Health Literacy and Older Community-dwelling Icelanders:

A Participatory Perspective on Individual Abilities and Environmental Options

Sonja Stelly Gústafsdóttir

Thesis for the degree of Philosophiae Doctor

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Heilsulæsi og eldri Íslendingar búsettir í heimahúsi:

Þátttökubundin sýn á getu einstaklinga og möguleika í umhverfinu

Sonja Stelly Gústafsdóttir

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Ágrip

Markmið

Meginmarkmið doktorsverkefnisins var að rannsaka heilsulæsi (HL) út frá þátttökubundinni sýn á iðjuréttlæti með áherslu á fólk 65 ára og eldra, sem bjó í heimahúsi, á strjálbýlum svæðum á Norðurlandi. Rannsóknin, sem er í þremur hlutum, miðar að því að rýna í víxlverkandi samspil einstaklings- og umhverfisþátta og áhrif þess á getu eldra fólks til að framkvæma HL-tengd verk í sínu umhverfi. Undirmarkmiðin fólu í sér að: **I)** þýða, staðfæra og notkunarprófa stuttu útgáfuna af evrópska spurningalistanum um heilsulæsi (HLS-EU-Q16), ásamt því að setja viðmiðstölur fyrir HL á Íslandi; **II)** mæla HL eldra fólks á Norðurlandi með því að nota HLS-EU-Q16-IS, bera kennsl á þau svið sem eru krefjandi og rannsaka tengsl HL stiga við ýmsa einstaklings- og umhverfisþætti; og **III)** rannsaka reynslu og þarfir eldra fólks á Norðurlandi sem lúta að því að vera heilsulæs.

Aðferðir

Rannsókn I var aðferðafræðileg og lýsandi og fól í sér: **a)** þróun íslenskrar útgáfu af HLS-EU-Q16 matlistanum með að nota þriggja þrepa þýðingarferli sem innihélt þýðingu og bakþýðingu (n = 4), álit sérfræðinga (n = 6) og ígrundandi samtöl við almenning (n = 17); **b)** mat á próffræðilegum eiginleikum listans með lagskiptu slembiúrtaki með 251 þátttakenda á aldrinum 18–85 ára (M = 55, ± SD 18,98) þar sem 52% voru konur og 48% karlar. Gögnin voru greind með Cronbach's α fyrir innra samræmi, leitandi þáttagreiningu og meginþáttagreiningu auk fjölbreytu línulegri aðhvarfsgreiningu; **c)** að setja fram viðmiðstölur fyrir HL sem byggði á sama úrtaki og próffræðilega greiningin. **Rannsókn II** byggði á lýðgrunduðu slembuðu þversniðsúrtaki 175 eldri einstaklinga á aldrinum 65–92 ára (M = 74,2, SD ± 6,3) sem bjuggu heima. Þátttakendur voru valdir af einu þéttbýlissvæði og tveimur dreifbýlissvæðum á Norðurlandi, þar af voru 43% konur og 57% karlar, og alls bjuggu 40% í dreifbýli. Gögnum var safnað með einstaklingsviðtölum þar sem HL-EU-Q16-IS og þrjú önnur alþjóðlega viðurkennd matstæki voru notuð ásamt ýmsum spurningum um einstaklings- og umhverfisþætti. Notuð var lýsandi tölfræði ásamt einbreytu og fjölbreytu línulegri aðhvarfsgreiningu til að greina gögnin. **Rannsókn III** var eigindleg, með leitandi sniði. Tuttugu einstaklingar voru markvisst valdir úr hópi þeirra 175 sem tóku þátt í verkefni II. Allir valdir þátttakendur þáðu boð um þátttöku og samþykktu einstaklingsviðtöl. Þetta var fólk á aldrinum 70–96 ára (M = 77,3), 12 konur og átta karlar. Viðtölin voru greind með eigindlegri innihaldsgreiningu sem fól í sér flokkun og undirflokkun gagna.

Niðurstöður

Rannsókn I: Ellefu atriði HLS-EU-Q16 voru endurorðuð í kjölfar þriggja þrepa þýðingarferilsins. Innra samræmi listans var $\alpha = 0{,}88$. Meginhlutagreining skilaði fjórum þáttum með eigingildum > 1,0 þar sem hver þáttur lagði til 3–5 atriði ($\alpha = 0{,}73$–$0{,}85$). Greiningin skýrði 62,6% dreifingarinnar. HL mældist á bilinu 2–16 stig ($M = 13{,}52$, $SD \pm 2{,}69$), 71,3% höfðu fullnægjandi HL (13–16 stig), 22,1% takmarkað HL (9–12 stig) og 6,6% höfðu ófullnægjandi HL (0–8 stig). Svið heilsuverndar og forvarna voru metin mest krefjandi og tengdust því að fá álit annars læknis og upplýsingum í fjölmiðlum. Betra mat á eigin heilsu spáði sjálfstætt fyrir betra HL ($p = 0{,}008$). **Rannsókn II**: Viðmiðstölur fyrir HL voru á bilinu 6–16 stig ($M = 13{,}25$, $SD \pm 2{,}41$); 65% þátttakenda höfðu fullnægjandi HL, 31,3% takmarkað og 3,7% ófullnægjandi HL. Svið forvarna og heilsueflingar voru metin mest krefjandi og tengdust upplýsingum í fjölmiðlum. Betra HL tengdist einstaklings- og umhverfisþáttum þar sem meiri menntun ($p = 0{,}014$) og að aka bíl til að komast um ($p = 0{,}017$) spáðu sjálfstætt fyrir betra HL. **Rannsókn III**: Innihaldsgreiningin gaf af sér fjóra flokka: „Væntingar til ábyrgðar", „Gjá milli væntinga og getu/aðstæðna", „Að finna eigin leiðir" og „Að brúa gjána". Flokkurinn „Væntingar til ábyrgðar" lýsti þeirri upplifun að ætlast sé til að hver einstaklingur taki ábyrgð á eigin heilsu sem endurspeglaði einnig skoðun viðmælenda. Hins vegar var þessi ábyrgð oft ekki í samræmi við færni/aðstæður þeirra eins og fram kom í flokknum „Gjá milli væntinga og getu/aðstæðna" sem krafist aðlögunar með eigin hætti, og er lýst í flokknum „Að finna eigin leiðir". Í flokknum „Að brúa gjána" lýstu viðmælendur þörf fyrir sameiginlega ábyrgð og viðráðanlegri kosti til að geta tekið rökstuddar heilsutengdar ákvarðanir og ratað um heilbrigðiskerfið.

