage in a range of active health decisions in daily life, but to date no assessment of child HL has been complete beyond the functional HL domain.
- A cross-sectional pilot test was conducted to determine the feasibility of measuring 10-13 year old children's HL in schools with the HL measurement framework developed previously (see Figure 15).
- The HL measurement framework guided the outcomes considered, with functional, communicative and critical HL for direct HL, and self-efficacy and health behaviours for proxy HL, alongside demographics.
- Survey responses suggest child HL survey administration length reflects practical completion times.
- The findings indicate difficulty bypassing primary and secondary school gatekeepers, though participants recruited through personal networks were able to complete all survey components.

- Future studies measuring HL in schools may benefit from collaborating with schools early on, communicating across all school channels, minimising workload for school stakeholders, and maintaining flexible protocols.

Chapter 5 – Overall Discussion and Conclusion

An Overview of the Thesis

This thesis presents three important studies. The first, in Chapter 2, views recent HL measurement as predominantly unidimensional for community HL interventions. The interventions assessing HL were focusing on functional HL mainly, and unidimensional assessments of the construct were appropriate. The review conducted in Chapter 2 raised concern around this focus, as several interventions did not consider communicative or critical HL. Moreover, few HL interventions implemented objective and subjective HL instruments, instead opting for either objective or subjective instruments in isolation. Given that a range of models guided HL measurement and no child HL interventions were synthesised (Sawyers et al., 2022), forming a Delphi panel was prioritised to achieve consensus.

Building on these views, Chapter 3 provided the central finding of this research, presenting an overview of the most important HL outcomes at the direct and proxy level for adults and children. Experts prioritised the Nutbeam model of HL for community adult and child contexts at the direct level (Nutbeam, 2000). From a proxy HL perspective, experts valued information gathering competence, cues to action, health perceptions and self-efficacy across adults and children, and highlighted context-specific HL in adults and retrieval of information in children as unique for each population. Additional clarity towards important considerations for HL research has therefore been produced (see Figure 15).

Chapter 4 presented an initial pilot-test of a HL assessment in community children. Focusing on the feasibility of conducting such an assessment, problems emerged recruiting primary and secondary schools in the East Midlands and Yorkshire, providing an opportunity to unpack methodological and wider feasibility issues associated with assessing child HL. This study provided the third key finding for this thesis, denoting several HL framework components as feasible to assess in 10-13 year old community children in, with school recruitment barriers also identified. Recommendations were presented, providing future research with support when measuring child HL in England.

The final study in Chapter 4 presents insight into a previously unfamiliar area for national research, and provides the initial structure for a successful full-scale follow-up assessment of child HL in England. Given the limited nature of the pilot, a further full-scale follow-up will be required to gain a better understanding of the feasibility of measuring child HL in England.

The implications of the findings from this thesis are varied, and Chapter 5 subsequently aims to clarify and discuss these further.

Implications from a Research Perspective

A central tenet to this thesis concerns the need for clarity regarding the measurement of HL. In providing guidance on key HL measurement considerations, several notable implications have arisen. These can be separated into two key areas: implications for the researcher, and implications for policy.

Firstly, researchers may find the process of considering HL as a variable of interest more appealing than previously. Experienced HL researchers may not require the framework, as they may have a similar perspective to the expert panel (see Chapter 3) for measuring HL in community adult and child research. Researchers with an interest in implementing a HL measure who are less familiar with the field may, however, find the HL measurement framework a useful guide to determine the outcomes important to consider. This may increase the frequency of community research featuring HL in community intervention, cross-sectional, or wider study designs, as the framework may empower researchers to measure direct and proxy outcomes and simplify the research design process. Researchers investigating HL have previously stated the measurement of HL to be inconsistent, leading to difficulty making interpretations regarding the data and problems drawing comparisons (Jordan, Osborne, & Buchbinder, 2011). A similar observation can be noted from the scoping review conducted in Chapter 2 (Sawyers et al., 2022), with many direct and proxy instruments retrieved and various outcomes tested. When considering the wider literature in reference to this thesis, researchers with an interest in considering HL as an outcome may find the HL measurement framework proposed in Chapter 3 useful.

Having a brief, visual overview of HL at the direct and proxy level informs researchers of the outcomes to consider. As such, researchers can focus on the appropriateness of the outcomes within the HL measurement framework and the instruments to assess these with. Before the development of this expert-led framework, researchers would have to make their own inferences on the direct and proxy components important for community adult and child population research, taking up time and energy, and making the study design process more challenging. Through the development of this framework, this may increase the frequency in which researchers are actively considering the concept of HL in the evaluation and study design stages; something which has been noted as an issue in recent years (Nutbeam et al., 2018). Researchers with less expertise in HL can be guided at the initial study onset, and the process of measuring community population HL may therefore be more appealing as a consequence.

The findings from this thesis may also promote a shared understanding of HL consistent with experts' perspectives, allowing a more consistent and comparable array of evidence in years to come. Circulation of the framework may also expose researchers to a multidimensional narrative of HL compared to the narrow rhetoric in decades gone (IOM, 2004), influencing the HL landscape towards a more accepted multidimensional view (Pleasant et al., 2016). Though a broadened, but consistent view of HL is welcomed, reducing ad-hoc interpretations to evaluate HL is also be encouraged, which the measurement framework attempts to do. Simplifying the HL measurement process is therefore a central implication of this thesis from a research lens.

A second important, and previously unmet, implication of this thesis pertains to the potential increase in accessibility of child HL research. The lack of conceptual clarity regarding what constitutes childhood HL is a well-known issue, and has led to fragmentation in research approaches to child HL (Bollweg & Okan, 2019). This thesis does not aim to theoretically clarify the differences in childhood – compared with adulthood – HL, but rather provide a guiding, expert-led HL measurement framework across community population research. Both adult and child HL research have notable issues with measurement consistency, but the broader measurement structure in place for adult HL, such as the theoretical models (Nutbeam, 2000; Sørensen et al., 2012), the extensive number of instruments (Haun et al., 2014), and the field conceptualising HL in adults initially (Kindig, Panzer, & Nielsen-Bohlman, 2004) means that researchers are more familiar with conducting HL research on adults than in children. Checking the feasibility of the HL measurement framework in a community child population in Chapter 4 was therefore prioritised, particularly given the focus in recent times on children as active health practitioners (Fairbrother et al., 2016).

This view has been exemplified during the Covid-19 pandemic, where an international investigation of children aged 7-12 observed an awareness of Covid-19-related information. This was also observed when children were being shielded from the topic matter or having Covid-19-related information filtered or adapted to them (Bray et al., 2021). This is not to discount the importance of adult HL during the Covid-19 pandemic either, with approximately one third of adults possessing inadequate HL levels, and an estimated 47.8% finding it difficult to judge their trust in media sources in the context of Covid-19 information (Okan et al., 2020). Due to the recent pandemic spotlighting the potential benefit of a health literate population (Paakkari & Okan, 2020), and the increasing desire to view children as active health practitioners, the clarity provided by this thesis on child HL measurement may contribute to an increase in accessibility for child HL research. As a consequence. the development of the measurement framework within this thesis may also act as a catalyst for increased child HL research production.

Though a key message from this thesis is in the clarity provided for measuring child HL, this thesis may also encourage researchers to conduct child HL research across schools in England. Chapter 4 provided clarification on the key challenges facing child HL research conducted in schools. As a consequence, researchers may be able to implement the recommendations from this thesis to navigate the complexities of child HL research more effectively. Schools are an exceptional site for HL research due to the minimal disruption to daily life, the ability to control the intervention and/or assessment to a high degree, and access to a large sample (Alibali & Nathan,

2010) from a difficult-to-reach population with safeguards in place. Increasing researchers' confidence in using schools as study sites may therefore yield larger samples and thus well powered research, added stakeholder involvement for the research process (Nussbaum, 2017), increased trust in the research project and subsequent recruitment phase, and better retention rates (Bartlett et al., 2017).

The recommendations proposed in Chapter 4 of this thesis for child HL researchers may support future follow-up work from this pilot and provide insight into the challenges of conducting child HL research in school contexts. This thesis provides an understanding of potential challenges to consider for conducting HL research in schools across two regions of England, alongside recommendations to deal with these. Though additional work is required to ascertain the feasibility of measuring child HL in schools, there may be an increase in researchers considering schools as recruitment sites for HL research. The findings from this thesis may thus act as a potential catalyst for future child HL research, given the challenges and recommendations provided.

Implications from a Policy Perspective

Though research implications are an important aspect of this thesis, policy is an important consideration for public health. Given that HL is viewed as a key determinant of a range of modifiable public health factors (de Buhr & Tannen, 2020; Svendsen et al., 2020), it is expected that this thesis may impact policy in England, particularly through indirect means. For example, an expected consequence of this thesis is the added interest in measuring HL in adults and children, as discussed above. A consequence of the increase in production of HL-relevant research in community populations is increasing attention on public HL policy. Public health policy is a complex area, with the term policy conceptualised broadly. In the interest of clarity, policy is defined in line with Crammond and Carey (2017), who suggested policy can be better understood in the following forms: the constitution, legislation, delegated legislation, municipal and local government rules, the rules and policies of statutory bodies, judicial decisions, regulatory review, corporate policy and self-regulation, treaties, additional parliamentary policy, and policy as discourse and action (Crammond & Carey, 2017).

However, not all areas are appropriate to the discussion of the implications of this thesis. To combat this, the following areas will be considered in the discussion: legislation and delegated legislation; municipal and local government rules; regulatory review; and policy as discourse and action, with these viewed as the most impactful in reference to the thesis content. Although the UK constitution is integral to political discourse, legislation is the primary mechanism for health-related policy change in England, and a major tool for parliamentary sovereignty – the defining component of the UK constitution (UCL, 2023) – for implementing health policy change. For these reasons, and given that the UK constitution is not centrally documented, the policy implications for this thesis will not be considered from a constitutional lens directly.

A major policy implication from this thesis is the indirect progression of community HL research in adults and children on policy as discourse and action. As previously discussed (see Chapter 5, sub-section *implications from a research perspective*), the development of a HL measurement framework clarifies an important grey area for researchers interested in the measurement of HL. In providing this, a clearer view of adult and child HL can be established, potentially leading to an increase in prevalence of comparable HL research data internationally. Given that only one community HL intervention was identified from England in the scoping review herein (see Chapter 2), HL funding in England may therefore be minimal, or provided through unclear funding pathways. The Higher Education Reform Act of 2017 (UK Government, 2017) led to the development of 9 funding committees, with each governed by the United Kingdom Research and Innovation (UKRI) body who, in-turn, are sponsored by the science budget for the UK Department for Business, Energy and Industrial Strategy. Presently, a search of *"health literacy"* on the UKRI website and a sub-search of *"health literacy"* in the funding finder search platform of the UKRI yields one recently closed funding opportunity around engaging the public on health and care in the UK. Currently, researchers may need to add a creative spin to a HL project to capture the remit of existing national funding calls. With the current HL landscape, this may lead to difficulty for UK-based researchers securing funds for community HL projects.

Poor HL potentially costs the NHS an estimated 3-5% of the annual budget (Berry, 2016; CHLF, 2014; Eichler, Wieser, & Brügger, 2009), with low HL leading to communication and advocacy challenges, treatment and medication errors, poor lifestyle factors, and higher rates of hospitalisation, which in-turn contribute to increased healthcare costs (CHLF, 2014). Given this, it is important to have clear HL-relevant funding pathways in place for researchers to access. An increase in research activity nationally may call for greater attention to the funding routes, leading to more centralised approaches for government-backed HL funding calls, taking ideas from the CDC's HL research webpage (CDC, 2021).

