



From hierarchies of exclusion to participant-led inclusion: A qualitative research agenda for health information literacy

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ABSTRACT

Health information literacy links people to the information sources and ways of knowing that they need to make informed decisions about wellbeing. Qualitative research methods provide a powerful way to centre how people use information to learn about health as well as the conditions and social structures that enable and constrain information practice. This approach challenges health information literacy's more traditional focus on the measurement of normative, approved skills. Collaborative enquiry analysis of three recent studies into critical health literacy and children, chronic illness (irritable bowel syndrome) and vaccine hesitancy establishes a research agenda for qualitative health information literacy research. Producing four themes, including positioning information settings as health literate organisations, literacies for life, scaling up infrastructure and empowerment, the research agenda outlines directions for future theoretical, practical, and methodological health information literacy research.

1. Introduction

Health literacy is a “critical determinant” of individual and population health (The Lancet, 2022). As an overarching concept, health literacy includes health information literacy, which enables people to access, evaluate, understand, create, and apply health information effectively to give meaning to and make informed decisions about their own health or the health of others (Lawless, Toronto, & Grammatica, 2016). Encompassing a set of social practices necessary to navigate the complexity of an evolving health information environment (Nutbeam, 2023), health information literacy also incorporates how people deal with health-related misinformation and disinformation as well as physical, digital, and hybrid settings. Qualitative methods, with their focus on generating rich descriptions of social reality, are starting to be recognized as a useful way to explore how people link to information sources and ways of knowing they need to cope with and make these decisions about wellbeing (Lloyd, Bonner, & Dawson-Rose, 2014; Papen, 2008; Samerski, 2019). However, nuanced and non-traditional approaches to health information literacy research call for joined-up research priorities within the field and a consideration of emerging gaps and omissions for health information literacy research to keep pace with the evolving health information environment. Through a

collaborative narrative enquiry of three recently published qualitative health information literacy studies, the research agenda presented here established four major directions for future qualitative health information literacy studies. While information literacy research has often focused on the design of teaching interventions, the focus of this research agenda centered upon establishing research directions for the phenomena of information literacy itself.

2. Research problem

Health literacy research has increasingly started to recognize the important role information plays in health and wellbeing decision-making (Samerski, 2019). Simultaneously, there has been increasing interest in understanding and engaging with the health context within information literacy policymaking (Chartered Institute of Library and Information Professionals (CILIP), 2018; Health Education England (HEE), 2021). Yet, research in health information literacy still tends to be dominated by quantitative rather than qualitative study designs, as exemplified by a continued reliance on standardized tests, surveys, and numerical data (Chinn, 2011; Hicks, 2022; Samerski, 2019). The sidelining of qualitative research methods is problematic because it centers health information literacy on narratives of provision and

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attainment (Lloyd, 2021) or the measurement of approved information skills rather than the conditions and social structures that enable and constrain information practice. The scope of health information literacy research is limited by centering the competencies people are perceived to lack rather than the complex and everyday ways people use information to learn about health and wellbeing, including how they create, discover, access, organize, and trust relevant forms of knowledge.

The value in developing a research agenda for qualitative health information literacy research lies in the production of richer data about how people make health-related decisions, and the role information plays in shaping health and wellbeing activities. Extending data collection and creation by challenging assumptions about the information resources that are useful to people, a qualitative health information literacy research agenda increases the understanding of information activities that support a person's transition to knowledgeable health practice, particularly during emotionally turbulent periods. A greater awareness of the complexity of health information landscapes will lead to the creation of richer and more meaningful health and information literacy educational models and guidelines. This research agenda will benefit health and information researchers by providing theoretical, empirical, and methodological direction for increasing the complexity and the scope of scholarship in the field. Greater understanding of health activity will also benefit information and health professionals who are involved in the design of formal and informal educational opportunities.