Ályktanir

Niðurstöður studdu við notagildi HLS-EU-Q16-IS á Íslandi. Eldra fólk í rannsókn II mældist með takmarkaðra HL samanborið við almenning í rannsókn I og samband var á milli HL og ýmissa einstaklings- og umhverfisþátta sem bendir til flókins samspils. Iðjubundið óréttlæti birtist í upplifaðri togstreitu eldra fólks á milli eigin ábyrgðar á heilsu og oft skorts á möguleikum í umhverfinu til að bregðast við. Þetta óréttlæti takmarkar þátttöku þeirra í mikilvægri iðju fyrir heilsu og vellíðan. Því þarf að huga að valdajafnvægi í öllum aðgerðum tengdum HL, til að vinna að sameiginlegri ábyrgð á heilsu og inngildingu eldra fólks.

Lykilorð: Heilsulæsi, öldrun, þátttaka í iðju, iðjuréttlæti, búseta í þéttbýli og dreifbýli.

Abstract

Aim

The overall objective of the thesis was to investigate health literacy (HL), focusing on community-dwelling adults aged 65 and older in sparsely populated areas of northern Iceland, from a participatory occupational justice perspective. The three-part, interdependent research aimed to examine the dynamic interaction of personal and environmental factors influencing older adults' ability to perform HL tasks within their context. This included: **I)** translating, adapting, and validating the Health Literacy Questionnaire, short version (HLS-EU-Q16), as well as establishing norms for HL among the general Icelandic population; **II)** measuring HL and identifying challenging domains among older adults in northern Iceland using the HLS-EU-Q16-IS, and investigating the associations of HL points with various personal and environmental factors; and **III)** exploring the experiences and needs of older adults in northern Iceland regarding being health literate.

Methods

Project I was methodological and descriptive and involved: **a)** developing an Icelandic version of the HLS-EU-Q16 instrument using a three-step translation process that included translation-back-translation (*n* = 4), specialist reviews (*n* = 6), and cognitive interviewing of laypeople (*n* = 17); **b)** evaluating the psychometric properties in a stratified random sample that included 251 participants aged 18–85 (*M* = 55, ± *SD* 18.98), thereof were 52% women and 48% men. Internal consistency with Cronbach's α, exploratory factor analysis and principal component analysis, as well as multivariate linear regression, were used for analysis; **c)** establishing preliminary HL norms using the same sample as in the psychometric analysis. **Project II** was cross-sectional population-based with a random selection of 175 community-dwelling adults aged between 65 and 92 (*M* = 74.2, *SD* ± 6.3). The participants were selected from one urban and two rural areas in northern Iceland; 43% were women, 57% were men, and a total of 40% lived in rural areas. Data was collected via face-to-face interviews using the HL-EU-Q16-IS, three other internationally recognised instruments, and various single items representing contextual factors. Descriptive statistics, univariate, and multivariable linear regression analysis were used. **Project III** was qualitative, using an explorative design. Twenty people were purposefully selected from the 175 participants in Project II. All chosen participants, 12 women and eight men aged 70–96 (*M* = 77.3), accepted participation and were interviewed individually. The interviews were analysed using qualitative content analysis, which involved categorising and subcategorising the data.

Results

Project I: Eleven HLS-EU-Q16 items were reworded using the three-step process. The internal consistency was $\alpha = 0.88$, and the principal component analysis presented four latent constructs with eigenvalues > 1.0 with 3–5 items each ($\alpha = 0.73–0.85$). The analysis explained 62.6% of the variance. Preliminary norms for HL ranged from 2–16 points ($M = 13.52$, $SD \pm 2.69$); 71.3% had sufficient HL (13–16 points), 22.1% had problematic HL (9–12 points), and 6.6% had inadequate HL (0–8 points). The most challenging domains of HL were health care and disease prevention related to a second opinion from a doctor and information in the media. Better self-rated health was an independent predictor for better HL ($p = 0.008$). **Project II:** HL levels ranged from 6–16 points ($M = 13.25$, $SD \pm 2.41$); 65% of participants had sufficient HL, 31.3% problematic, and 3.7% inadequate HL. The most challenging domains of HL were disease prevention and health promotion related to information in the media. Better HL was associated with personal and environmental factors, with more education ($p = 0.014$) and driving a car ($p = 0.017$) as independent predictors of better HL. **Project III:** Four categories emerged from the content analysis: "Expectations for responsibility", "A gap between expectancy and ability/context", "Finding one's own ways", and "Bridging the gap". The category "Expectations for responsibility" described the experience of older adults that individuals are expected to take responsibility for their health, which was also reflected in the participant's position. However, this responsibility often did not align with participants' skills/situations described in the "A gap between expectancy and ability/context" category, which pushed them to adapt with their own ways described in the category "Finding one's own ways". In the "Bridging the gap" category, participants highlighted the need for shared responsibility and more manageable options to facilitate informed health-related decisions and navigation within the healthcare system.

Conclusion

The HLS-EU-Q16-IS version was valid for use in Iceland. Older adults were measured with more limited HL compared to the general adult population in Project I. There was a correlation between HL points and various personal and environmental factors, indicating a complex interaction. Occupational injustice was apparent in the experienced tension between older adults' responsibility for health and often lack of environmental-related options to respond. This limits their participation in meaningful occupations essential for health and well-being. Therefore, it is necessary to consider power balance in all actions related to HL to work towards shared responsibility for health and inclusion of older adults.

Keywords: Health literacy, ageing, occupational participation, occupational justice, urban and rural residence.