With most global HL research being produced in America (Qi et al., 2021), advertising government HL funding more effectively may be an important contributing factor towards increasing research production. Future action to promote a centralised digital space for government HL funding calls may thus form an important, indirect policy implication of this thesis, where increased research production is desired. Moreover, this may lead to attention with regards to the role of delegated – or secondary – legislation as well, where adjustments to the UK funding landscape may be considered in reference to the Higher Education Reform Act of 2017 (UK Government, 2017). From a policy perspective, increasing discourse and subsequent action from a digital advertising and legislative perspective may indirectly occur as a consequence of increasing the prevalence of HL research conceived and produced in England. An important policy message from this thesis is that, where the HL measurement framework promotes HL research production, this may generate discourse and subsequent action with regards to the national HL research landscape.

A second important policy implication of this thesis, again, relates to the increase in research from the HL measurement framework herein. With the increase in production of research on community HL, future conversations with regards to policy action may surface. Public policy plays an integral role in focusing efforts to reduce public HL concerns, particularly given the adverse impact on healthcare costs and public health which disregarding policy action exacerbates (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). The development of national action plans are thus an important strategic tool towards improving public HL, and generally forms several documents detailing a national or regional strategy, or strategies, incorporating recommendations to promote public HL from a political perspective (Weishaar, Hurrelmann, Okan, Horn, & Schaeffer, 2019). With the principle of framing – referring to the selection and communicative application of elements within a perceived reality to increase its salience (Entman, 1993) – viewed as influential for the wider political agenda (Weishaar et al., 2019), tools to support this process for public HL may act as a catalyst for future political action. As discussed previously, the

HL measurement framework may lead to an increase in accessibility for HL research, which in-turn may lead to a more informed view of HL in England. The research evidence may consequently lead to added discourse on public HL in England, promoting political pressure to develop a solution.

While ongoing pressures to address HL exist internationally, including the WHO (Apfel & Tsouros, 2013) and the subsequent Shanghai Declaration's 2030 Agenda for Sustainable Development (WHO, 2016), there remains less national pressure in England beyond key organisations like Health Literacy UK, the National Institute for Health and Care Research, and notable University affiliates. Increased accessibility to HL research – including study designs considering the measurement of adult and child HL, and the use of schools as HL research sites – may provide additional pressure to reconsider the political HL agenda. Future political impacts from a national action plan perspective may be in the refinement of key government HL publications (PHE, 2015a, 2015b), with attention towards wider community HL considerations in addition to the previous focus on healthcare professionals' HL roles. Pressure from HL discourse, which may be affected by the contents of this thesis, may therefore lead to HL-relevant policy updates or the refinement and development of national HL action from the UK Health Security Agency (which replaced PHE in 2021).

Several HL national action plans have been developed in recent years, with notable examples in Australia (Queensland Government, 2020), Scotland (Scottish Government, 2017), America (DHHS, 2010), Wales (Puntoni, 2010), and Germany (Schaeffer, Gille, Vogt, & Hurrelmann, 2023). Standalone HL investigations have been attributed as important antecedents for the development of national HL action plans, with many of the aforementioned strategies formed due to emerging HL population data (Weishaar et al., 2019). Particularly, the emergence of evidence demonstrating the high prevalence of limited HL was attributed as a key reason for the development of these HL action plans (Weishaar et al., 2019). Though low HL prevalence estimates from population data exists in England (Protheroe et al., 2017; Simpson et al., 2020), this has predominantly led to the evaluation of local initiatives and identification of priority areas (PHE, 2015a, 2015b) as opposed to a national plan. In making inferences, a national HL action plan may be approaching, but additional research outputs, particularly from large-scale general population research, may be required before scalable HL strategy discourse can take place.

Nevertheless, national HL action plans are an important focus for the provision of policy efforts to address limited HL, and, pending further population estimates for adult and child HL, is an important consideration for improving HL levels in England and population health overall. In an evaluation of international HL policies and linked activities, a myriad of successful initiatives driven by national policy have been observed, leading to reductions in smoking, increased confidence (OEPGK, 2016), improvements in medication management (Junge, 2009), quality of life, general service use, and overall self-care (Bujan et al., 2015; Rowlands et al., 2018), to name a few. The contents of this thesis may act as a catalyst for England to receive these benefits, as they directly attribute to a more accessible HL research sphere, which in-turn may lead to increased HL research production and the development of a national HL action plan succeeding existing plans (PHE, 2015a, 2015b).

Attention towards the reformation of existing plans into a national HL action plan is a welcome indirect policy implication of this thesis, and the hope is that the improved accessibility of adult and child community HL research translates into political discourse and subsequent pressure. In-turn, important local priorities (PHE, 2015a, 2015b) can be reframed with new HL evidence to develop new national initiatives, which in-turn can be supported through legislation and delegated legislation, local government rules, and organisational regulatory review.

In reference to the policy implications of this thesis, the central policy implications discussed, including HL funding implications and national action plan attention, are based on influencing policy as discourse and action, and thus being a catalyst for future action through the promotion of HL on the political agenda. The key policy message of this thesis is to use the HL measurement patterns identified in the review, the HL measurement framework, and the HL assessment recommendations herein to conduct more HL research. Through this, improvements to the HL landscape can be made, whether through national HL funding adjustments, action plans, or the research itself. Nevertheless, important policy implications are present from this thesis.

Future Recommendations

With the key implication from this thesis acting to increase the accessibility of community adult and child HL research, both in terms of the measurement of HL and investigations in the school context, it is important for researchers to apply the contents of this thesis for future research purposes. In line with this, future researchers may want to consider integrating two key information sources in the conceptualisation phase of future HL work. These are: the HL measurement framework presented in Chapter 3; and the recommendations for conducting HL research in schools from Chapter 4.

Firstly, the HL measurement framework is an important tool for researchers to understand the multidimensional differences in HL between community adult and child populations, while also allowing the identification of areas considered most important to assess in these populations. Given the ambiguity facing HL measurement in recent years (Nguyen et al., 2017; Pleasant et al., 2016), clarifying the outcomes viewed as important is essential. As frequent attempts to provide new multidimensional definitions of HL exist (Liu et al., 2020; Pleasant et al., 2016), confusion faces the field as to the most appropriate interpretation, leading to inconsistent measurement practices and poor comparability of the findings. The framework avoids the need to repeatedly re-define HL and foster confusion (Parker & Ratzan, 2019), and instead uses expert consensus to highlight the direct and proxy HL outcomes viewed as most important for researchers to investigate. By using the measurement framework, HL researchers can conceptualise the specific HL variables of interest and additional proxy components at the study design phase, while at the same time diverting attention to key areas identified by HL experts. Due to the framework components being identified by active HL experts, the attention to HL-relevant items forming the framework may enable more rapid systemic HL change in the form of public health policy, with the framework promoting more effective knowledge transfer to the political agenda. The health policy implications discussed previously (see Chapter 5, subsection *implications from a policy perspective*) may thus become a reality. The findings from this thesis subsequently encourage researchers to use the HL measurement framework as a measurement guide for future community adult and child HL research.

The value of the framework is that it does not require a specific HL instrument, but instead allows the researcher to integrate any instrument assessing the constructs of interest. Similarly, the measurement framework does not require a specific number of outcomes to be applied. The only inherent rule is that community adult and/or child HL measurement studies use the framework. The HL measurement framework could be used alongside the UK Medical Research Council's (MRC) guidance for developing and evaluating complex interventions (Kathryn et al., 2021) where HL interventions are being developed, for example. Core elements within the MRC may be supported by the HL measurement framework where HL interventions are of interest, such as in aiding the underpinning programme theory, or understanding the most important HL components to improve health outcomes. Researchers are subsequently encouraged to use the framework to guide the study design process where a project incorporating adult and/or child HL measurement is to be considered.

In addition to researchers using the framework, further population HL assessments in the UK are recommended to add HL pressure on the political agenda. As stated previously, evidence indicative of high prevalence rates for limited HL have been identified as key facilitators for the development of national HL action plans (Weishaar et al., 2019). Using the HL measurement framework to embed HL into the political agenda may consequently lead to follow-up discourse from the initial HL policy brief in England (PHE, 2015b).

This leads to the second key recommendation from this thesis. Future research may want to consider the suggestions proposed in the pilot child HL assessment, and use these as a guide for using primary and secondary schools in England as research sites. For future research, if the HL measurement framework is used to inform study design from a measurement perspective, and the recommendations are followed for conducting research in primary and secondary schools, a broader national view of HL can be established.

Where future research identifies concern around adult and child community HL, active engagement from researchers towards political discourse is urged. Presently, no national HL action plan exists in England, with the most recent national policy reports focusing on the implementation of local HL and community strategies (PHE, 2015a, 2015b). Promoting future research findings to the political agenda is thus needed, and researchers should consider focusing on disseminating general population HL assessments and school-based child HL research. Such dissemination strategies may include expanding the co-authorship base and involving key stakeholders – including policy stakeholders, publishing open access, using lay language policy briefs (lay summaries for policy stakeholders), podcasts, blogs, social media, and other analogous approaches (Tripathy et al., 2017).

Researchers may also wish to review future policy initiatives. Regulatory review occurs as a consequence of primary and delegated legislation for new policy proposals, and enables cost-benefit analyses and subsequent evidence-led policymaking (Crammond & Carey, 2017). Problematically, regulatory review can negatively impact policy, as stringent criteria for passing regulatory review can lead to a lack of promotion of potentially beneficial health policy. This has previously been identified in attempts to reduce obesity rates in Australia, where policy changes were not advanced due to concern regarding being unable to pass regulatory review due to the available evidence and complex policy at the time (Crammond et al., 2013). Researchers may therefore have an important role to play in ensuring future large-scale HL developments in England – which are sufficient enough to warrant regulatory review – are successful in future regulatory review.

Researchers may wish to consider using a broad range of research designs to establish qualitative and quantitative evidence for review, including text-based, survey, analytical, ethnographic and experimental approaches (Kreps, 2014). Evaluations of health initiatives and non-governmental health interventions are not new ideas, and have existed in decades gone by. However, given the expected increase in HL research outputs and dissemination, and subsequent impact on the political agenda, it may be timely for researchers to consider evaluation research when research on the concepts forming adult and child HL (see Figure 15) become more prevalent.

Future research on evaluations of government and non-government HL initiatives may draw parallel approaches to existing evaluations. The Wales National Exercise Referral Scheme (RCGP, 2022), for example – a 16-week initiative to improve national physical activity levels – was evaluated with a pragmatic randomised controlled trial, where an increase in physical activity across participants in the NERS scheme was noted when compared with care as usual (Murphy et al., 2012). A quantitative example can be seen in the NHS Health Check evaluation, where a longitudinal observational study design was selected. In aiming to reduce cardiovascular morbidity, the evaluation found the programme led to the identification of new comorbidities and new prescriptions of statins and antihypertensive therapy, indicating potential indirect reductions in cardiovascular events (Robson et al., 2016). National qualitative intervention examples can be seen in the NHS Diabetes Prevention Programme, where a combination of observation and field note data were indicative of positive and negative patient experiences and general service delivery concerns (Hawkes, Cameron, Cotterill, Bower, & French, 2020). Though these are not an exhaustive list, they provide an indication of the types of evaluations future researchers may want to consider for HL initiatives moving forward.

With existing government publications acting as an overview for present-day and future national HL initiatives, more HL initiatives may arise guided by these reports.

It may consequently be timely to consider the evaluation of these from a research perspective in addition to developments expected from the increased outputs potentially stemming from the findings of this thesis.

Limitations of this thesis

Though this thesis provides novel insight into community HL measurement in adults and children, several limitations exist.