3. Literature review

3.1. Health literacy and information literacy

Health literacy and information literacy form two related concepts that have been considered in isolation from each other due to their emergence from different disciplinary areas (Hicks, 2022). Although both fields share origins in the United States' global competitiveness agenda (Brandt, 2004), information literacy evolved to focus on information use within academic library contexts (Lawless et al., 2016) while health literacy became entrenched in medical initiatives (Huber, Shapiro, & Gillaspay, 2012). However, as information literacy starts to encompass information use within everyday life (Chartered Institute of Library and Information Professionals (CILIP), 2018) and health literacy begins to include school and organizational wellbeing within its remit (Paakkari & Paakkari, 2012), some effort has been made to re-align the two areas of study. A series of reviews provides evidence of shared citation networks (Galvin & Lee, 2020; Hicks et al., 2023; Huhta, Hirvonen, & Huotari, 2018a; Huhta, Hirvonen, & Huotari, 2018b; Klem et al., 2019; Pinto, Escalona-Fernández, & Pulgarín, 2013) while conceptual comparisons of the two fields (Dalrymple, Zach, & Rogers, 2014; Lawless et al., 2016) demonstrate a grounding in similar goals and aims. More recent research has argued that the sociocultural turn provides a potential point of synergy between the two fields (Hicks, 2022), an idea that is also being explored through Finnish work into "health information literacy" (Hirvonen et al., 2020; Multas, 2022). More commonly, research continues to treat each concept separately, with recent infodemiology scholarship perpetuating traditional divisions (Abel & McQueen, 2021; Eysenbach, 2020; Koltay, 2022).

Conceptual distance is even more surprising given the connections between the two fields of study (Hicks, 2022). Libraries offer both health and information literacy educational opportunities, with public libraries constituting recognized yet under-utilized partners for health literacy education (Naccarella & Horwood, 2020; Whitelaw, Coburn, Lacey, McKee, & Hill, 2017). Similar opportunities are also starting to be noted within the academic and school library sector, although mental health and wellbeing initiatives need to be more grounded in a professional knowledge base (Cox & Brewster, 2020; Cox & Brewster, 2021; Merga, 2022). Studies have further started to identify shared theoretical connections between the two fields, particularly as research moves around the sociocultural turn (Hicks, 2022). Criticality forms one area, with

both health and information literacy research drawing from Freirian pedagogy to establish social-justice focused models of practice (Chinn, 2011; Tewell, 2015). More recently, assumed relationships between empowerment and information work have become the focus of attention (Cron Dahl & Eklund Karlsson, 2016; Hicks & Lloyd, 2021). Embodiment forms another emerging area of shared interest with recent focus in somatic health knowledge (Samerski, 2019) catching up with information literacy's interest in "information that is produced, reproduced, and circulated and accessed in ways that are not articulated or expressed textually" (Lloyd et al., 2014). These shared points of interest illustrate the importance of developing a unified or complementary research agenda.

3.2. Qualitative methods

Both fields admit quantitative methods have been the most "conventional" way of collecting data on health or information literacy (Pinheiro, 2021, p. 94; Lloyd, 2021). Shaped by a broader disciplinary emphasis on measuring and comparing (Pinheiro, 2021, p. 94), the use of quantitative tools for health and information literacy research has been connected to ongoing needs to prove educational interventions are "worthwhile" (Chinn, 2011, p. 65). However, as commentators are starting to point out, a reliance on quantitative methods presents a limited picture of the complex ways people interact with health information in all its forms. The use of standardized health literacy tests, which measure people's knowledge "against the demands of the healthcare system," (Samerski, 2019, p. 1) will only ever position people as lacking skills while eliding broader considerations of power, including what and whose knowledge is authorized (Lloyd et al., 2014, p. 209). Quantitative research designs are also critiqued for gearing understandings of health information literacy towards a "rationalistic and individualistic understanding of human action," (Samerski, 2019, p. 1) an orientation that equates information work with outdated models of knowledge acquisition (Brinkley-Rubinstein, Bethune, & Doykos, 2015; Hicks, 2022). While these criticisms remain somewhat isolated within both fields, they represent an increasingly visible challenge to the positivist epistemological frameworks that have dominated for the last forty years.