Acknowledgements

Somewhere, it says it is neither the destination nor the journey that is important but rather the company. There are many people I would like to thank for their valuable support and encouragement in the making of this research project. In the front row are the members of the doctoral committee: Sólveig Ása Árnadóttir, the supervisor; Árún K. Sigurðardóttir and Lena Mårtensson, co-supervisors. They always believed in me, gave me the proper support, challenges, and freedom to develop as a researcher, and showed understanding when life unexpectedly affected my study plans. I would also like to thank them for contributing to the manuscripts and the review process.

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Contents

List of Abbreviations

CA: Capital area

CCA: Cross-cultural adaptation

CD-RISC: Connor-Davidson Resilience Scale

DP: Disease prevention

EC: European Commission

EU: European Union

GDS: Geriatric Depression Scale

HC: Health care

HL: Health literacy

HLHCO: Health literate health care organisation

HLS19: European Health Literacy Population Survey 2019-2021

HLS-EU: The European Health Literacy Consortium working group

HLS-EU-Q16: The European Health Literacy Survey Questionnaire- short version

HLS-EU-Q16-IS: Icelandic version of the European Health Literacy Survey Questionnaire-short version

HP: Health promotion

ICF: The International Classification of Functioning, Disability, and Health

ICT: Information and communications technologies

M-POHL: WHO Action Network on Measuring Population and Organizational Health Literacy

OECD: The Organization for Economic Cooperation and Development

OHL: Organizational health literacy

PCA: Principal Component Analysis

PHC: Primary health care

POJF: The Participatory Occupational Justice Framework

SRH: Self-rated health- single item question

WHO: World Health Organization

List of key definitions

Health literacy (HL):	„Personal knowledge and competencies that accumulate through daily activities, social interactions, and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them“ (WHO, 2021a, p. 6).
Occupational performance and participation:	The doing of occupations is based on occupational performance, which enables participation in an interaction between the person, the occupation, and the environment (Baum & Christiansen, 2005).
Personal factors:	Include, for example, physiological, cognitive, spiritual, neurobehavioral, and psychological intrinsic factors that describe a person's ability (Baum & Christiansen, 2005).
Environmental factors:	Include, for example, extrinsic factors such as social support, social and economic systems, culture and values, the natural and built environment as well as technology (Baum & Christiansen, 2005).
Occupational justice:	Includes equal opportunities, resources, privileges, and rights for every individual to participate to their full potential in diverse and meaningful occupations (Townsend & Wilcock, 2004a, 2004b).
Urban areas:	A continuous built-up area with a minimum of 200 inhabitants, a clear street network, and a maximum of 200 meters between houses (Sindradóttir & Harðarson, 2012).
Rural areas:	Agricultural regions or villages with fewer than 200 residents (Statistics Iceland, 2020b).

List of Figures

List of Tables

List of Original Papers

This thesis is based on the following original publications, which are referred to in the text by their Roman numerals (I - III):

I. Gustafsdottir, S.S., Sigurdardottir, A.K., Arnadottir, S.A., Heimisson, G.T. and Mårtensson, L. (2020) Translation and cross-cultural adaptation of the Icelandic version of the European Health Literacy Survey Questionnaire, HLS-EU-Q16. BMC Public Health, 20(61). https://doi.org/10.1186/s12889-020-8162-6

II. Gustafsdottir, S. S., Sigurdardottir, A. K., Mårtensson, L., and Arnadottir, S. A. (2022). Making Europe health literate: Including older adults in sparsely populated Arctic areas. BMC Public Health 22(511). https://doi.org/10.1186/s12889-022-12935-1

III. Gustafsdottir, S.S., Mårtensson, L., Sigurdardottir, A.K. and Arnadottir, S.A. (2024). When great responsibility comes with limited options: Experiences and needs of older community-dwelling adults regarding accessing, understanding, appraising, and using health-related information. BMC Geriatrics. 24(640). https://doi.org/10.1186/s12877-024-05236-2

Declaration of Contribution

Along with writing this doctoral thesis, I, Sonja Stelly Gustafsdottir (SSG), have been involved in all parts of the research projects presented under the guidance of supervisor Solveig A. Arnadottir (SAA) and co-supervisors Arun K. Sigurdardottir (AKS) and Lena Mårtensson (LM). All parties performed the project design, revision, and final conception.

Research project I and paper I: The translation of the instrument, along with data collection, analysis, and interpretation, was carried out by SSG in collaboration with a graduate student, Gudrun Heida Kristjansdottir. SSG also drafted the manuscript. AKS was the project guarantor, grant holder, and holder of permission to work on an Icelandic translation of the HLS-EU-Q16 instrument. Additionally, AKS supervised the adaptation process and data collection, acted as a senior statistician, and contributed to data interpretation, drafting, and revising the manuscript. SAA participated in the interpretation of data, as well as in coordination, drafting, and revising the manuscript. Gudmundur Torfi Heimisson aided in statistical analysis and revised the manuscript. LM contributed to drafting and revising the manuscript. All authors read and approved the final manuscript.

Research Project II and Paper II: SSG analysed and interpreted the data, authored the manuscript, and held a grant. AKS was the project leader for the research "Health and Wellbeing in northern Iceland" and was responsible for securing central funding. AKS also contributed to the interpretation of data and the drafting and revision of the manuscript. LM assisted in drafting and revising the manuscript. SAA contributed to data interpretation, coordination, drafting, and revising the manuscript. All authors reviewed and approved the final manuscript.

Research Project III and Paper III: SSG collected, analysed, and interpreted the data, drafted the manuscript, and held the grant. LM contributed to the analysis and interpretation of the data, as well as drafting and revising the manuscript. SAA and AKS participated in the interpretation of the data and the revision of the manuscript. AKS was also a grant holder. All authors read and approved the final manuscript.

This thesis was written using Grammarly, an English language writing assistant software tool that provides stylistic guidance, rewriting suggestions, and tone adjustments.