Firstly, the HL measurement framework does not capture any conceptual differences in measurement across community samples ≤9 or between 13-24 years. Initially, the focus of recruitment was to ensure an appropriate panel of HL experts was established, both at the commencement of – and throughout – the Delphi study. Online Delphi study designs comprise of iterative round-based surveys, and the time-consuming nature of each round, lack of in-person interaction and wait time between rounds can discourage participant recruitment and negatively impact retention rates (Hall, Smith, Heffernan, & Fackrell, 2018). For these reasons, the decision was made to prioritise the recruitment and retention of HL experts throughout the process, rather than allowing for breadth of survey content. Reducing the number of rounds, overall Delphi study timescale, and effort expected of participants were therefore considered, as these have been suggested as important contributors to reducing attrition in Delphi studies (Flanagan, Ashmore, Banks, & MacInnes, 2016). Due to the study design, adding a third community HL context, such as adolescent HL, would have led to significant repetition of questions relating to direct and proxy outcomes being identified, likely impacting the time of completion for each round by an estimated 5-10 minutes and potentially the motivation of experts to complete the process.

By prioritising the user experience of the Delphi study, conceptual clarity on adolescent HL and the potential differences in outcomes viewed as important were missed. The findings from this thesis are thus not applicable for the measurement of HL beyond the community population parameters established in Chapter 3. Additionally, an original draft of the Delphi rounds intended to establish factors beyond the population which may impact the measurement of HL, however these were not considered for the same feasibility reasons listed above. Importantly, however, an expert panel sample in line with literature suggestions was recruited (Naisola-Ruiter, 2022), with retention rates not enough the notably impact the Delphi process. To combat the narrowed scope, a strong focus was placed on the panellist selection process, with experts who demonstrated an initial interest asked to provide a list of recent activity in the field and their identified areas of expertise. Participants were additionally requested to invite individuals they believed to be relevant to the study. When taken collectively, this process enabled the selection of experts with active involvement in the field and varied expertise. Although the content that the experts were asked to complete in the Delphi study was narrower than initially hoped, the emphasis on recruitment, selection of panellists, and retention supports validity of the consensus established (Veugelers, Gaakeer, Patka, & Huijsman, 2020) and an appropriate panel size. Nevertheless, future research should consider the identification of potential differences in community adolescent HL measurement to provide a full view of HL measurement deviations across the developmental journey.

Shifting towards the cross-sectional child HL pilot study, a second important limitation to acknowledge is the recruitment of participants through schools. Although the low recruitment figures have been discussed in depth already (see Chapter 4, sub-section *challenges and recommendations for a full-scale study*), the lack of two-way discourse between the research team and potential school sites meant reflection on the process was not based on direct school rejections to participate. With minimal communication from schools, evaluating the low recruitment of school sites in the pilot was done through assumptions and literature inferences. Though this provides an important understanding of the key issues facing recruitment where school-based research is conducted, this could only be established from the research team's perspective. Additional insight for conducting child HL assessments across schools in England may therefore have been obtained if a more responsive recruitment process was established. The infrequent communication from schools – in response to research enquiries – is an important limitation of the pilot study, as further insight on the current stance of schools in the East Midlands and Yorkshire may have been established if further discourse was yielded.

Liaising with schools for research opportunities has been a notable challenge in past efforts. For example, the 2011 European School Survey Project on Alcohol and Other Drugs, a large-scale European survey of substance abuse in 15-16 year olds, found only 74 schools participated out of 1,255 approached in the UK. When asked, schools cited a lack of interest to participate, bad timing, recent participation in other research opportunities, and were required by existing school policy to not participate in external research projects (Hibell et al., 2012). When taken with the view that, during the Covid-19 pandemic, the majority of teachers (98%) reported students being behind compared with typical curriculum expectations (Sharp et al., 2020), schools may have prioritised tackling the pandemic-inflicted learning gap rather than external research opportunities. Given that the child HL assessment study was intended to be a full-scale assessment, and not a pilot, the findings of Chapter 4 were inconclusive regarding the state of child HL in England, but instead assessed the feasibility of conducting such an assessment with schools in England as research sites. Consequently, the pilot study presents an important foundational step to guide the study design for a successful child HL assessment on a national level. Future researchers are thus encouraged to consider the methodology and subsequent recommendations presented in Chapter 4 before embarking on a follow-up direct and/or proxy assessment.

Lastly, this thesis does not provide a HL measurement framework which informs researchers which outcomes are required for specific study designs, instead acting as a guide in reference to the population of interest. The framework requires an understanding of the study design and subsequent inference from the researcher – or research team – to successfully implement the outcomes. As such, the framework should be used by researchers with an interest in measuring HL in participants representing the community adult and child age ranges identified. Researchers should then consult their study aim(s) and study design, and implement the outcomes within the appropriate contexts (direct and/or proxy) which best capture this.

As a future follow-up, there may be scope for an online tool for community adult and child HL measurement, adapted from the initial framework. For clarity, a tool for understanding the specific outcomes to apply dependent on responses to a series of study design questions may be a suitable adaptation, and may draw parallels to the Health Research Authority's NHS Research Ethics Committee decision tool (NHS) – a tool designed to streamline initial confusion regarding the correct process to follow depending on the study design. Although uncertainties with the HL measurement tool in its current iteration can be clarified by consulting with a HL expert, a digital translation enabling personalised HL outcome recommendations allows researchers without access to a HL expert to investigate HL-relevant aspects in a valid and comparable manner. Given the value of the Delphi methodology for developing consensus where knowledge is incomplete (Nasa et al., 2021), implementing a Delphi study to identify key questions and/or forms for a digital iteration of the HL measurement framework may be a useful approach to consider moving forward.

Conclusion

The conceptual nature of HL is a long-standing issue in the field, and it is only in recent years that a shift towards multidimensionality has been established (Altin et al., 2014; Sørensen et al., 2012; Tian, Xu, Mo, Dong, & Wong, 2020). As evidenced through this thesis, various models and interpretations of outcomes to measure HL multidimensionally exist, though less attention has been placed on the conceptual differences between adults and children. The findings of this thesis provide important information on these conceptual differences, with a review identifying community HL measurement patterns; a Delphi study exploring community adult and child HL measurement; and a pilot study exploring the measurement of child HL across two regions of England.

The aims and objectives presented in Chapter 2 were addressed, with important research and policy implications anticipated – particularly the potential of the framework to influence community adult and child HL research production, and its indirect impact on the development of national HL policy initiatives. While the framework is an important innovation, a pragmatic view should be taken. Using an approach with no hierarchical ordering of research methods and knowledge types (Hothersall, 2019) may make it simpler to use outcomes from the framework that are: applicable to the project, psychometrically strong, feasible to complete, and sensitive to change (Glasgow & Riley, 2013). In doing so, gaps can be established, and HL outcomes can be identified relative to the study design. Given recent calls to measure HL pragmatically (Lane & Aldoory, 2019), this is timely to consider with respect to the measurement framework herein.

The contents of this thesis attempt to catalyse a shift towards solution-centred practices rather than definitions. This thesis hopes to increase researcher confidence regarding HL measurement and encourage a pragmatic approach, both in-terms of building the measures for a given study, identifying gaps in HL measurement, and also in approaching schools as research sites for HL projects. In the emergence of new evidence, researchers should be pragmatic in their view of this framework. Where elements of the framework can be improved or adapted, or adjustments important to school HL research are made which are not covered in the contents of this thesis, researchers are encouraged to do this.

Given the importance of discourse and action on public policy (Crammond & Carey, 2017; Didier et al., 2017), this thesis encourages researchers and policymakers to continue investigating and advocating for the HL needs of the general population and the wider HL research landscape. Researchers are encouraged to use the HL measurement framework and subsequent pilot recommendations to provide consistent research outputs. The contents of this thesis are intended to support community HL researchers to assess HL comprehensively, compare findings effectively, and increase HL pressures on the national political agenda. As the HL measurement framework is applicable globally, given the international Delphi panel formed (see Chapter 3), international researchers are also encouraged to adopt the HL measurement framework where appropriate.

Researchers play a critical role for policy and wider systemic change, and through consistent, comprehensive, and conceptually agreed-upon measurement practices, significant public HL advances can be made.

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Appendices

Appendix 1: Preliminary Review – Inclusion and Exclusion Criteria

Studies will be eligible for inclusion if they:

1. Sample community participants – those with no existing or known health
2. conditions/illnesses (Nutbeam et al., 2018).
3. Conduct a HL intervention aiming to improve person-centered/environmental HL.
4. Are published during and after 2010.
5. Are English-text publications.
6. Include HL as a significant outcome of interest.

Studies will be excluded if they:

1. Sample from a distinctive subgroup that are atypical members of society, like prison populations.

Appendix 2: Preliminary Review – Data Charting Form

Study Aspects	Variables of Interest
General study information	Date of publication. Geographical location of study. Aim/objective(s). Age of sample. Sex distribution of sample. Community sampled from (schools, universities, colleges, workplaces, community centres, etc). Specific study type (randomised controlled trials, qualitative intervention, mixed-methods intervention, etc).
Intervention	Level of public involvement. Domains of health literacy implemented (functional, communicative/interactive, critical). Intervention context (school, adult basic education, university education, online forum, home, etc). Content of intervention (medicines safety/efficacy/rational use, physical activity, diet, health service use, healthcare services, etc).
Mode of intervention delivery	Method(s) used (teach-back, role-play, interactive activities, use of technology, exercise, etc). Who delivered the intervention (teacher, researcher, health care professional, pharmacist, psychologist, etc). Length of intervention (day workshop, semester-long module, one hour interactive workshops, regular one hour online forums, week-long adult basic education course, five hour health literacy game, etc).
Evaluation	Outcomes assessed. Frequency of measurement (pre, post, post-6 months, etc). Methods of outcome(s) data collection (self-report, interview/focus groups, test/exam, etc).
Findings	Effectiveness of study at post-intervention and follow-up if available (significance value of intervention between control and intervention group(s).

Appendix 3: Preliminary Review – Direct Health Literacy Frequency Table

Health literacy direct outcomes frequency table

Measure Instrument	Frequency	Domain Assessed	Studies Utilised
Newest vital sign	4	Functional	(Carolyn et al., 2019; Creech, 2014; McCaffery et al., 2019; Otilingam et al., 2015)
Rapid estimate of adult literacy in medicine	4	Functional	(Alqudah, 2014; Gazmararian et al., 2010; Keller et al., 2019; Nowak, 2019)
Test of functional health literacy in adults	6	Functional	(Ayaz-Alkaya et al., 2019; Khaleghi et al., 2019; Soto Mas et al., 2014; Soto Mas et al., 2015; Soto Mas et al., 2018)
Health literacy questionnaire	1	Functional, communicative, critical	(McCaffery et al., 2019)
Unspecified functional health literacy assessment	1	Functional	(LaScala et al., 2019)
The adult health literacy scale	1	Unknown[a]	(Ayaz-Alkaya et al., 2019)
Lenartz's German health literacy questionnaire[b]	1	Self-perception, health proactivity, dealing with health information, self-control, communication and cooperation, and self-regulation	(Stassen et al., 2020)
Health literacy for Iranian adults questionnaire	1	Functional, communicative, critical	(Bayati et al., 2018)
Chinese citizen health literacy questionnaire[c]	1	Knowledge, attitude, practice, skill	(Liu et al., 2018)
European health literacy survey questionnaire	2	Functional, communicative, critical	(Fernandez-Gutierrez et al., 2019; Uemura et al., 2018)
The health literacy scale-14	1	Functional, communicative, critical	(Uemura et al., 2018)

Single-item literacy screener	1	Functional	(McCaffery et al., 2019)
Rapid assessment of health literacy questionnaire	1	Functional	(Zhuang et al., 2016)
Adapted functional, communicative, critical health literacy scale for Diabetes	1	Functional, communicative, critical	(Muscat et al., 2016)
Functional health literacy course-content study-specific measure	1	Functional	(Muscat et al., 2016)
Study-specific simulation to manage health resources	1	Functional, communicative, critical	(Bayati et al., 2018)
Over-the-counter medication label literacy	1	Functional	(Abel et al., 2012)
Medication literacy questionnaire	1	Functional	(Chang et al., 2015)
Communicative/critical health literacy questionnaire	1	Communicative, critical	(Tsai et al., 2018)
Communicative and critical health literacy scale	1	Communicative, critical	(Ishikawa et al., 2018)

Note.
[a] No mention of the domains assessed in the adult health literacy scale, and the original paper is not in English and is uninterpretable (Sezer & Kadioğlu, 2014), hence no conclusion could be made regarding the domains assessed.
[b] Based on the structural model of health literacy (Soellner, Lenartz & Rudinger, 2017).
[c] Based on the knowledge-attitude practice model (WHO, 2008).