Qualitative health and information literacy research has been far more piecemeal but has recently started to become more visible within each field (Lloyd, 2021). Enabling researchers to capture different perspectives and "ordinary" people's point of view (Papen, 2008, p. 21), a qualitative research design broadens the scope of health literacy analysis by shifting attention to a "readiness to use health information to the actual act of reading or writing health information," or how skills manifest (Pinheiro, 2021, p. 95). The ability to tap into material complexity, or how health information practices emerge, has sparked interest in moving beyond numerical forms of data. One qualitative methodology is ethnography (Papen, 2008; Samerski, 2019), auto-ethnography (Grant, 2019), and institutional ethnography (Jenkins, Sykes, & Wills, 2022), emphasizing social organization while positioning everyday settings and activities as the site of research. There is also growing interest in the use of visual, creative, and participatory methods, which provide a way for participants to represent and develop "resonance" (Mullett, 2008, p. 461) about health challenges in their community (Ardiles, Casteleijn, Black, & Sørensen, 2019; Estacio, Nathan, & Protheroe, 2020; Mullett, 2008; Multas, 2022; Nash et al., 2021). Complementing more traditional interview techniques (Lloyd et al., 2014), these methods facilitate insight into unexplored health information topics, such as information creation (Multas, 2022). At the same time, there has been little sustained consideration of the impact qualitative methodological approaches have upon health and information literacy research and future research directions.

4. Methods

This research agenda was established through analysis of three recent studies by the authors that employed qualitative methodologies to explore health information literacy practice. This analysis facilitated the joint identification of several directions for future research.

While qualitative research acknowledges that subjectivity shapes the research process, there is a need to be honest and transparent about researcher biases and motivations (Tracy, 2010, p. 842). Researcher positioning is presented below to acknowledge the impact of the authorial team's interdisciplinary reflexivity on the construction of this research agenda:

- AH is an information literacy researcher who worked for ten years as a practicing teaching librarian. Their disciplinary home is LIS, and they are currently employed in a LIS department at a university, where they carry out qualitative research. Health forms a key research theme within their research agenda and within the department's teaching. Their interest in health literacy arose from the COVID pandemic and from working with health sciences researchers on arts-based approaches for vaccination research.
- VG is a librarian-researcher who trained in supporting Evidence Based Medicine before undertaking an auto-ethnographic interdisciplinary PhD in health literacy. Situated between a School of English, a Medical School, and a University Library, their doctoral research deconstructed the hierarchy of clinical evidence to create space for qualitative approaches, capturing counter-narratives based on patients' experiences of living with the long-term health condition, irritable bowel syndrome.
- CJ is a public health practitioner with a background in information science. Their interest in health literacy can be traced back to their work with a NHS library service, where they were employed in a pilot role overseeing health literacy awareness training for NHS staff and public library staff. Their PhD in health literacy focused on the potential for public libraries to support children's development of critical health literacy skills. They now teach and research in the field of public health, with a continued focus on health literacy and organizational health literacy.

4.1. Reflexive appreciative inquiry

In keeping with the qualitative focus of the research, a reflexive appreciative inquiry that adopted collaborative creative writing was employed to surface shared themes and interests from the three individual studies. The aim was not to synthesize the three studies, but rather to collectively explore synergies through a narrative approach. Reed (2007) articulates how appreciative inquiry can be usefully employed in research projects, highlighting the connection with narrative methodologies through their shared potential to evoke and develop ideas about how the world is, and how it might be. Harnessing playful provocations through the poetic principle of appreciative inquiry (Cooperrider, Whitney, & Stavros, 2008), this collaborative narrative enquiry facilitated the discovery and sharing of the strengths of each individual research project, the forming of synergies and the collaborative imagining of the future for health information literacy. As an initial step in the collaborative enquiry process, the researchers each responded to the following three prompts:

- On the subject of my health information literacy research, I would like to say ...
- On the subject of health information literacy, the changes I would like to see are...
- Either sketch, paint, create, or find an image that represents your most provocative view on health information literacy.

The researchers came together as a group to present and discuss their responses to these questions. As part of this conversation, each researcher asked questions about responses and shared methodological reflections and connections from their own study, which they discussed in relation to their own positionality. The group also reflected on the absences and silences within these discussions, or the topics that were not surfaced through this collaborative enquiry process.

4.2. Analysis and coding

During this initial discussion, each researcher took their own set of detailed notes of the broader group conversations. This session was not audio-recorded to encourage sharing and exploration. The three researchers reflected on the broader conversation and individually open coded their own set of notes using the inductive and constant comparative techniques employed in constructivist grounded theory methods (Charmaz, 2014). The researchers came back together as a group to discuss and compare the emergent connections and coding across the group. Through this process, the group reconciled and established a more focused set of codes, which were used to refine the emerging research agenda themes.