1 Introduction

Health literacy (HL) is considered essential to the health and well-being of people of all ages. The concept is multidimensional (Sørensen & Pleasant, 2017; Sørensen, 2019) as the World Health Organization (WHO) (2021a, p. 6) states:

> Health literacy represents the personal knowledge and competencies that accumulate through daily activities, social interactions, and across generations. Personal knowledge and competencies are mediated by the organizational structures and availability of resources that enable people to access, understand, appraise and use information and services in ways that promote and maintain good health and well-being for themselves and those around them.

By this definition, HL is presented as a relational concept, a two-sided aspect. On the one hand, there is the person's ability to access, understand, appraise, and use information and services to make health decisions; on the other hand, the healthcare system's structure and availability of health information. Despite European policymakers' increased attention to HL over the last few years and the establishment of cross-country collaborating working groups on developing instruments to measure general HL, Icelandic officials have not been actively involved in that work; therefore, the availability of tools and information on HL in Iceland is limited (Frederiksen & Wångdahl, 2022).

Older adults have been measured globally with lower HL scores than other adult age groups (Dietscher et al., 2019; Sørensen et al., 2015), although somewhat inconsistent across countries (Pelikan et al., 2021). Limited HL has been connected to worse health outcomes and increased health expenditure (Palumbo, 2017). Differences in health across populations, known as health disparities, are consistent and relevant within any country (Marmot et al., 2012), including Iceland (Haraldsd. Elínardóttir et al., 2021). These differences in health have been connected to people's opportunities to be healthy within their socioeconomic position in life, that is, the social determinants of health (WHO, 2021b). However, the causal relationship between social conditions and health outcomes is often debated on an ideological and political basis, which in turn influences ideas and actions on the best way to improve health (Nutbeam & Lloyd, 2021).

There are indications of health inequalities in old age, reflecting accumulated disadvantages due to gender, socioeconomic status, and location. Ageist attitudes and practices, along with the absence of adequate laws and policies that provide equality and the rights to health and social security, are believed to contribute to age-related inequalities (Department of Economic and Social Affairs programme on ageing, 2018). In the context of the rapidly worldwide ageing population (United Nations, 2019), age-related inequalities have become increasingly urgent. Although most older adults will live in low—and middle-income countries, all nations, including high-income countries like Iceland, face challenges in making the most of these democratic changes and promoting healthy ageing (WHO, 2020).

1.1 Theoretical frameworks

The participatory perspective is rooted in occupational science and occupational therapy. The focus is on the connection between a person's ability to perform tasks that are meaningful to them and its influence on health and well-being within the context of where the tasks are undertaken. The Participatory Occupational Justice Framework (POJF) is based on the interaction between a person, occupations, and the environment. It recognises the importance of human rights and societal power dynamics as key factors influencing occupational participation (Whiteford et al., 2018). While the POJF provides a foundation for understanding HL through the lens of occupational justice, the International Classification of Functioning, Disability, and Health (ICF) offers a complementary, interdisciplinary perspective and a common language (WHO, 2001). It situates HL within a broader framework that includes health, functioning, and contextual factors. Although the POJF and the ICF share some concepts and commonalities (like occupational justice being compatible with participation restriction) (Townsend & Whiteford, 2005), the ICF does not include considerations about meaningful occupational participation. ICF focuses on whether a person's ability to perform tasks and activities goes with or without restrictions and limitations, not on the value of the task or activity. Therefore, the POJF is used as the theoretical framework for this thesis.

1.1.1 The Participatory Occupational Justice Framework

Participating in meaningful and valued occupations is central to everyday life, health, and well-being (Townsend & Wilcock, 2004a). Participation refers to "the doing" by people in a broad sense and results from the dynamic interaction between a person (intrinsic factors), the environment (extrinsic factors), and the occupation (structure of a task). Personal factors include cognitive, physiological, spiritual, neurobehavioral, and psychological characteristics. Environmental factors encompass the natural and built environment and technology, support from interpersonal relationships, social and economic systems, and culture and values. All these factors can enable or hinder occupational performance and participation (Christiansen et al., 2005). Occupational justice has been proposed as occupational therapy's foundation and fundamental purpose. Townsend and Wilcock (2004a, 2004b) define it as the equal opportunities, resources, privileges, and rights of every individual to participate to their full potential in diverse and meaningful occupations. Occupational injustice arises when participation in occupations is in any way limited (Townsend & Wilcock, 2004b).

The POJF, based on the interaction between a person, occupation, and the environment, considers explicitly the complexities of people's everyday lives, as various people live in different sociopolitical contexts (Whiteford et al., 2018). The framework acknowledges human rights and social power dynamics as crucial factors influencing occupational participation. It also addresses the justice of difference, which promotes social inclusion and allows all citizens, individuals, families, and social groups to participate in everyday life (Townsend & Whiteford, 2005). The POJF is presented as interconnected non-linear processes that aim, for example, to raise awareness of occupational injustice, increase collaboration with partners, and inspire advocacy for sustainability. These processes are adapted to the local practices and systems contexts as well as the socio-cultural, economic, and political circumstances (Whiteford et al., 2018).

By examining the interaction between the abilities of older Icelanders, HL, and the environment through the lens of the POJF, this study emphasises the significance of accessing, understanding, appraising, and using health-related information for participating in chosen and meaningful occupations essential to daily life, health, and well-being. Being health literate facilitates occupational performance. Furthermore, human rights and power dynamics are highlighted in pursuing justice and equity in occupational participation.

1.1.2 The International Classification of Functioning, Disability, and Health

The ICF examines the perspective of a health condition, functioning, and contextual factors. It is a conceptual framework and a classification used primarily to describe health and health-related conditions (WHO, 2001). However, it can also describe a person's functioning without assigning a disease or disability label, thus enabling its use in various situations (van der Veen et al., 2023). According to the ICF, health conditions are broad terms encompassing, for example, diseases, disorders, injury, trauma, and other circumstances, such as ageing, that affect and are affected by many factors (WHO, 2001). The strength of the ICF is that it is an interdisciplinary model and provides a common language for various stakeholders (van der Veen et al., 2023; WHO, 2001). Therefore, reflecting aspects of HL and the ageing process within the framework is relevant.