Appendix 4: Preliminary Review - Proxy (Indirect) Health Literacy

Frequency Table

Health literacy indirect outcomes frequency table

Measure	Frequency	Domain assessed	Studies utilised
Blood pressure	1	Physiological	(Carolyn et al., 2019)
Cardiovascular health questionnaire (adapted)	1	Health behaviours	(Soto Mas et al., 2018)
Short form-12 questionnaire of life quality	1	Health-related quality of life	(Khaleghi et al., 2019)
Health-promoting lifestyle profile-II	2	Health promotion engagement	(Bayati et al., 2018; Carolyn et al., 2019)
Health empowerment	1	Health-related control	(Tsai et al., 2018)
Health behaviours	1	Behavioural	(Ayaz-Alkaya et al., 2019)
Healthy lifestyle behaviour scale-II	1	Health-promoting behaviours	(Ayaz-Alkaya et al., 2019)
Healthy lifestyle behaviours	1	Health behaviours	(McCaffery et al., 2019)
Consumption frequencies questionnaire	1	Dietary habits	(Uemura et al., 2018)
Fat-related diet habits questionnaire	1	Dietary habits	(Otilingam et al., 2015)
Health-smart behaviour frequency scale	1	Healthy behaviour engagement	(Carolyn et al., 2019)
Perception of health scale	1	Self-perceived health	(Ayaz-Alkaya et al., 2019)
Perceived health status questionnaire	1	Self-perceived health	(Keller et al., 2019)
Perceived health confidence measure	1	Confidence in dealing with health	(Keller et al., 2019)
Study-specific perceived health confidence measure	1	Confidence in performing health-related tasks	(Muscat et al., 2016)
Five-item patient trust measure	1	Trust in the medical profession	(Ishikawa et al., 2018)
Patient activation measure	1	Knowledge, skills and confidence for the self-management of a person's health[a]	(McCaffery et al., 2019)
Dietary fat knowledge	1	Knowledge of dietary fats	(Otilingam et al., 2015)
Medication knowledge test	1	Knowledge of medicines	(Creech, 2014)

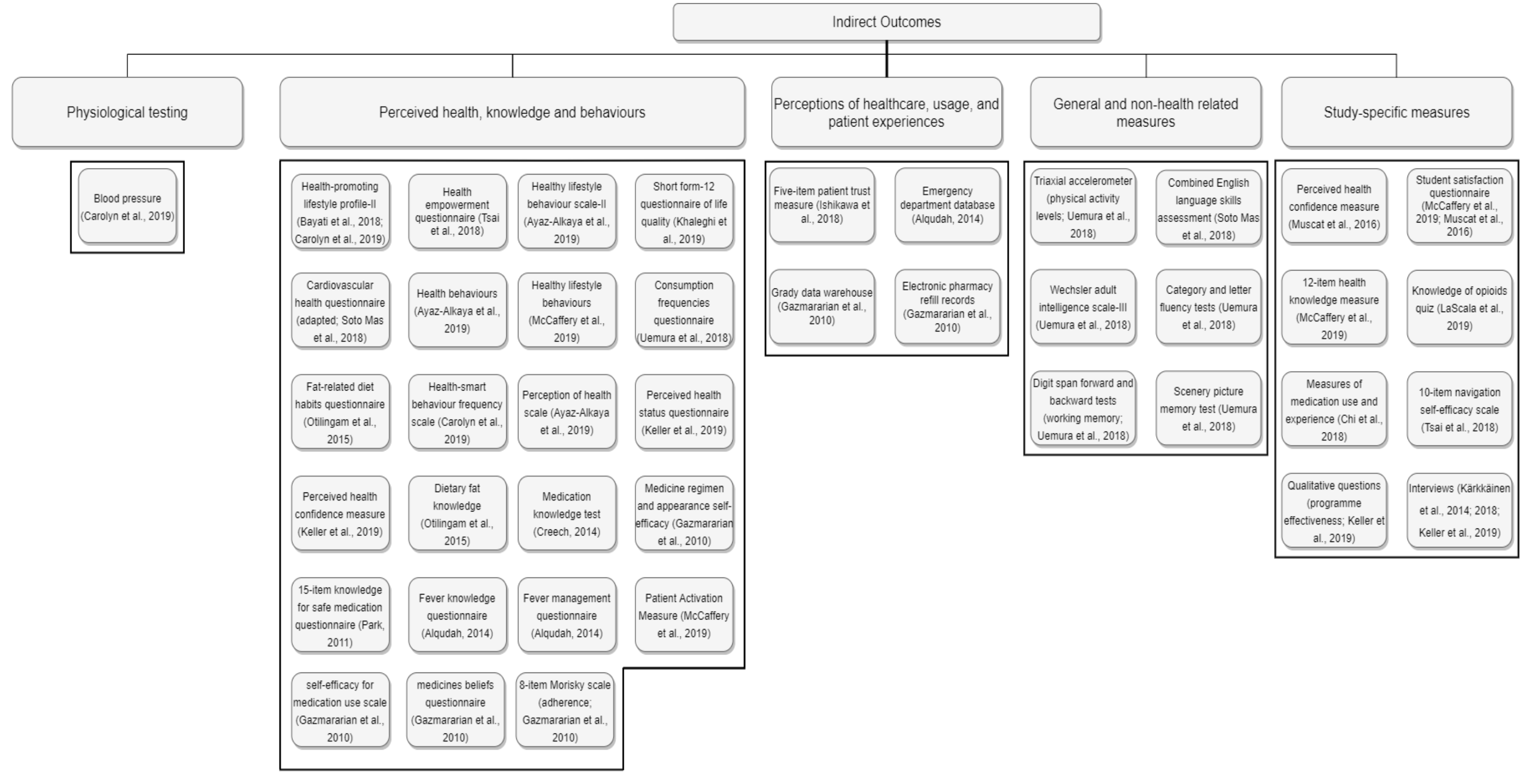
12-item study-specific health knowledge measure	1	Retention of intervention health materials	(McCaffery et al., 2019)
Study-specific knowledge of opioids quiz	1	Knowledge of opioid medications	(LaScala et al., 2019)
Study-specific measures of correct medication usage, pain medication usage and pain medication experience	1	Level of correct general and pain medication usage	(Chi et al., 2018)
15-item knowledge for safe medication questionnaire	1	Knowledge regarding safe medications	(Park, 2011)
Fever knowledge questionnaire	1	Knowledge regarding fever	(Alqudah, 2014)
Fever management questionnaire	1	Anticipated fever management practices	(Alqudah, 2014)
Emergency department database	1	Emergency department admissions	(Alqudah, 2014)
Grady data warehouse	1	Healthcare utilisation	(Gazmararian et al., 2014)
Study-specific student satisfaction questionnaire	2	Self-perceived satisfaction	(McCaffery et al., 2019; Muscat et al., 2016)
Medications prescribed (demographic)	1	Number of medications being taken	(Uemura et al., 2018)
Medication indication regimen and appearance measure	1	Medication understanding and management capacity	(Gazmararian et al., 2010)
Medication indication regimen and appearance self-efficacy measure	1	Medication understanding self-efficacy	(Gazmararian et al., 2010)
Study-specific medication survey	1	Over-the-counter use and method of administration	(Abel et al., 2012)
Self-efficacy for appropriate medication use scale	1	Self-efficacy for taking medicines in difficult and uncertain or changing circumstances	(Park, 2011)
Adverse drug events questionnaire	1	Adverse effects of medication	(Gazmararian et al., 2010)
Beliefs about medicines questionnaire	1	Medication-related beliefs	(Gazmararian et al., 2010)

Electronic pharmacy refill records	1	Refill adherence (cumulative medication gap)	(Gazmararian et al., 2010)
8-item Morisky scale	1	Self-reported levels of adherence	(Gazmararian et al., 2010)
Study-specific 10-item navigation self-efficacy scale	1	Self-reported navigation skills for healthcare encounters	(Tsai et al., 2018)
Combined English language skills assessment	1	Assessment of grammar while reading	(Soto Mas et al., 2018)
Wechsler adult intelligence scale-III	1	Processing speed	(Uemura et al., 2018)
Category and letter fluency tests	1	Verbal fluency	(Uemura et al., 2018)
Digit span forward and backward tests	1	Working memory	(Uemura et al., 2018)
Scenery picture memory test	1	Visual memory	(Uemura et al., 2018)
Triaxial accelerometer	1	Physical activity levels	(Uemura et al., 2018)
Demographic smoking habit question	1	Smoking frequency	(Uemura et al., 2018)
Demographic alcohol consumption	1	level of alcohol consumption	(Uemura et al., 2018)
Qualitative interviews	3	Intervention efficacy and fidelity	(Kärkkäinen et al., 2014; Kärkkäinen et al., 2018; Keller et al., 2019)
Study-specific qualitative questions	1	Programme effectiveness	(Keller et al., 2019)

Note.

[a] Definition from Rademakers, Nijman, van der Hoek, Heijmans and Rijken (2012).

Appendix 5: Preliminary Review – Proxy (Indirect) Health Literacy Outcome Categorisation Table



Note. From top to bottom: the figure topic, indirect outcome categories and outcome measurements.

Appendix 6: Scoping Review – Data Charting Form

Pre-calibration Data Charting Form

Study Aspects	Variables of Interest
General study information	• Date of publication. • Geographical location of study. • Aim/objective(s). • Age of sample. • Sex distribution of sample. • Community sampled from (primary schools, secondary schools, universities, colleges/sixth forms, workplaces, etc). • Specific study type (randomised controlled trials, qualitative intervention, mixed-methods intervention, etc).
Intervention development and content	• Level of patient/public involvement. • Domains of health literacy implemented (functional, communicative/interactive, critical). • Intervention context (school, adult basic education, university education, etc). • Content of intervention (medicines safety/efficacy/rational use, physical activity, diet, health service use, etc).
Intervention delivery and type	• Method(s) used for improving HL (teach-back, role-play, interactive activities, use of technology, etc). • Who delivered it? (teacher, researcher, health care professional, etc). • Length of intervention (day workshop, semester-long module, week-long adult basic education course, etc).
Evaluation	• Direct and indirect outcomes assessed. • Frequency of measurement (pre, post, post-6 months, etc). • Type of measurement used per outcome.