The three studies that informed this research are detailed below.

4.3. Study 1: The potential of public libraries as settings for children's development of critical health literacy (Jenkins et al., 2022)

The first study that formed the basis for the research agenda was a doctoral study exploring the potential for public libraries to be supportive environments for the development of critical health literacy in children. Critical health literacy enables people to critique, reflect on, or participate in social and political processes relevant to health and to plan, implement, or evaluate actions to address the wider determinants of health. Promoting critical health literacy from early childhood can improve health and wellbeing in later life, but children's opportunities to develop critical health literacy are currently rare and tend to be limited to school settings.

The study was designed in consultation with a Children's Advisory Group of eight children from across the UK. The study setting was a public library system in England. The Children's Advisory Group provided feedback on the study design and ethics and piloted an ice-breaker activity using drawing elicitation and a data collection tool based on the Interview to the Double technique. The theoretical and methodological framework was institutional ethnography, in which the standpoint of children was adopted by the researcher to foreground children's interests. Semistructured interviews were conducted with a further 13 child informants, and semistructured text-elicitation interviews were conducted with 19 public library staff and community stakeholders.

Findings indicate the public library was not generally viewed as a setting for health. Texts from the public library sector in England described health literacy support for local communities as part of the national library service offer, but children's health literacy and the political nature of critical health literacy were considered to be outside this remit. Critical health literacy promotion for children was evidenced only as a one-off project in an individual library branch, not embedded across the library system.

The study proposes a conceptual model of the public library system's role in supporting children's critical health literacy. The model situates the public library in a partnership with other settings for health literacy development, including but not limited to schools (Jenkins et al., 2022). The study provides recommendations for how the development of critical health literacy in children can be coordinated across other everyday settings where children spend their time. Suggested priorities include supporting the information needs of children in health literacy mediator roles (e.g., Young Carers), integrating health literacy and health information literacy capacity-building into extracurricular youth activities (e.g. Scouts/Brownies badgework) and facilitating children's

meaningful involvement in health literacy and health information literacy research.

4.4. Study 2: Patients as active producers of information (Grant, 2019)

The second study that informs this research agenda is a doctoral study that sought to expand models of health literacy by positioning patients as engaged and active producers of health information. It was developed through interdisciplinary doctoral research situated between the University Library, the Medical School, and the School of English Literature at the University of Sheffield (Grant, 2019). The study focused on health information literacy for chronic health conditions and worked with people living with irritable bowel syndrome (IBS). Comorbidities amongst participants were common and included anxiety, depression, epilepsy, chronic fatigue syndrome, Ehlers Danlos syndrome, hyperparathyroidism, postural tachycardia syndrome and Raynaud's syndrome. Although all participants had been diagnosed with IBS, or suspected IBS, symptoms were varied and frequently incongruent to the symptomology described in IBS clinical guidelines (Spiller et al., 2007; National Institute for Health and Care Excellence (NICE), 2008).

The project utilized participatory action research methods, and the original aim was to empower patients through enhanced access to information alongside advocacy for open research and patient participation in medical studies. However, feedback and reflections took the project in a new direction as participants advocated for greater understanding of their individual lived experiences, for their voices to be heard and acknowledged, and for them to overcome isolation by having more opportunities to connect with each other. Themes of silencing, exclusion, and shame emerged, mirroring the findings of isolation, worthlessness, and invisibility found in a similar study, the Women's Health in Midlife project (Mullett, 2008). In line with action research methodology, the reflections lead to a reshaping of project plans. The new focus was an exploration of whether a different epistemological approach to health literacy could enable transformative change for people living with complex long-term health conditions. The aim was to move beyond information provision and education to enable creative and meaningful connections within and amongst participants.

The revised, more epistemologically inclusive project was influenced by Paulo Freire (1970, 1998, 2014) and centered on a series of shorter workshops. Spanning several months, the structure enabled reflection between sessions and allowed for the reconstruction of individual first-person illness narratives through creative and life writing, poetry, art, collage, and stitch craft. Collaborative information discovery led to the shared reading of patient memoirs (Lee, 2011; Spencer, 2014), clinical guidelines, medical journals, and social media discussions. A sense of connection was further developed using name stories, collaborative portraits, and paired and group discussions. The project focused on the following three broad questions:

- What happened to you?
- What works for you?
- What would you like to change?