Figure 1 shows the main components of the ICF conceptual framework (WHO, 2001), emphasising how aspects of the ageing process and HL can be reflected in the model, with arrows representing the interrelationships. Body functions and structures are needed for self-care activities, including accessing, understanding, appraising, and using health-related information and services. Impairments of the body, limitations in performing tasks, or restrictions in participation in self-care can negatively influence the interaction of functioning. Furthermore, environmental factors, such as service systems, technology, distance, and attitude, as well as personal factors, such as level of education, chronological age, gender, and other health conditions, can also facilitate or hinder functioning.

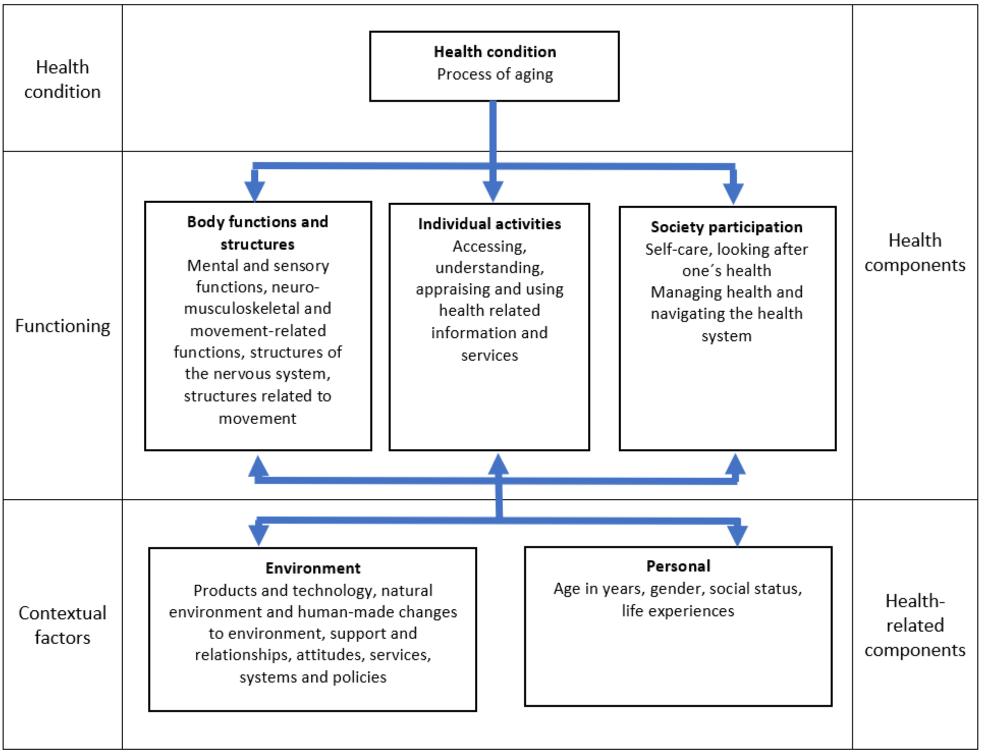

Figure 1. International Classification of Functioning, Disability and Health framework reflecting the ageing process and aspects of health literacy.

Source: World Health Organization (2001), adapted.

1.2 Health literacy

HL consists of the tasks of accessing, understanding, appraising, and using health information and services that sustain and promote good health and well-being (WHO, 2021a). From an occupational participatory perspective, all tasks that collectively make up an occupation have a specific structure and require particular abilities and circumstances to be performed (Christiansen et al., 2005).

Defining HL and its role in health is an ongoing process (Nutbeam & Lloyd, 2021). The concept has, for example, moved away from being objective to more subjective and includes various perspectives of a) specific individual skills or competencies needed, b) specific types of settings and target groups, and c) the role of the environment, including policy setting.

Being health literate is believed to empower people to manage their health and well-being in everyday life (M-POHL, 2023). Empowered people are considered free of choice and action and should, therefore, be responsible for their health (de Souza, 2011). The shift from people being passive recipients of health information towards more autonomy and responsibility has called for increased self-management in health and health-related matters (de Souza, 2011; Okan, 2019). Navigating the health care system and making well-founded health decisions is considered vital, and therefore, HL has become a priority for health in Europe in the 21st century (Sørensen, 2019).

Originating in the education system, the primary focus of HL has been on the person's ability to read and understand information, often in the medical or healthcare context, generally referred to as functional HL (Okan, 2019; Sørensen, 2019). As such, HL is viewed as a skill-based process that people can use to identify and transform information into knowledge and action. This has influenced research, for example, in developing frameworks and using instruments to measure people's HL levels and explore their association with health outcomes. Implementations are often in the form of education, focusing on adapting people's skills and abilities to the health sector's demands to access, understand, appraise, and use health-related information and services. That is, empowerment is considered on the individual level in meeting the educational needs of those lacking the skills (Sørensen, 2019).

Further development of the HL concept has supported a broader range of context and content to apply different skills in different situations and unfamiliar settings (Nutbeam & Lloyd, 2021). Other dimensions beyond the functional have been identified, such as interactive (social) and critical (cognitive) skills or competencies. The setting for creating and using these individual HL skills has also broadened beyond the clinical into the public and everyday life setting. By now, specific types of HL are used in diverse contexts, for example, Vaccination HL, Digital or e-HL, Communicative HL, Navigational HL, General HL (The HLS19 Consortium of the WHO Action Network M-POHL, 2021), maternal HL, and diabetes HL (Sørensen, 2019). A study in 2017 revealed over 100 types of specified HL (Sørensen & Pleasant, 2017).