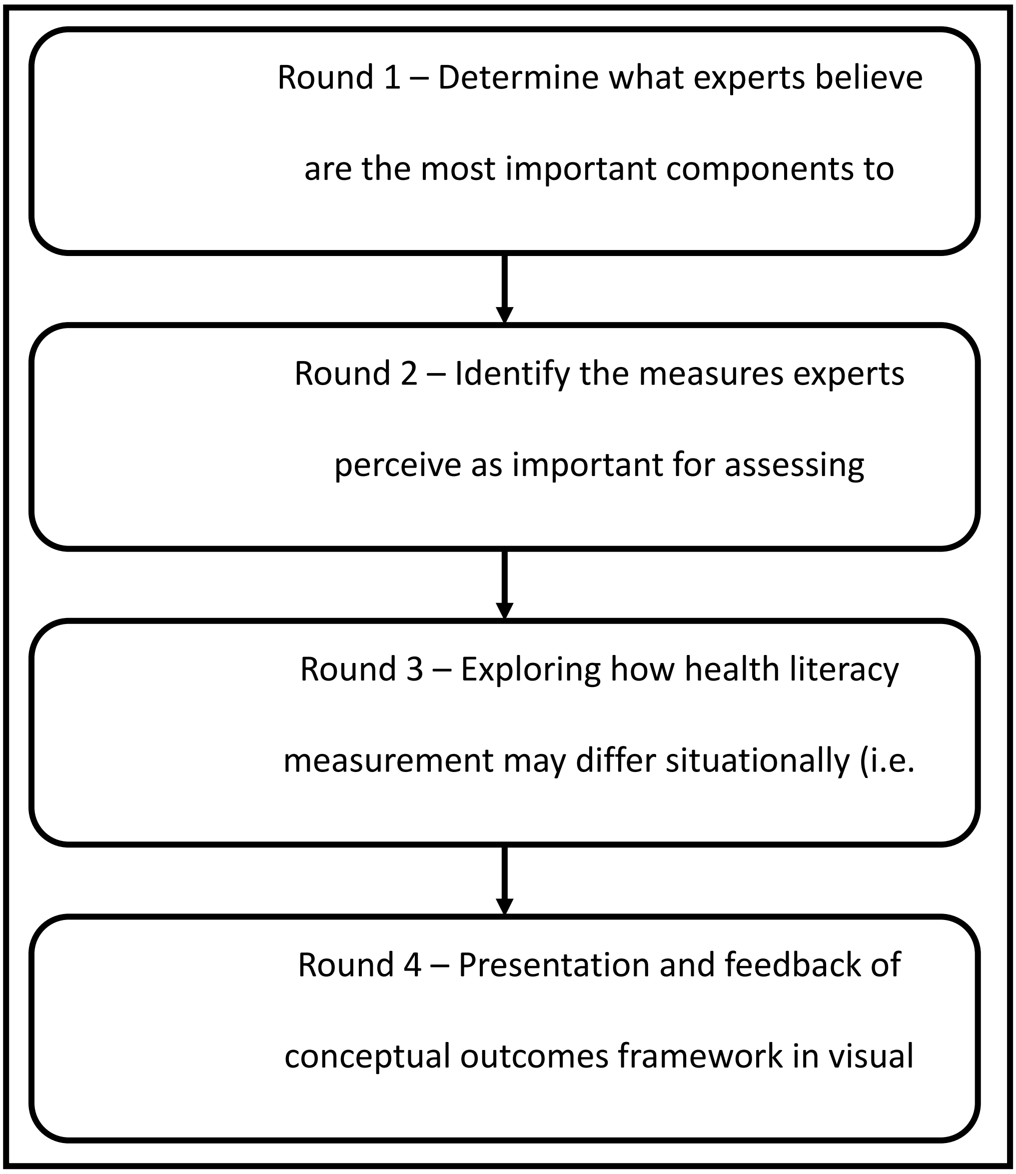
Findings	• Effectiveness of study at post-intervention and follow-up if available (significance value of intervention between control and intervention group(s).

Post-calibration Data Charting Form

Study Aspects	Variables of Interest
Study Credentials	• Author(s). • Publication date. • Geographical research location (England, America, Australia, etc).
Sample	• Age. • Gender. • Community sampled from (primary schools, secondary schools, workplaces, leisure centres, universities, etc). • Nationality of sample. • Additional sample characteristics (athletes, postpartum females, etc)
Intervention type and content	• Intervention delivery method (online web portal, in-person education, etc). • Intervention context if applicable (school, adult basic education, online university portal, leisure centre, workplace, etc). • Intervention content (healthy lifestyle, medication safety, health service navigation, etc). • Health literacy domain(s) targeted through intervention material (functional, communicative, critical, and other health literacy model domains). • The person delivering the intervention if applicable (teacher, researcher, health care professional, etc). • Length of intervention (day workshop, semester-long module, week-long adult basic education course, etc).
Intervention evaluation	- Direct outcomes used (that directly relate to either Nutbeam's (2000) model of health literacy or an alternative model, like science and civic literacy). - Proxy outcomes used (any other outcome applied, with the exclusion of general demographics, such as patient activation).

- Frequency of direct and proxy measurement (pre, post, post-6 months = 3 times, etc).
- Type of measurement used per outcome (i.e. patient activation measure, newest vital sign, etc).

Appendix 7: Delphi Study – Initial Flow Chart of Rounds



Appendix 8: Delphi Study – Email and Personal Website Recruitment Invitation

Dear ______,

We would like to invite you to participate in the above study as you are an expert in the field of health literacy. This study is a collaboration between:

- Mr Luke Sawyers, Dr Li Shean Toh, and Prof Claire Anderson; the University of Nottingham, England.
- Mr Gregory Duncan; Monash University, Australia.
- Prof Parisa Aslani, The University of Sydney, Australia.

Aim and method:

To develop and validate a conceptual outcomes framework for health literacy community research. Delphi methodology will be used to attain expert consensus towards the most important components for health literacy outcome measurement in community adult and child health literacy research. We plan to do this across four contexts:

1. Adult (≥24 years) direct health literacy.
2. Adult (≥24 years) proxy health literacy.
3. Child (10-13 years) direct health literacy.
4. Child (10-13 years) proxy health literacy.

What you will need to do if you agree to participate:

If you agree to participate, you will be provided with a series of short 10-15 minute surveys in a round-based format, and provided with feedback after the completion of each round for each preceding round.

Responses will be analysed between rounds and used to develop the succeeding rounds, aiming to achieve consensus regarding the most important health literacy outcome measurements to consider across the four community participant contexts. Participants will be asked to identify and subsequently rate items perceived to be important in the measurement of health literacy for the four community contexts stated above. Further information regarding participant confidentiality, anonymity, the study methodology and participant requirements can be found in the attached participant information sheet.

If you are interested in participating, **please respond to this email** with the following:

- Confirm your interest in participating.

- Outline whether you wish to be named or not as part of the expert panel in future publications and/or communications.

This will be a great opportunity to express your thoughts on an important component of health literacy research, and your input will help shape expert recommendations for health literacy outcome measurement in community populations moving forward.

We would greatly appreciate involvement from the health literacy community. If there are any questions pertaining to the study, please contact me on the same email this invitation was received from (msxls17@nottingham.ac.uk). Additionally, if you have any contacts/colleagues who you feel would be able to contribute to this project as a participant, we would be grateful for their contact details to discuss their participation further.

Thank you for your time in reading our research invitation, and we look forward to hearing back from you soon.

Kind regards,

Luke Sawyers.

Appendix 9: Delphi Study – Twitter Recruitment Invitation

Dear _______

My name is Luke Sawyers, a second year PhD student at the University of Nottingham's School of Pharmacy.

As a health literacy researcher, I was wondering if you'd be interested in helping support the recruitment phase of my upcoming research project about health literacy outcome assessment, where we plan to gather expert consensus towards the outcome measures used for community health literacy interventions. As a prominent health literacy organisation/group active on Twitter, it would be great if you were able to support my study recruitment as the reach your profile has for health literacy participants far surpasses mine alone. If you were interested in supporting the study recruitment, it would be great if you could help disseminate a study recruitment advertisement I plan to place on Twitter by simply retweeting the pinned Tweet on my profile when I post this - I'll send another DM when the Tweet becomes available.

In return for your support, I can offer a mention in the acknowledgements section of the potential publication succeeding this research to your group/organisation if this would be something of interest to you.

Thanks in advance for reading and I look forward to hearing your response.

Best wishes,

Luke.

Appendix 10: Delphi Study – Participant Consent Form

PARTICIPANT CONSENT FORM

Project Title: Direct and Proxy Health Literacy: A Delphi Investigation into the Most Important Components for Health Literacy Assessment in Community Child and Adult Samples.

Researcher's Name: Mr Luke Sawyers.

Tutor's/Supervisor's Name: Dr Li Shean Toh, Dr Gregory Duncan, Prof Parisa Aslani, Prof Claire Anderson.

Participant Serial Identification Code: S2-XX
Please initial boxes:

- I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. I understand and agree to take part. ☐
- I understand the purpose of the research project and my involvement in it. ☐
- I understand that I may withdraw from the research project at any stage and that this will not affect my status now or in the future. ☐
- I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential. ☐
- I understand that data will be stored securely, where digital material copies will be uploaded to the University of Nottingham OneDrive, whereby only the researcher and above supervisors will be able to access this information. The University of Nottingham hold research data for a period of seven years for legal purposes, and will be securely destroyed at the end of this time. ☐
- I understand that I will be provided with a privacy notice under the General Data Protection Regulation ☐
- I understand that I may contact the researcher or tutor if I require further information about the research, and that I may contact the Research Ethics Committee of the School of Pharmacy, University of Nottingham, if I wish to make a complaint relating to my involvement in the research. ☐

Signed ………………………………………………………………… (Lead Investigator)

Signed ………………………………………………………………… (Research Participant)

Print Name …………………………………… **Date** …………………………………

Please indicate your identified area of expertise (i.e. child health literacy, health literacy psychometrics, general health literacy health literacy interventions):

……………………………………………………………………………………………………

Please list any recent experience you have in the field of health literacy (conferences attended/keynotes given, involvement with relevant committees, publications, books, chapters, interviews, teaching, reviewer, etc):

……………………………………………………………………………………………………

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Contact Details:

Researcher: *Mr Luke Sawyers, University of Nottingham, School of Pharmacy, Division of Pharmacy Practice and Policy.* Email: msxls17@nottingham.ac.uk

Supervisor: *Dr Li Shean Toh, University of Nottingham, School of Pharmacy, Division of Pharmacy Practice and Policy. Room C04, School of Pharmacy Building, University Park*

Nottingham, NG7 2RD. Email: lishean.toh@nottingham.ac.uk

School of Pharmacy Research Ethics Officer: PA-PHARM-ETHICS@exmail.nottingham.ac.uk

Appendix 11: Delphi Study – Participant Information Sheet

University of Nottingham
UK | CHINA | MALAYSIA

Participant Information Sheet: Work Phase 1

(Version 1.0: 19/01/2021)

Title of Study: Direct and Proxy Health Literacy: A Delphi Investigation into Health Literacy Measurement for Community Child and Adult Samples.

Name of Researcher(s): Mr Luke Sawyers, Dr Li Shean Toh, Dr Gregory Duncan, Prof Parisa Aslani, Prof Claire Anderson.

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. If anything is unclear, please feel free to contact us to discuss any concerns with the contact details listed at the end of this document.

What is the purpose of the study?

The purpose of this study is to clarify the ambiguity behind current health literacy outcome practices for community (otherwise healthy) health literacy research, with the aim of determining expert consensus regarding the measurement of health literacy for children (10-13 years) and adults (≥ 24 years), separately, at the direct and proxy level. The following definitions are stated below to clarify our project:

- Health literacy – A skill which refers to a person's ability to access, understand, apply and be critical of health information in order to make appropriate judgements and decisions in everyday life regarding health promotion, disease prevention, and healthcare in order to maintain or improve quality of life (Sørensen et al., 2012).
- Direct – We define direct measurement as those measures which investigate key components of health literacy models, such as Nutbeam's (2000) functional, communicative/interactive, and critical health literacy.
- Proxy – We define proxy measurement as those measures which do not fall under direct measurement, and are used as adjunctive measurements – health behaviours, patient activation, and adherence are some potential examples. These measurements typically are not directly identified in conceptual models of health literacy.

A previous scoping review extracted all direct and proxy outcomes according to the above definitions from community (non-disclosed illness/disease/condition or otherwise healthy populations) health literacy interventions conducted from 2010-2020. These were categorised into grouping terms indicating what they aimed to assess and will guide some of the questions asked in the Delphi process if you choose to participate.

Why have I been invited?

You are being invited to take part because you are an academic/healthcare professional/other professional who has worked within the field of health literacy in any capacity, such as by being involved in the publication process of health literacy research, a book or book chapter, conference proceeding, white paper, green paper, play a health literacy advisory role, an editing role or any other means of health literacy-related work.