Workshops were guided by the poetic, collaborative, and constructionist principles of appreciative inquiry, which have been found to be well suited to action research because of its ability to generate actionable change (Duncan, 2015). This qualitative and participatory research design recognized an inclusive approach, valuing the subjectivity of participants, as necessary for complex and deeply individual chronic health conditions. Embracing subjective experiences enabled participants to unite through moments of connectivity without having to achieve universal consensus. The project found patient narratives to be beneficial in enabling an active approach to learning, a reconstruction of the lived experience, and a more inclusive approach to health information literacy. Patient narratives could also be more actively curated and shared as a discoverable source of health information. However, this shouldn't detract from the process of coming to know through

engagement and reconstruction of lived experiences, which has value to health information literacy, independent of knowledge curation and discovery.

4.5. Study 3: Information literacy and COVID-19 vaccine hesitancy (Hicks & Lloyd, 2022)

The third study that informs this research agenda examined the information literacy practices of vaccine hesitant people during the COVID-19 pandemic (Hicks & Lloyd, 2022). Prior research has acknowledged the important role information plays within vaccine decision-making processes, including the potential of information literacy in improving vaccine take-up. However, the linking of vaccine hesitancy to poor quality information and information literacy as an 'inoculation' against poor decision-making positions people as manipulable and ignores how becoming informed is developed through reference to situated and embodied ways of knowing. This study addressed these issues by examining the shape information literacy practice took for vaccine-hesitant people, a sociological approach that situates information and learning at the center of inquiry.

The qualitative research design comprised in-depth, one-to-one interviews that were carried out with adults in the UK after they had been given the opportunity to book a COVID-19 vaccination. In total, interviews were conducted with 22 participants, of whom 14 were unvaccinated at the time of interview. Findings from the study were based on the responses of the unvaccinated participants. Participants were offered a GBP£20 gift card in exchange for their time and were recruited through adverts placed on social media sites. Interviews lasted between 25 and 45 min and were audio-recorded. Questions focused on the sources of information that informed vaccine decision-making and questions related to misinformation, information overload, and prior medical experience. Interviews were professionally transcribed and coded by both researchers using an iterative constant comparative method (Charmaz, 2014). Limitations of the study include the use of online recruitment methods, which may have limited the study's sample.

Findings indicated vaccine hesitant people become informed about the COVID-19 vaccination through reference to social, experiential, embodied, and institutional information through listening to stories, reading the body, pooling, confirming against expertise, and hedging against misleading information. These findings suggested information literacy emerges in the liminal space where knowledge becomes contested and reconciled, and in relation to agentic practice, people actively protect themselves from ambiguous vaccine knowledge by delaying decision-making. These findings have several implications for practice, including challenging the perception that vaccine hesitant people are uninformed about the COVID-19 vaccine or have an uncritical approach to information. Findings also challenge the narrative that is present in both information and health literacy research by illustrating how agentic action references delay rather than the more typically assumed proactive engagement with society.

4.6. Limitations

The positionality of the authors will have shaped this agenda and the three studies underpinning it. The process of reflection, as part of the appreciative inquiry undertaken here, was therefore important for thinking through the implications of the authors' subjectivity on the selection of the studies and the combined proposals resulting from them. This process included peer-review of each of the studies by the two authors not involved in each case. The interdisciplinary backgrounds of the authors can also be seen as a strength insofar as the different positionalities have contributed multiple perspectives that can help address the "silencing" of health literacy and information literacy concepts.

5. Findings & Discussion

Collaborative analysis produced four themes within the health information literacy research agenda: positioning information settings as health literate organisations, literacies for life, scaling up infrastructure, and empowerment.

5.1. Position information settings as health-literate organisations

The first area of emphasis identified in the research agenda analysis relates to the role and the potential for information settings to support health literacy and health-literate practices. Health literacy has been critiqued for being positioned as an individual trait or achievement, as befits the attainment approach that is promoted within quantitative health information research (Hicks, 2022). However, study findings that illustrate the opportunities public libraries offer for informal health information sharing (Jenkins et al., 2022), as well as the reluctance people with chronic illnesses may feel about consulting formal medical contexts (Grant, 2019), demonstrate there is considerable scope for information settings to support the multifaceted shape of health information literacy needs through information discovery, creation, connection, dialogue, counter narratives, and reconstruction. The World Health Organization (2022) recognizes that health literacy development is influenced by settings and changes over the lifecycle, and one of the key action areas of the Ottawa Charter (World Health Organization, 1986) is to facilitate the creation of supportive environments for health literacy work. However, there has been little focus on how information settings such as libraries might become health-literate organisations that support a systematic orientation of “daily routines towards HL [health literacy]” (Nowak, Dietscher, & Sator, 2019, p. 464), despite the vital role these locations play in enabling “individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others” (Brach & Harris, 2021, p. 1084).