The understanding of HL as a relational concept advocated for recognising it as more than a one-sided issue but rather based on personal skills and the requirements and complexity of systems and settings (M-POHL, 2023; Parker, 2009). By combining skills with appropriate social resources, HL will support individuals in becoming more resilient and empower them to participate in activities that address the root causes of health inequalities (Kickbusch et al., 2013). All reported national population surveys have provided consistent evidence of the association between HL and social and economic disadvantage (Nutbeam & Lloyd, 2021), supporting the view that HL is based on a wide range of skills that interact with the social and cultural contexts of people's lives (Mårtensson & Hensing, 2012). Thereby acknowledging that people with, for example, lower educational skills, chronically ill people, and migrants (Frederiksen & Wångdahl, 2022) do not have the same opportunities to be health literate. However, this relationship between HL and the social determinants of health has been studied less (Nutbeam & Lloyd, 2021).

Following the relational view of HL, health-literate or health literacy-friendly/responsive organisations are becoming an ever-more significant area of research and intervention. The point that not all resources are available for people to make healthy choices calls for systemic and organisational changes (M-POHL, 2023). This means empowerment is viewed at the individual and organisational levels of the availability and accessibility of information and services needed to make healthy lifestyle choices. Therefore, the responsibility for health is also systematic in creating opportunities for people to "do".

Health literate healthcare organisations (HLHCOs) refer to how organisations and systems ensure that information and health services are accessible and comprehensible to people on a structural level. Most Organizational health literacy (OHL) concepts and tools refer to healthcare settings and focus on navigation support, personnel training, and techniques to assist individuals in better understanding information, the quality of communication, and the informational material provided. Moreover, several measurements for HLHCO have been developed but are primarily based on self-assessment within an organisation (Brach et al., 2012; Trezona et al., 2018), and none are applicable in evaluations of interventions (Aaby et al., 2024). However, a framework for evaluating OHL responsiveness is being developed to enable assessments of interventions of any scope (Aaby et al., 2024).

Furthermore, delegating the responsibility for health to systems in creating opportunities for people to engage in HL tasks has elevated the role of policy in the notion of empowerment (Kickbusch et al., 2013). Sörensen et al. (2021) suggest a systematic transformation by strengthening the HL system's capacity beyond organisational and individual behaviour change, thereby presenting HL further as a political choice.

1.2.1 The European concept of health literacy

Following North America and Australia, the European Commission (EC) prioritised HL in its health agenda from 2008 to 2013. The European Health Literacy (HLS-EU) Consortium working group was established to define and conceptualise the concept, measuring levels of HL based on personal skills among populations and comparing them across countries (Sørensen et al., 2012). In 2018, the WHO established the Action Network on Measuring Population and Organizational Health (M-POHL) and initiated its work.

The definition of HL most commonly used in Europe (M-POHL, 2023) was developed in 2012 by the HLS-EU working group as a basis for measuring general HL of populations:

> Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve quality of life during the life course (Sørensen et al., 2013, p. 2).

Numerous versions of comprehensive general HL instruments were developed in the European project, and collaboration (The HLS-EU Consortium, 2012): the original version HLS-EU-Q47, the extended version Q86 (with additional items relating to determinants and outcomes), the short version Q16, and the short-short version Q6 (Pelikan et al., 2014). In 2018, the HLS-EU-Q12 version was developed (Waldherr et al., 2021).

Two large-scale comparable HL population studies have taken place using HLS-EU-developed instruments. The first study, which provided the first population data on HL within the European Union (EU), was conducted from 2009–2012 in eight countries using the HL-EU-Q86-item instrument. Results indicated that, on average, 47% of citizens had limited HL levels. HL points were considerably lower in particular subpopulations compared to the total population, which was linked to individuals' socioeconomic status, particularly their level of education, financial situation, and advanced age. Based on the two-sided approach of considering both personal and environmental factors in HL (Parker, 2009), Sörensen et al. (2015) suggested emphasising strengthening citizens' skills by redesigning user-friendly and user-involving systems, educating and training health professionals to meet the challenges of HL better and increasing people's expectations of being active partners in health matters.

The second study, referred to as the HLS19, was conducted in 2019–2021 in 17 EU countries using an adapted short-form instrument, the HLS19-Q12, to collect data. Furthermore, navigational and digital HL instruments were used. The findings indicated that 25–75% of the respondents had limited HL. The general findings from the first study on the relationship between people's socioeconomic status and levels of HL were confirmed. In both studies, financial deprivation and societal level had the most substantial effects on the mean HL levels across all countries, but they had somewhat smaller values than in the HLS19. Age, for example, had, on average, much smaller and, in some cases, opposite effects for countries than reported in the HLS-EU findings. Based on the results, recommendations were made with the pretext that the data did not provide evidence for specific concrete interventions. However, those considered at-risk groups, being financially deprived and having a lower level in society, should be targeted explicitly to reduce the health gap between groups. Moreover, health policy should encompass investment in longitudinal studies, regular measurement and monitoring of population health literacy, and the systematic implementation of interventions to enhance HL (Pelikan et al., 2021).

1.2.2 The HLS-EU-Q16 instrument

One comprehensive general HL skill-based instrument originating from the HLS-EU cooperation is the 16-item shortlist HLS-EU-Q16. The original 47-item instrument was considered too time-consuming (10 minutes) for research intended for the general population. Therefore, two short forms were developed: the short-scale HLS-EU-Q16 (three minutes), and the short-short scale HLS-EU-Q6 (one minute) (Duplaga, 2020). Guided by a conceptual model (Sørensen et al., 2012), the original instrument was developed within four identified competencies (access, understand, appraise, and use) within three domains (health care (HC), disease prevention (DP), and health promotion (HP). Item selection for the Q16 instrument from the original one was made on construct validity based on Rasch modelling. Table 1 shows how the 16 items are categorised within the conceptual model of four competencies and three domains.

Respondents answer each of the 16 items on a four-point rating scale: very easy, fairly easy, fairly difficult, and very difficult. The total points are calculated if at least 14 out of 16 questions are answered. Responses to each question are grouped into two categories to calculate the points. Responses of "very easy" and "fairly easy" are combined and assigned one point, while "fairly difficult" and "very difficult" are combined and assigned zero points. These individual points are then summed to produce a total score ranging from 0—16 points. The total score on the questionnaire reflects the overall assessment of health skills, categorised as 13—16 points- sufficient HL level, 9—12 points- problematic level of HL, and 0—8 points- inadequate HL level (Pelikan et al., 2014; Röthlin & Ganahl, 2013).