We would like to find out your views towards the measurement of health literacy in community population research, and the aspects you perceive to be most important when considering assessing health literacy across four contexts: child (10-13 years) direct health literacy, child (10-13 years) proxy health literacy, adult (≥ 24 years) direct health literacy, and adult (≥ 24 years) proxy health literacy. Consequently, we are inviting a variety of people like yourself to participate in a Delphi consensus study – a consensus method aiming to find general agreement among an expert panel on a particular topic through iteratively managed, round-based surveys.

Do I have to take part?

It is up to you to decide whether or not to take part. You will be provided a consent form and information sheet to read. If you do decide to take part you will be provided with a unique identification code within your consent form, be asked to sign the consent form and additionally read/understand the information sheet. Your unique code will be used to ensure your anonymity from the researcher during participation, as well as with other participants taking part in the study. Your unique code will also be used as a point of reference to your data in the event that the research is published, thus allowing a confidential write-up of the study findings. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

Once you decide to take part, please return the completed consent form to the lead researcher by email (Luke Sawyers, contact details at the bottom of this sheet). You will be asked to participate in a series of brief online questionnaires lasting no longer than 10-15 minutes each. Each questionnaire is referred to as a round, and there will be three rounds in total. The initial round questionnaire will provide a brief introduction and a series of short questions regarding what you perceive to be important components to assess for health literacy across the four contexts (adult direct, adult proxy, child direct, child proxy). The link to this will be provided to you in the weeks after a reasonable sample of participants have been recruited, and the lead researcher (Luke Sawyers) will disseminate this by email.

A deadline will be set by the researcher, ranging around two to four weeks per questionnaire round, where participants will be required to complete the questionnaire within the allocated timeframe conveyed in the relevant round's email communication. If participants have less than one week to complete the questionnaire for a given round, the researcher will prompt participants to complete this via a short reminder email. Once the deadline has passed, the researcher will begin analysing the data for each round and devise the succeeding rounds/questionnaires accordingly. The remaining rounds will cover the same topic within the questionnaire (what participants perceive to be the most important components to assess in child and adult populations, separately, at the direct and proxy level of health literacy measurement), but use a different approach/structure to obtain new data to facilitate consensus. This same process will repeat until three rounds of questionnaires have passed.

Any questionnaires which are not completed in the relevant timeframe will be excluded from the final analysis and participants will be thanked for their time and will not be sent the relevant link for the following round if there are succeeding rounds to still complete.

Once the third and final round questionnaire is completed by participants, the researcher will collect and analyse the responses and provide feedback to all participants via email of the overall consensus reached towards measurement across the four contexts. You will be able to ask any questions to the researcher throughout the study via email regarding any concerns or queries you may have.

After the final consensus has been achieved and the summary provided, participants will be thanked for their time and invited to contact the lead researcher (Luke Sawyers) for any questions pertaining to the study they may have via email.

Expenses and payments

Unfortunately we cannot pay you to participate in the study. No known expenses will be incurred for participants.

What are the possible disadvantages and risks of taking part?

There are no major risks of taking part in this study. The main disadvantage is the time you will be asked to contribute, which will be approximately one hour (including the time taken to complete all rounds and read email communications).

What are the possible benefits of taking part?

The findings of this study are expected to provide a framework for the assessment of child and adult health literacy at the direct and proxy level of measurement. Thus, it can be assumed that the consensus gained from this study will provide clarity towards a construct which is frequently assessed inconsistently. By achieving consensus towards health literacy measurement, this research will streamline the application of health literacy research across both interventional studies, general population assessments and many more study design types utilising community samples. Providing the foundations for a consistent approach to health literacy research will enable more rigorous comparisons and conclusions to be made for future research in the field.

One expectation from the findings of this study in particular is that a greater understanding towards child and adult health literacy can be obtained. Both areas have conveyed inconsistency by which health literacy is assessed as an outcome, whether this be across the differing approaches taken towards health literacy measurement for interventions (Ayaz-Alkaya, Terzi, Isik & Sonmez, 2019; Ishikawa et al., 2018; McCaffery et al., 2019) or the notable conceptual and/or psychometric health literacy measurement critique identified in recent reviews (Haun, Valerio, McCormack, Sørensen & Paasche-Orlow, 2014; Okan et al., 2018). Collating an expert panel to determine the most important components for community child and adult health literacy assessment at the direct and proxy level of measurement will therefore promote more valid and reliable outcome practices for future research in the field, consequently improving the quality and consistency of future community health literacy research.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Prof Clive Roberts, Chair of the Pharmacy School Research Ethics Committee, Boots Science Building, University of Nottingham, University Park, NG7 2RD, UK clive.roberts@nottingham.ac.uk 00 44 115 9515101 .

Will my taking part in the study be kept confidential?

We will follow UK ethical and legal practice and all information about you will be handled in confidence.

All participants will agree beforehand to treat anything said during the Delphi study as confidential and will be reminded not to relay any of the information discussed to anyone outside the room.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham, Monash University and the University of Sydney who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about you which leaves the University's OneDrive will have your name removed (anonymised) and a unique code will be used so that you cannot be recognised from it. UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (Mr Luke Sawyers) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally-identifiable information possible. You can find out more about how we use your information and read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

Your personal data (address, email address, telephone number) will be kept for six months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Although what you say in the Delphi process is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then we will no longer collect information about you or from you, but the information collected prior to this cannot be erased as we are unable to tamper with study records, and this information may have already been used in some analyses and may still be used in the final analyses. In order to stop receiving unnecessary reminders as part of the general procedure for Delphi rounds, inform the lead researcher (Luke Sawyers) via email that you do not wish to participate any further. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

Findings may be submitted for publication in any relevant scientific journals and wider university publications. If you are interested in receiving a copy of the published work, please notify the researcher via email. Your identity will be kept confidential in any reports or publications produced from this research, unless you request otherwise.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and has no funding.

Who has reviewed the study?

All research in healthcare is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The School of Pharmacy Research Ethics Committee (Ref 014-2021).

Further information and contact details

Lead Researcher:

Mr Luke Sawyers

PhD Student, Division of Pharmacy Practice and Policy, School of Pharmacy, University of Nottingham

C21, School of Pharmacy Building, University Park, Nottingham, NG7 2RD

UK

Msxls17@nottingham.ac.uk

Supervisors:

Dr Li Shean Toh

Assistant Professor, Division of Pharmacy Practice and Policy, School of Pharmacy, University of Nottingham

Room C04, School of Pharmacy Building, University Park, Nottingham, NG7 2RD

UK

Telephone: +44 (0) 115 95 15168

lishean.toh@nottingham.ac.uk

Professor Claire Anderson

Professor of Social Pharmacy, Division of Pharmacy Practice and Policy, School of Pharmacy, University of Nottingham

Room C01 School of Pharmacy Building, University Park, Nottingham NG7 2RD

UK

Telephone : +44 (0)115 9515389

claire.anderson@nottingham.ac.uk

Research participant privacy notice

Privacy information for Research Participants

Privacy information for research participants

The University of Nottingham, University Park, Nottingham, NG7 2RD, United Kingdom (+44 115 951 5151) is committed to protecting your personal data and informing you of your rights in relation to that data. The University of Nottingham is registered as a data controller under the Data Protection Act 1998 (registration No. Z5654762 – https://ico.org.uk/ESDWebPages/Entry/Z5654762).

One of the University's responsibilities as a data controller is to be transparent in our processing of your personal data and to tell you about the different ways in which we collect and use your personal data. The University will process your personal data in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

For information about the University's obligations with respect to your data, who you can get in touch with and your rights as a data subject, please visit: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you are concerned about how your personal data is being processed, please contact the University's Data Protection Officer at dpo@nottingham.ac.uk. The postal address of the Data Protection Officer is:
Data Protection Officer,
Legal services
A5, Trent Building,
University of Nottingham,
University Park,
Nottingham, NG7 2RD
United Kingdom

Why we collect your personal data

We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning.

Legal basis for processing your personal data under GDPR

The legal basis for processing your personal data on this occasion is Article 6(1a) consent of the data subject.

How long we keep your data

The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researcher who gathered and processed the data may also store the data indefinitely and reuse it in future research. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data. Measures to safeguard your stored data include:

- Electronic data will be kept on the University of Nottingham's encrypted OneDrive. The data will only be accessed by the research team. Electronic data will be backed up every 24 hours to both local and remote media in encrypted format.
- Computer held data including the study database will be held securely and password protected. All data will be stored on a secure dedicated web server. Access will be restricted by user identifiers and passwords.
- Paper documents that include youth data will be held securely, in a locked room, or locked cupboard or cabinet. Access to the information will be limited to the researcher and any relevant regulatory authorities.

Appendix 12: Cross-sectional Study – Social Media Recruitment Messages

Facebook:

Hi everyone – I'll keep this short!

I'm currently looking to recruit participants for the final stage of my PhD. We've just opened a quick 10-15 minute survey – how original – to understand more about child health literacy in the UK (how children understand, access, appraise and apply health information).

If you know any parents and/or carers with 1) 10-13 year old children and 2) are living in the UK presently, or if you yourself fit this criteria, I would greatly appreciate it if you could send across the below survey link to them or take part if you are eligible. The first two sections require parents/carers to complete a brief consent form and some demographics (general information about the participant), and the remaining survey is for the child to complete independently – this will be clearly signposted within the survey. All data collected will remain strictly confidential. The survey link and further information pertaining to our study can be found below:

https://nottinghampharmacy.fra1.qualtrics.com/jfe/form/SV_ea3J2DR1DDEIoya

If you have any questions/queries/problems, please do let me know. Any shares or dissemination of the survey link would be greatly appreciated.

Thank you 😊

Twitter:

We are now recruiting participants as part of my PhD project, and we would greatly appreciate your support to better understand health literacy in the UK! Please see the attached leaflet for further details and find the survey link here: http://shorturl.at/cdJY4

[Study leaflet inserted here]

LinkedIn:

We are now recruiting participants as part of my PhD project, and we would greatly appreciate your support to better understand health literacy in the UK! Please see the attached leaflet for further details and find the shortened survey link here:

http://shorturl.at/cdJY4

[Study leaflet inserted here]

Mumsnet:

Helping children to help themselves - parents and 10-13 year old children needed!

We are looking to recruit UK-based parents of 10-13 year old children, and children themselves, to complete a very short online survey. Please see the link below for further details and find the shortened survey link here:
http://shorturl.at/cdJY4

Special Interest Groups:

A variation of the school email (see Appendix 13) was used, removing school-relevant elements.

Note:

The leaflet disclosed in the communications above represents the leaflet seen in Appendix 12 (see below).

University of Nottingham
UK | CHINA | MALAYSIA

Child health literacy – we need your help!

We are looking to recruit children to complete a short survey about their health, self-efficacy, and their experiences with health information.

We are looking to recruit:

- **Children aged 10-13 years.**
- **Currently reside in the UK.**

What we want from you:

- 10-15 minutes of you and your child's time to participate in a brief survey.

Parents/carers will be required to give consent in the first part of the survey and answer some brief questions, and children will complete the remaining sections.

If you and your child fit the above criteria, please scan the QR code at the bottom right corner of this leaflet or visit the link below:

https://nottinghampharmacy.fra1.qualtrics.com/jfe/form/SV_ea3J2DR1DDEloya

For any questions or queries relating to the study, please contact Mr Luke Sawyers via email (msxls17@Nottingham.ac.uk)

Nottingham.ac.uk/pharmacy

Appendix 14: Cross-sectional Study – School Recruitment Letter and Email

School email:

Dear _____,

I hope this message finds you well. My name is Mr Luke Sawyers, a PhD student at the University of Nottingham's School of Pharmacy. As part of an ongoing project, myself and my research team (Dr Li Shean Toh; Prof Claire Anderson) are looking to recruit children aged 10-13 years as part of a project to assess child health literacy levels in England (their ability to access, understand, appraise and apply health information), alongside some additional elements (their self-efficacy, health behaviours, and some brief demographics). This study has been approved by the School of Pharmacy Research Ethics Committee (Ref: 018-2021), and all information will remain strictly confidential and anonymous.