The research agenda calls for a more overt exploration of how information settings can support health literacy, including relating to the spaces, resources, and possibilities for connection they offer. Research should draw from studies of the pedagogy of space, how information settings support the development of belonging for refugees (Lloyd & Wilkinson, 2019), and international students (Lauersen, 2015), to explore how the configuration of social spaces facilitates health information work (Moore Kingston Smith, 2023). Further research should also focus on the opportunities that would enable academic libraries to become more health-focused institutions through collaborative research partnerships and support for staff and student wellbeing. Content and collections teams have a role to play in diversifying health collections, including acquiring nontraditional health texts such as biographical health memoirs that will enable the discovery of multiple perspectives and access to the lived experiences of patients. The lack of prior research into settings that do not yet have a “health-promoting” prefix in widespread use calls for the development of a specific set of principles by which nontraditional health-literate organisations’ responsiveness to the health literacy needs of the communities they serve can be evaluated.

5.2. Literacies for life

A second theme within the research agenda considered the goal of lifelong learning from a more nuanced perspective. Lifelong learning is frequently positioned as a core outcome of health information literacy education, but research demonstrating that information use is socially and contextually shaped (Lloyd, 2005), illustrates how educational interventions cannot form one-time vaccinations that will protect people going forward. Findings from the analyzed studies exemplify the need to recognize the complexity of health information literacy learning over the life course. Jenkins et al. (2022) demonstrates the importance of engaging children in health information literacy contexts from an early

age, noting that supporting children to share the lived realities of their lives reveals perspectives that differ from adults’ views of how health information literacy should be done. Grant (2019) further unpacks these tensions by demonstrating how a focus on subjectivity provides a gateway to learn about complex chronic conditions that frequently involve more than one system and acquire complications over time (Alexander, 2010). The reminder that medicine is a human story with “an ever-changing complex, dynamic ... (intertwining) art and science ... chaos and complexity” (Rambihar & Rambihar, 2010) is picked up in Hicks and Lloyd (2022), which notes health information literacy often takes on a different rhythm within a crisis, including the need to slow down, build trust, and protect wellbeing. Illustrating the insights that emerge when research is carried out “with” or “by” members of the public, rather than “to,” “about” or “for” them (Rouncefield-Swales et al., 2021), these findings speak to the benefits of positioning both adults and children as adept and dynamic practitioners of health information literacy (Jenkins, Wills, & Sykes, 2023).

Given these complexities, the research agenda calls for a focus on the tensions of lifelong learning and socially situated information activities. One way this might take place is by focusing on questions of transition (Hicks, 2019) or how learners’ health information literacy practices can be supported when their specific needs, skills, and abilities change rather than assuming information skills will “autonomously” (Street, 2003) set people up for complex and changing life course needs. Further research should also challenge the belief that all relevant information should be considered in decision-making (Wilson, 1995) to examine the benefit of knowledge within health situations and the impact and wellbeing advantages of information avoidance or ignorance. Future research could include the complications of too much information and the ways open access health information is used and communicated outside academic contexts (Nunn, 2019). A focus on lifelong learning means research should further engage beyond the impact of illness to explore what other situations might call for health information literacy practices, for example living well during times of austerity, trauma, or future global pandemics.