However, another way to calculate points of the HLS-EU-Q16 has been noticed in the literature (Eronen et al., 2019; Tiller et al., 2015), using the following formula: Index = (mean per item – 1) × (50/3) as used in index construction of the 47-item original instrument where the four answering operations are not dichotomised. Only cases with at least 80% of answered items are calculated from "very difficult", scored as one point to "very easy", scored as four points. Higher points indicate better HL (Pelikan et al., 2014). This formula yields a score ranging from 0—50 points divided into four levels: 0—25 points- inadequate HL level, 26—33 points- problematic HL level, 34—42 points- sufficient HL level, and 43—50 points- excellent HL level.

In a systematic review (Niedorys et al., 2020) 17 studies are reported using the HLS-EU-Q16 measurement. Several language versions of the HLS-EU-Q16 have been evaluated for their psychometric properties, for example, Swedish (Bergman et al., 2023), Finnish (Eronen et al., 2019), Arabic/French (Bas-Sarmiento et al., 2020), Italian, (Lorini et al., 2019), an Indian version (Dsouza et al., 2021), Japanese (Maie et al., 2021) and French (Rouquette et al., 2018). The findings indicate that the versions are psychometrically sound, although the Japanese version of the HLS-EU-Q16 had weak validity.

Table 1. Guiding item formulation matrix adapted to the HLS-EU-Q16 short-scale

HLS EU Matrix	Accessing information on health	Understanding information on health	Appraising information on health	Using information on health
Health care (HC)	Q1 find information on treatments of illnesses that concern you? Q2 find out where to get professional help when you are ill?	Q3 understand what your doctor says to you? Q4 understand your doctor´s or pharmacist´s instruction on how to take a prescribed medicine?	Q5 judge when you may need to get a second opinion from another doctor?	Q6 use information the doctor gives you to make decision about your illness? Q7 follow instructions from your doctor or pharmacist?
Disease prevention (DP)	Q8 find information on how to manage mental health problems like stress or depression?	Q9 understand health warnings about behaviour such as smoking, low physical activity and drinking too much? Q10 understand why you need health screenings?	Q11 judge if the information on health risks in the media is reliable?	Q12 decide how you can protect yourself from illness based on information in the media?
Health promotion (HP)	Q13 find out about activities that are good for your mental well-being?	Q14 understand advice on health from family members or friends? Q15 understand information in the media on how to get healthier?	Q16 judge which everyday behaviour is related to your health?	

Q = Question number in the instrument. Source: The HLS-EU Consortium (2012), adapted

The Q16 instrument has been criticised for having no item regarding using information about health in the domain of health promotion (Guzys et al., 2015). The HLS-EU-Q12, short form, was developed with 12 items, one for each cell in the conceptual HLS-EU matrix. The instrument was constructed using the HLS-EU data from 10 countries based on Rasch analyses (Waldherr et al., 2021) and used in the HLS19 research (The HLS19 Consortium of the WHO Action Network M-POHL, 2021).

1.3 Health literacy and older adults

No available information appears to directly address HL from a participatory occupational justice perspective, emphasising the dynamic interaction between the person, the tasks and the environment affecting the act of "doing". Research on the HL concept presents various definitions, scopes, emphases, methodologies, and measures, making comparison challenging. In alignment with the development of the HL concept, the literature primarily reflects research on measuring individual skills for HL tasks across various dimensions or settings. Furthermore, the connection between HL scores and several factors has been studied. Information on HL related to older adults is presented here as personal and environmental factors that can enable or hinder older adults' occupational performance and participation in meaningful occupations. Personal factors describe people's ability to participate in tasks based on, for example, cognitive, physiological, psychological, and neurobehavioral intrinsic factors (Baum & Christiansen, 2005). While these characteristics are not directly addressed in the literature, they indirectly connect to a person's ability to perform tasks. Environmental factors encompass external factors such as social support, economic and social systems, cultural values, the built environment, technology, and the natural world (Baum & Christiansen, 2005).

1.3.1 Personal factors and health literacy

Although inconsistent across countries, there are indications that chronological age impacts levels of HL. Older adults have, therefore, been identified as an important target group for HL (Dietscher et al., 2019; Pelikan & Ganahl, 2017). In systematic reviews (Berkman et al., 2011; Kamal et al., 2018; Zamora & Clingerman, 2011), older age was associated with lower HL. A thematic review of research from 2010–2018 using the HLS-EU-Q16 instrument also found that older adults had lower levels of HL (Niedorys et al., 2020). Population-based studies among adults have also shown lower HL scores with increased age. In the first European Health Literacy Survey, findings identified older people as a group with limited HL; five countries showed significant differences in HL and age (Sørensen et al., 2013). Other European countries have made the same conclusion using the European measurements as findings from Portugal (Espanha & Ávila, 2016) indicate. Furthermore, study results from other continents, like Taiwan, using the HLS-EU-Q47 version, indicate the same (Duong et al., 2015). Following the second European study, the inconsistency concerning age and HL between countries is pointed out. In the second study, although the overall level of HL decreased with age, it had a smaller and opposite effect, with negative effects for eight countries and positive ones for five (Pelikan et al., 2021). Some population-based studies among adults have shown the same. For example, findings from a Danish study (Svendsen et al., 2020) of 9,007 participants aged 25 years and older using the HLS-EU-Q16 indicate that younger people had more difficulties with HL than older people. The researchers point out that older people might have improved their HL through their experience with doctors and other healthcare staff and that older Danes are relatively well-educated. In a Polish study (Duplaga, 2020) using the HLS-EU-Q16 instrument, limited HL was less common among participants aged 50–59 than among those aged 18–29. Furthermore, an HLS-EU-Q16 survey conducted among 1.107 participants aged 55-91 in Germany showed that HL increased with age (Tiller et al., 2015).