Through this study, we hope to use the data collected to improve the state of child health outcomes in England, and we cannot do this without your help. We would greatly appreciate any support you can provide in reaching the above sample we mentioned, and would be happy to draft a school email for you to disseminate with regards to the study if this is preferred. We are also happy to discuss any potential incentives associated with any dissemination you provide, including having one of our experts from the school host a workshop/seminar/lesson on a health-related topic of interest for the children. Please do let me know if you are interested in this, and we can take it from there.

We have a quick online survey link which can be disseminated to parents/carers of children who fit the above age range, which is here: https://nottinghampharmacy.fra1.qualtrics.com/jfe/form/SV_ea3J2DR1DDEIoya

Parents will be asked to complete the first two sections of the survey, and then children will complete the remainder of the survey.

If you have any additional questions or queries, please do not hesitate to get in touch with me directly at msxls17@nottingham.ac.uk. Further information regarding the study is available on request.

Thank you for your time in reading this email, and I look forward to hearing from you in due course.

Kind regards,

Mr Luke Sawyers.

School contact letter (attached to email):

University of Nottingham
UK | CHINA | MALAYSIA

School of Pharmacy, Division of Pharmacy Practice and Policy
University of Nottingham
University Park
Nottingham
NG7 2RD

[Date: XX XXX XXXX]

Recipient's name

Recipient's department name

Address 1

Address 2

City

County

Postcode

Dear ________

My name is Luke Sawyers, a second year PhD student from the University of Nottingham's School of Pharmacy, Division of Pharmacy Practice and Policy. As part of my PhD project, I plan to investigate child Health Literacy (HL) levels in England as a means to determine whether future strategies and resources targeting child HL are necessary. HL refers to a person's capacity to understand, interpret, appraise and apply health information, and there are currently no assessments of child HL in England to a reliable standard.

What we would like to do is to measure child HL via a short survey, and in order to provide a sufficient overview, we plan to utilise the school context to obtain an accurate and independent HL score for year 6 children in England. This would form part of the wider population assessment for 10-11-year-old child HL, with year 6 of primary schools being an effective way of collecting a large sample while ensuring that children complete the assessment independently.

Understanding child HL levels in England is a vital step for improving child health outcomes and health behaviours, and will enable interventions to be developed to foster the HL skills children will need in everyday life. As such, we would like to invite your school to participate in this project. You would be required to: **Distribute consent forms, information sheets** (adult and child versions; year 6 children and parents/carers of children) **and the HL survey to year 6 children**; **make sure the participating children complete the survey during class time** (any time convenient to you – no more than 10-15 minutes; age-appropriate health-related questions within the survey); **gather rough estimates regarding length taken for children to complete survey and child ability to independently complete the survey**; **and send across completed consent forms and surveys.**

Once the questionnaires are complete, these can be redistributed back to myself (Mr Luke Sawyers) at the email address at the bottom of this letter through scanning the completed documents (to minimise the potential transmission of Covid-19). Your participation will then be complete. Upon request you will be able to see the study findings in an anonymised and strictly confidential format when they undergo academic publication.

If you have any questions or queries pertaining to the proposed project, please email me (Mr Luke Sawyers) back at the email address listed below. We are also flexible in the approach we take regarding data collection within reason, and are happy to make alternative arrangements to cater to your participation. Due to the Covid-19 pandemic we have made the necessary arrangements to ensure the risk of Covid-19 transmission is minimal, hence the study materials being provided virtually for printing/online use on-site as opposed to externally. However, we are happy to make additional changes to the methodology that you feel are necessary. Lastly, we would be happy to discuss any non-financial compensation for your time (such as an online/pre-recorded education workshop on medicines/health/etc or any other ideas with our academics/PhD students for any year group) If this is something of interest to you.

Thank you in advance for reading and we very much look forward to hearing back from you soon.

Kind regards,

Appendix 15: Cross-sectional Study – Child Consent Form

Child participant consent form

(Version 2.0: 27/08/21)

Project title Looking at Children's Health Literacy in England.
Researcher Mr Luke Sawyers.
Supervisor's Dr Li Shean Toh, Professor Claire Anderson.

Please return this form to [insert name] by [insert day, month year]

I have **read** the Information Sheet and understand the research project and what I will be doing.

I **agree** to take part in the research project.

I **talked** about the research project with my parent/guardian.

I **understand** that if I don't want to stay in the research project, I can **leave** at any time and I won't get into any trouble.

If anything is written about me, I will get a **different name** so that nobody will know who I am.

Print name (child)
……………………………………………………………………………………

Signed (child)
……………………………………………………………………………………

Date ………………………………………

Contact Details

Researcher: Mr Luke Sawyers, msxls17@nottingham.ac.uk.

Tutor/Supervisor: Dr Li Shean Toh, lishean.toh@nottingham.ac.uk.

School of Pharmacy Research Ethics Officer: PA-PHARM-ETHICS@exmail.nottingham.ac.uk

Appendix 16: Cross-sectional Study – Adult Consent Form

PARTICIPANT CONSENT FORM
(Version 2.0: 27/08/2021)

Project title: A Multi-area Assessment of Child Health Literacy in England.
Researcher's name: Mr Luke Sawyers.
Tutor's/Supervisor's name: Dr Li Shean Toh and Prof Claire Anderson.
Participant Serial Identification Code: S3-XX **Please initial boxes:**

- I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. I understand and agree for my child to take part. ☐
- I understand the purpose of the research project and my child's involvement in it. ☐
- I understand that I may withdraw my child from the research project at any stage and that this will not affect my or my child's status now or in the future. ☐
- I understand that while information gained during the study may be published, myself and my child will not be identified and my child's personal results will remain confidential. ☐
- I understand that data will be stored securely, where hard copies of the study materials will be scanned and uploaded to the University of Nottingham OneDrive, whereby only the researcher and above supervisors will be able to access the information. This will also be the case for any electronic study materials utilised. The University of Nottingham hold research data for a period of seven years for legal purposes, and will be securely destroyed at the end of this time. ☐
- I understand that I will be provided with a privacy notice under the General Data Protection Regulation ☐
- I understand that I may contact the researcher or tutor if I require further information about the research, and that I may contact the Research Ethics Committee of the School of Pharmacy, University of Nottingham, if I wish to make a complaint relating to my involvement in the research. ☐

Signed …………………………………………………………………………
(Parent/Guardian/Carer of research participant)

Print name (Parent/Guardian/Carer) …………………………………… **Date** …………………………………

Child Age …………… **Child Gender** …………… **Child Postcode** ……………

Contact details

Researcher: *Mr Luke Sawyers, University of Nottingham, School of Pharmacy, Division of Pharmacy Practice and Policy.* Email: msxls17@nottingham.ac.uk

Tutor: *Dr Li Shean Toh, University of Nottingham, School of Pharmacy, Division of Pharmacy Practice and Policy. Room C04, School of Pharmacy Building, University Park*
Nottingham, NG7 2RD. Email: lishean.toh@nottingham.ac.uk

School of Pharmacy Research Ethics Officer: PA-PHARM-ETHICS@exmail.nottingham.ac.uk

Appendix 17: Cross-sectional Study – Child Participant Information Sheet

(Version 2.0: 27/08/21)

Hello! On this page, we will tell you a little bit about our project. We will tell you what we want to do, and what you will be doing in the project if you take part.

My project

The project looks at how children understand, use and apply health information, which we will do with a short questionnaire. I want to see how children understand and use health information.

Activities

During the project, we will ask you to complete a short questionnaire about your experience with health information. In the project, I will not be present but I will provide the questionnaire for you to complete in an online or paper format. Once you have finished the questionnaire, these will be either automatically passed on to me, or I will arrange with your parents for them to be passed to me.

Things you need to know

You can **always** ask any questions to me by email (or you can ask your parents to ask me for you).

I will keep a copy of the questions sheet you complete so I can study them. If I write anything about you, I will give you a **secret name** so that nobody will know who you are.

You can **stop** at any time. You don't have to give a reason and nothing will happen to you as a result.

If you are happy with what I have told you and want to take part in the project, you can sign your name on the survey before you start. This will be given to you shortly through either an online link or a paper survey.

Mr Luke Sawyers, PhD Student, University of Nottingham, Division of Pharmacy Practice and Policy. Msxls17@nottingham.ac.uk.
School of Pharmacy Research Ethics Officer: PA-PHARM-ETHICS@exmail.nottingham.ac.uk

University of Nottingham
UK | CHINA | MALAYSIA

Participant Information Sheet: Work Phase 1
(Version 2.0: 27/08/21)
Title of Study: A Multi-School Assessment of Child Health Literacy in England.
Name of Researcher(s): Mr Luke Sawyers, Dr Li Shean Toh, Prof Claire Anderson.

We would like to invite your child to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. If anything is unclear, please feel free to contact us to discuss with the contact details at the end of the document.

What is the purpose of the study?
The purpose of this study is to assess the health literacy level of primary school children who are currently in year 6 and reside in England. Health literacy is a skill which refers to a person's ability to access, understand, apply and be critical of health information in order to make appropriate judgements and decisions in everyday life regarding health promotion, disease prevention, and healthcare in order to maintain or improve quality of life.

Why have I been invited?
You are being invited to provide consent for your child to take part because they are currently a year 6 student in a primary school in England. We would like to find out more about their health literacy skills and we have therefore invited them to participate in a short survey assessing their health literacy skills during school time.

Do I have to take part?
It is up to you to decide whether or not your child should take part. You will be given a consent form and information sheet to read with your child. If you do decide to take part you will be asked to sign a consent form and make sure you have read and understood the information sheet. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?
Once you decide for your child to take part, you will hand back the completed consent forms (both adult and child forms) to the school, as the information sheets will be yours to keep. Due to the Covid-19 pandemic, no researchers will be physically present in the school to conduct the research, and all of the materials will be provided to the school for your child to complete during school time.
At some point during term time, your child will be provided with a short survey to complete which will ask them a variety of questions about health-related material, aiming to test their ability to understand, apply and appraise health information. A member of staff from the school will be available for any questions relating to the completion of the survey your

child may have, and they will have the opportunity to ask any questions relating to the research.
Once the survey is complete, a member of staff from the school will collect them up and they will be sent across to us at the University of Nottingham for further analysis. The demographic information we are collecting (such as child age, gender and postcode) will be used for analysis only, where we will use this information to predict child health literacy levels in the future which will allow us to develop more effective targeting strategies for promoting child health literacy. This is the sole purpose of your child's demographic information and will only be used for analysis purposes.

Expenses and payments
Unfortunately we cannot pay you or your child to participate in the study.

What are the possible disadvantages and risks of taking part?
There are no major risks of taking part in this study. The main disadvantage is the time your child will be asked to contribute, which will be approximately 10-15 minutes, plus a small amount of time beforehand for the relevant school staff member to explain the study and collect the materials.

What are the possible benefits of taking part?
The findings of this study are expected to provide new information regarding children's health literacy levels in England, which can assist in helping develop new ways for improving health outcomes for children during childhood, adolescence, and their transition to adulthood. This may also help determine whether any changes should be made to the school curriculum to improve a child's ability to understand, navigate, and be critical of health information in real-world health contexts.
Further to this, the survey may act to provide children with a chance to apply the literacy and critical thinking skills they have learned throughout their school education to that of a new – and highly relevant – context: health and wellbeing.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Prof Clive Roberts, Chair of the Pharmacy School Research Ethics Committee, Boots Science Building, University of Nottingham, University Park, NG7 2RD, UK
clive.roberts@nottingham.ac.uk +44 115 9515101.

Will my taking part in the study be kept confidential?
We will follow UK ethical and legal practice and all information about you and your child will be handled in confidence.
If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as research participants and we will do our best to meet this duty.
All information which is collected about you and your child during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the school will have your name and

address removed (anonymised) and a unique code will be used so that you cannot be recognised from it. UK Data Protection laws state the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

Your personal data (address, email address, telephone number) will be kept for six months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Although what you say in classroom is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

Findings may also be submitted for publication in any relevant scientific journals and wider university publications. If you are interested in receiving a copy of the published results, please notify the researcher via email. Your identity will be kept confidential in any reports or publications produced from this research.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and has no funding.