5.3. Scaling up infrastructure

A third identified emphasis within the research agenda analysis was the need to scale up the provision of health information literacy support. Jenkins et al. (2022) directly established the link between public libraries and health information literacy; existing public library infrastructure and the trust that is accorded to library workers (Vårheim, 2007) means additional health resourcing and library staff training forms a clear way to support community needs. However, the social isolation that many of Grant (2019) chronically ill respondents highlight and the range of people that play a role within Hicks and Lloyd (2022) examination of vaccine decision-making, suggests community support needs to go beyond a public library focus. This research agenda consequently calls for broader conversations about how the library profession might recenter itself on questions of health and wellbeing. One angle for this research is how non health related sectors might support health information literacy work. For example, studies have demonstrated concepts of wellbeing are often used superficially within academic libraries (Cox & Brewster, 2021), while there is little understanding about what health-focused library practice might look like in the corporate sector or in related initiatives such as toy libraries. A more complex focus for this research is how existing library practice undermines questions of health and wellbeing. While research has started to edge around how able-bodied assumptions are embedded in health information literacy work (Andrews, 2016; Hicks, 2022; Peach & Tuke, 2021), there is an urgent need for future research in this area, including what might enable or constrain shifts in practice.

Any research exploring these ideas should acknowledge the impact health-oriented library work would have on library staff. Library professionals are neither social workers nor medical experts and already

suffer from burnout linked to increased responsibilities in a time of reduced staffing and budgets (Lindén, Salo, & Jansson, 2018). Research should examine the limits or boundaries of relational work, and the management and support needs that such a shift would entail. One potential model for how the wider library profession might think about addressing these tensions comes from archival studies and the trauma-informed work that has been done to support the safety of people creating, keeping, using, or representing sensitive and potentially traumatizing materials (Sexton, 2023). Research should also look beyond librarianship to explore how nonlibrary-based information intermediaries support and mediate health information literacy work. Referring to people who “act as information mediums or agents for others” (Buchanan, Jardine, & Ruthven, 2019), information intermediaries such as nurses, social workers, and religious ministers support the mapping of health information landscapes by facilitating access and connections to relevant information. Future studies should build upon the scant research in this area to examine the pedagogical role of alternative information providers in more detail and best practices related to professional self-care.

5.4. Exploring the relationship between health information literacy and patient empowerment

A fourth area of emphasis within the research agenda analysis was the importance of critically exploring the relationships between health information literacy and patient empowerment. Empowerment plays a central role within health information literacy discourse where it is seen to emerge through critical information use and result in “self-directed behavior change” (Anderson & Funnell, 2010). However, since the 1990s, information production in Western medicine has favored a bias towards positivist ways of knowing through a hierarchical ranking of evidence, positioning a meta-analysis of randomized controlled trials as the gold standard for health knowledge (Oxford Center for Evidence-Based Medicine (CEBM), 2009). This has resulted in the production of patient education models that, underpinned by compliance focused quantitative methods, predicate empowerment upon a passive assimilation of knowledge produced through medical power structures. Grant (2019) found such knowledge was used didactically in passive models of gastroenterology focused patient education programs through “structured health promotion (Colwell, Prather, Phillips, & Zinsmeister, 1998), reinforced information giving (van der Horst, Schellevis, van Eijk, & Bleijenberg, 1998), instruction and training (Quigley, 2013), multiple choice assessment (Jarrett, Barney, & Heitkemper, 2013; Yu, Ouyang, Zhang, Li, & Chen, 2014) and knowledge transmission via lectures, videos, slides, and handouts (Saito et al., 2004)” (Grant, 2019). Conceptualizations of empowerment based on transmissive pedagogy are neatly parodied by ulcerative colitis patient Liz Richardson in the opening act of her one-woman show *Gutted*: “I’m Dr Goodhand ... Now, here’s a leaflet about ulcerative colitis. And here’s another leaflet. And here’s a leaflet. And another leaflet. And here’s another leaflet. And here’s a leaflet about having a key (a radar key, to access disabled toilets) ... And another leaflet” (Richardson & Robinson, 2018, p. 3).

In contrast, findings from the studies analyzed in this research agenda demonstrate how qualitative methods disrupt this “illusion of power” (Gaventa & Cornwall, 2015) by creating counter narratives, involving multiple perspectives, and drawing attention to the role authoritative expertise plays within (dis)empowering practice. Thus, Grant (2019) built upon Håkanson, Sahlberg-Blom, Ternstedt, and Nyhlin (2012), who found it was a group setting and active encouragement of dialogue that enabled patients to learn more about themselves, drawing attention to the authentically empowering role active learning, as manifested through the co-creation of knowledge and patient solidarity, plays in the experiences of chronically ill people. Similarly, Hicks & Lloyd, 2022, p. 12 italics in original) demonstrated empowerment was signified by “the agentic performance of *delay*” for vaccine hesitant people rather than an active engagement with

information. Jenkins et al. (2022) consultation with a Children’s Advisory Group on the ethics and design of the study illustrates how children’s priorities for health research and understandings of health-related empowerment can be different from adult assumptions and conceptualizations.

A lack of research in this area means the scope of empowerment forms a key area for focus for a health information literacy research agenda. What does being enabled and empowered mean in a health context? How are considerations of empowerment informed by agency and capability, and what do these ideas look like within different health and wellbeing contexts, such as those related to chronic illness, disability, trauma, and mental health? The redesigned research methods for Grant (2019) indicates the relationship between information creation, patient narratives, and patient empowerment merits further study, including how the authority of patient experience to be created, curated, and communicated can be advocated within models of health information literacy.

6. A qualitative research agenda for health information literacy

Themes from the collaborative narrative enquiry process were drawn out to establish the following qualitative research agenda for health information literacy research. This research agenda is presented in

Table 1
A research agenda for qualitative health information literacy research.

Theme	Key questions	Areas for exploration
Information settings as health literate organisations	How might information settings, including libraries, become health-literate organisations (HLOs)? How could we evaluate non-traditional HLOs’ responsiveness to the health literacy needs of the communities they serve?	The pedagogy of library spaces, resources, and possibilities for connection. Diversified library collections, including the acquisition of non-traditional health texts such as biographical health memoirs.
Literacies for life	How does health information literacy enable and constrain transition? How do we acknowledge the nuances and tensions of lifelong health information literacy work, including related to the development of subjectivity?	Health information literacy within non-illness situations, including living well during times of austerity, trauma, or future global pandemics. Time, subjectivity, and lifelong learning within health contexts.
Scaling up infrastructure	How might non-health-related library sectors support health information literacy work? How might existing library practice undermine questions of health and wellbeing? What are the limits or boundaries of relational health information literacy work and what management and support needs would a shift to health information literacy work entail?	Able-bodyism and information literacy. Trauma-informed library work (and LIS education). The health information literacy roles of non-librarian information intermediaries.
Empowerment	What does being enabled and empowered mean in a health context? How are considerations of empowerment informed by agency and capability? How might the authority of patient experience be created, curated, and communicated within models of health information literacy?	Information creation, patient narratives, and empowerment. How children and young people are empowered in health settings. Empowerment within chronic illness, disability, trauma, and mental health contexts.

Table 1. Each of the research agenda themes was presented alongside suggested key questions for each of the four identified areas of interest alongside potential areas these themes could be explored.

7. Conclusion

Research into health information literacy has been dominated by quantitative approaches that focus on what people lack, rather than what they do (Samerski, 2019). This research challenged these ideas by establishing a qualitative agenda for health information literacy research. Shaped through a collaborative enquiry of three recent studies that have each taken a qualitative and participative approach to health information literacy, this research agenda responded to the nuanced complexities of social and embodied ways of knowing and foregrounding the conditions and social structures that enable and constrain information practice. The research agenda was further enhanced by the qualitative methods that informed its development. The reflexive creative writing techniques allowed the surfacing of shared themes and interests from the three individual studies and captured subjective and intersubjective qualitative research findings.

Future research could be enriched by paying more careful attention to intersectionality and health information literacy research in relation to race equality, disability justice, gender, LGBT+ rights, and age inclusivity. A future research agenda might also engage more complexly with the anti-colonial research movement, which explicitly calls out how “established hierarchies of superiority and inferiority naturalis[e] and normalis[e] unequal social and political relationships” (Ewing, 2021, p. 25). Research linking these ideas to the hierarchy of clinical evidence, which positions quantitative research as superior to qualitative approaches, would further embed subjectivity, complexity, criticality, and agency at the heart of health information literacy research. This research agenda is a first call to health information literacy practitioners and researchers to consider how taking a life-long approach with a sufficiently scaled up infrastructure would enable a person-centered empowering approach to health information literacy.

CRedit authorship contribution statement

Alison Hicks: Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing. **Vicky Grant:** Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing. **Catherine Jenkins:** Conceptualization, Formal analysis, Writing – original draft, Writing – review & editing.

Declaration of competing interest

None.

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