Who has reviewed the study?

All research in healthcare is looked at by an independent group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given favourable opinion by The School of Pharmacy Research Ethics Committee (Ref XXX-XXXX).

Further information and contact details

Researcher:
Mr Luke Sawyers

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Professor Claire Anderson
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Research participant privacy notice

Privacy information for research participants

The University of Nottingham, University Park, Nottingham, NG7 2RD, United Kingdom (+44 115 951 5151) is committed to protecting your personal data and informing you of your rights in relation to that data. The University of Nottingham is registered as a Data controller under the Data Protection act 1998 (registration No. Z5654762 – https://ico.org.uk/ESDWebPages/Entry/Z5654762).

One of the University's responsibilities as a data controller is to be transparent in our processing of your personal data and to tell you about the different ways in which we collect and use your personal data. The University will process your personal data in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018.

For information about the University's obligations with respect to your data, who you can get in touch with and your rights as a data subject, please visit: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you are concerned about how your personal data is being processed, please contact the University's Data Protection Officer at dpo@nottingham.ac.uk. The postal address of the Data Protection Officer is:

Data Protection Officer,
Legal services
A5, Trent Building,
University of Nottingham,
University Park,
Nottingham, NG7 2RD
United Kingdom

Why we collect your personal data

We collect personal data under the terms of the University's Royal Charter in our capacity as a teaching and research body to advance education and learning.

Legal basis for processing your personal data under GDPR

The legal basis for processing your personal data on this occasion is Article 6(1a) consent of the data subject.

How long we keep your data

The University may store your data for up to 25 years and for a period of no less than 7 years after the research project finishes. The researcher who gathered and processed the data may also store the data indefinitely and reuse it in future research. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data. Measures to safeguard your stored data include:

- Electronic data will be kept on the University of Nottingham's encrypted OneDrive. The data will only be accessed by the research team. Electronic data will be backed up every 24 hours to both local and remote media in encrypted format.
- Computer held data including the study database will be held securely and password protected. All data will be stored on a secure dedicated web server. Access will be restricted by user identifiers and passwords.
- Paper documents that include youth data will be held securely, in a locked room, or locked cupboard or cabinet. Access to the information will be limited to the researcher and any relevant regulatory authorities.

Appendix 19: Cross-sectional Study – Survey

Parent Briefing

This section is for parents to complete:

Thank you for taking an interest in our study titled "*A Multi-area Assessment of Child Health Literacy in the UK*". We are interested in understanding more about the state of child health literacy levels across the UK. Health literacy refers to a person's ability to understand, access, appraise and apply health information.
You and your child's response to this survey will help inform future research and policy across England. This survey is a collaborative research project within the University of Nottingham's School of Pharmacy, Division of Pharmacy Practice and Policy. For any concerns or queries regarding the project, please contact the lead researcher by email.

The research team is comprised of the following:
Mr Luke Sawyers (Lead Researcher; msxls17@nottingham.ac.uk), Prof Claire Anderson, Dr Li Shean Toh.
For further information regarding our study, please see the following participant information sheets, which you can download below:

[**Attachment**: Participant Information Sheet Adult Version]

[**Attachment**: Participant Information Sheet Child Version]

Parent Consent Form

You will shortly be prompted to hand over the survey to your child. For the moment, **parents/carers** please continue with the survey.

The following statements are from the parental consent form regarding your child's participation in this survey study. Please read each statement and respond accordingly.

	Response	
	Yes	No
I have read the Participant Information Sheet and the nature and purpose of the research project has been explained to me. I understand and agree for my child to take part. (1)	☐	☐
I understand the purpose of the research project and my child's involvement in it. (2)	☐	☐
I understand that I may withdraw my child from the research project at any stage and that this will not affect my or my child's status now or in the future. (3)	☐	☐
I understand that while information gained during the study may be published, myself and my child will not be identified and my child's personal results will remain confidential. (4)	☐	☐
I understand that data will be stored securely, where hard copies of the study materials will be scanned and uploaded to the University of Nottingham OneDrive, whereby only the researcher and above supervisors will be able to access the information. This will also be the case for any electronic study materials utilised. The University of Nottingham hold research data for a period of seven years for legal purposes, and will be securely destroyed at the end of this time. (5)	☐	☐
I understand that I will be provided with a privacy notice under the General Data Protection Regulation. (6)	☐	☐
I understand that I may contact the researcher or tutor if I require further information about the research, and that I may contact the Research Ethics Committee (contact details available in the Participant Information Sheet) of the School of Pharmacy, University of Nottingham, if I wish to make a complaint relating to my involvement in the research. (7)	☐	☐

Adult Consent Signature

Please sign below to confirm you have read and understood the above statements regarding you and your child's participation in this survey study.

○ Parent Name (1) ________________________________

○ Child Initials (2) ________________________________

○ Date (3) ________________________________

Consent Statement

Are you happy for you and your child to participate in our survey study?

○ Yes (1)

○ No (2)

Parent-provided Demographics

Age Demographic

How old is your child who will be completing this survey?

- ○ 10 years old (0)
- ○ 11 years old (1)
- ○ 12 years old (2)
- ○ 13 years old (3)
- ○ Another age (4)

Gender Demographic

What gender is your child?

- ○ Male (0)
- ○ Female (1)
- ○ Other (please specify below) (2)

____

Postcode Demographic

Please tell us the postcode you and your child live within (please note, this information will strictly be used to collate area poverty assessments. This information will not be used for any other purpose).

____

Important Note:

Parents, please now hand over to your **child** and allow them to continue the survey **independently**. They will begin on the next page, with the survey taking approximately 10-15 minutes.

Child Consent Form

Briefing

Children:
Hi, and welcome to our survey. We have some questions we would like to ask you about how you understand, use and apply health information. We are doing this because we are interested in how you use your skills with regards to your health. This survey will take around 10-15 minutes for you to complete. You will know you are finished when a "Thank you for taking part in our study" screen pops up. Before we begin the survey, we want to make sure you're happy to take part in our survey.

Child Consent Signature

Please put your details down on the right side if you are happy to take part in this survey.

Your First Name (1) ____

Today's Date (2) ____

Health Literacy Survey

Q1

How well do you understand the following information?

	Very bad (1)	Bad (2)	Moderate (3)	Good (4)	Very good (5)	I do not make use of this kind of information (0)
How well do you understand instruction leaflets for medication?	☐	☐	☐	☐	☐	☐

Q2

	Very bad (1)	Bad (2)	Moderate (3)	Good (4)	Very good (5)	I do not make use of this kind of information (0)
How well do you understand information brochures on health issues?	☐	☐	☐	☐	☐	☐

Q3

	Disagree strongly (1)	Disagree (2)	Agree (3)	Agree strongly (4)	I do not have experience with these issues (0)
When I have questions on diseases or complaints, I know where I can find information on these issues.	☐	☐	☐	☐	☐

Q4

	Disagree strongly (1)	Disagree (2)	Agree (3)	Agree strongly (4)	I have not been interested in these issues (0)
When I have questions on diseases or complaints, I know where I can find information on these issues.	☐	☐	☐	☐	☐

Q5

	Never (1)	Seldom (2)	Sometimes (3)	Often (4)	Always (5)	There have never been any questions (0)
How often were you able to help your family members or a friend if they had questions concerning health issues?	☐	☐	☐	☐	☐	☐

Q6

	Never (1)	Seldom (2)	Sometimes (3)	Often (4)	Always (5)	There have never been any questions (0)
When you came up with questions concerning health issues, how often were you able to get information and advice from others (family and friends)?	☐	☐	☐	☐	☐	☐

Q7

	Very bad (1)	Bad (2)	Moderate (3)	Good (4)	Very good (5)	I have not been interested in these issues (0)
How well are you doing in choosing the advices and offers that fit with you the most?	☐	☐	☐	☐	☐	☐

Q8

	Disagree strongly (1)	Disagree (2)	Agree (3)	Agree strongly (4)	I do not have experience with these issues (0)
Regarding information on health on the internet, I'm able to determine which sources are of high and which of poor quality.	☐	☐	☐	☐	☐

General Self-efficacy Scale

Q9

Please rate the following statements accordingly:

	Not at all true (1)	Hardly true (2)	Moderately true (3)	Exactly true (4)
I can always manage to solve difficult problems if I try hard enough.	☐	☐	☐	☐
If someone opposes me, I can find the means and ways to get what I want.	☐	☐	☐	☐
It is easy for me to stick to my aims and accomplish my goals.	☐	☐	☐	☐
I am confident that I could deal efficiently with unexpected events.	☐	☐	☐	☐
Thanks to my resourcefulness, I know how to handle unforeseen situations.	☐	☐	☐	☐
I can solve most problems If I invest the necessary effort.	☐	☐	☐	☐
I can remain calm when facing difficulties because I can rely on my coping abilities.	☐	☐	☐	☐
When I am confronted with a problem, I can usually find several solutions.	☐	☐	☐	☐
If I am in trouble, I can usually think of a solution.	☐	☐	☐	☐
I can usually handle whatever comes my way.	☐	☐	☐	☐

Health Behaviours Survey

Q10

Please indicate how much you do the below activities.

	Never (1)	Sometimes (2)	Usually (3)	Always (4)
I get between 7-9 hours of sleep every day.	☐	☐	☐	☐
I brush my teeth twice a day.	☐	☐	☐	☐
I visit the dentist every year.	☐	☐	☐	☐
I watch less than 2 hours of TV every day.	☐	☐	☐	☐
I eat fruit every day.	☐	☐	☐	☐
I eat vegetables every day.	☐	☐	☐	☐
I limit my intake of salty snacks and high-sugar snacks.	☐	☐	☐	☐
I say "no" to smoking cigarettes.	☐	☐	☐	☐
I stay away from alcohol.	☐	☐	☐	☐
I exercise regularly (1 hour per day; can include PE lessons, active play/sports, walking, cycling)	☐	☐	☐	☐

Health Learning Open Question

Q11

What would you like to learn about regarding your health?

____

____

____

End of Survey

We thank you for your time spent taking this survey.
Your response has been recorded.

Health and Wellness Wordsearch

Z	G	O	R	G	E	S	I	C	R	E	X	E	G	Y
V	S	W	I	E	U	N	K	C	A	B	C	O	A	S
P	N	V	Y	L	L	O	Y	B	O	R	A	R	S	L
O	E	Y	U	A	A	I	T	D	N	L	P	E	M	A
V	D	W	D	I	C	T	A	R	S	Y	N	Y	F	T
G	O	A	Z	C	T	P	M	B	O	L	N	P	I	N
N	H	L	A	O	I	I	C	G	L	P	F	A	N	E
I	Y	K	U	S	V	R	A	E	P	E	S	R	A	M
T	D	I	A	N	I	C	W	H	Y	G	I	E	N	E
A	R	N	T	V	T	S	G	G	E	E	E	H	C	L
E	A	G	O	Y	I	E	H	N	N	A	M	T	I	Z
B	T	B	Y	M	E	R	E	G	I	I	L	Z	A	S
O	E	J	M	R	S	P	E	R	U	K	P	T	L	Y
G	N	I	K	O	M	S	F	Y	R	A	I	O	H	B
B	W	S	P	I	R	I	T	U	A	L	L	B	C	Y

- activities
- coping
- financial
- healthy
- laugh
- pray
- smoking
- sport
- walking
- biking
- exercise
- goals
- hygiene
- no
- reliable
- spiritual
- volunteer
- yoga
- back
- eating
- give
- hydrate
- mental
- prescriptions
- social
- therapy
- wellness

Find the words listed above in the puzzle. Words can go in any direction, and can share letters as they cross over each other.