Education level and income have also frequently been studied in HL research, and evidence of a social gradient and lower HL score has been found in all reported national population surveys (Nutbeam & Lloyd, 2021). For example, in both studies within the EU countries, financial deprivation and societal level had the most substantial effects on the mean HL levels across all countries (Pelikan et al., 2021). In a literature review (Niedorys et al., 2020) of 17 studies using the HLS-EU-Q16 measurement, lower-educated individuals had lower HL than others. Studies focusing specifically on older adults have also reported a connection between limited HL scores and limited education and income; for example, a study among 65-year-olds and older in Kosovo using the HLS-EU-Q47 instrument (Toçi, 2013). A cross-sectional study also using the HLS-EU-Q47 among 475 Germans aged 65–99 showed a positive correlation between HL and education, income, and social status (Tiller et al., 2015). Furthermore, a systematic review of factors associated with limited HL in people 60 years and older revealed a connection to social and economic aspects, such as low educational levels and lower income (Lima et al., 2024).

Limited HL scores have been connected to worse health outcomes and increased healthcare expenditure both in general and explicitly connected to older adults (Berkman et al., 2011; Eichler et al., 2009; Fan et al., 2021; Lima et al., 2024; MacLeod et al., 2017; Niedorys et al., 2020; Palumbo, 2017). Numerous studies have also investigated the association between HL scores and self-reported health (SRH). SRH measures overall health status and is frequently used to predict health outcomes (Rohrer et al., 2007) and generally, SRH decreases with age (Huynh et al., 2022). A cross-sectional study using the HLS-EU-Q47 among older Germans aged 65–99 showed that limited HL was associated with worse health, such as lower cognitive abilities, depression symptoms, chronic diseases, reduced physical activity, and physical skills (Schaeffer et al., 2017).

1.3.2 Environmental factors and health literacy

One of the factors explored in HL research is the connection to the place of residence. A systematic review of HL in rural and urban populations (Aljassim & Ostini, 2020) was conducted to assess whether there are differences in HL between rural and urban populations and if rurality is a determinant. The review was based on 19 cross-sectional studies conducted in countries outside Europe using instruments other than the HLS-EU. Most included adults from 18 years old and other specific age ranges like 18–20, 40–89, and 15–64. Findings indicated that urban populations had higher HL than rural populations in most studies. However, those studies that performed covariate analysis showed that sociodemographic factors such as age, gender, education, income, and ethnicity play essential roles and that rurality alone might not explain rural-urban HL differences. In a study by Toçi et al. (2013), HL and socioeconomic factors were examined using the HLS-EU-Q47 among older adults. Residence had a predictive value for HL as the mean HL score was significantly higher among urban residents. However, a European population-based study in Germany among individuals 35–91 years old in Berlin and the surrounding rural area using the HLS-EU-Q16 instrument found higher HL scores in the rural area (Haeger et al., 2023). The authors point out that rural areas can vary in terms of infrastructure and those who choose to live there, as in the case of rural Berlin, where financially secure and educated people move for a quieter life. So, in some cases, differences in HL are more dependent on sociodemographic factors rather than residency (Haeger et al., 2023).

Sentell et al. (2017), have highlighted the gaps in empirical research regarding HL as a social construct, missing out on critical areas because of a relatively narrow focus on the social context. Others, like Agner et al. (2024), have echoed this need to broaden the scope of accessing, understanding, appraising, and using health-related information. For example, a person's ability is not only based on their cognition or values but also on the social network that includes other people, like family, friends, and healthcare staff. In a qualitative study interviewing 12 individuals aged 44–60 in Switzerland (Stormacq et al., 2023), findings indicate that being health literate is like an obstacle course where financial deprivation, accessing and understanding medical information, and using the internet were identified as barriers. The findings also highlight the importance of relatives as part of people's social networks and as essential resources; however, they often encounter the same difficulties that limit their ability to assist. Therefore, it is essential to understand people's performance when dealing with health information and the difficulties they encounter (Stormacq et al., 2019, 2023).

1.4 The Icelandic context for older adults' participation in health literacy

1.4.1 Older adults in Iceland

The personal factors potentially influencing the ability of older adults in Iceland to participate in HL tasks are reflected directly and indirectly in selected and available demographics and information on characteristics such as employment rates, income, education, SRH and internet use.

In 2018, 14% of the Icelandic population were 65 or older, compared to 20% in the EU (Statistics Iceland, 2020a). In 2024, this rate was nearly 15% (59,764) of the country's total population of approximately 390,000. These older adults were primarily native-born citizens; 48% were men, and 52% were women (Statistics Iceland, n.d.c). More than 21% were employed; 63% men and 37% women. Thereof, 69% were aged 65–69, and 31% were aged 70 or above (Statistics Iceland, n.d.d). Over the last 25 years, older people's income has grown faster than younger people's, and today, it is, on average, 97% of the average income of a person in the labour market (KPMG, 2023).

Generally, older adults in Iceland are defined as those aged 67, as it marks the official retirement age and entitlement to an old-age pension (Act on the affairs of older adults [Lög um málefni aldraðra nr. 125], 1999). Based on public information on 45,922 individuals 67 years old and older, around 44% had finished primary education, 31% men and 69% women; 38% had a secondary education, 65% men and 35% women; and 17% had a tertiary education, 52% men and 48% women (Statistics Iceland, n.d.e).

Education levels and internet use seem to be connected. A cross-Nordic comparison revealed that older adults with higher educational levels tend to be more frequent internet users (Huynh et al., 2022). In a study based on a random sample of 221 Icelanders 56 years and older, findings indicate that participants were motivated to get digital health information. However, most had not adopted new information and communications technologies (ICTs) for health information and about half considered it challenging to implement new ICT (Pálsdóttir, 2020).

Icelanders generally report good health status (75%) compared to EU countries (70% on average) (European Observatory on Health Systems and Policies, 2019). In a population-based study in Iceland, 57.2% of those 65 years and older rated their general health as very good/good compared to 72.8%–88% in younger age groups (Statistics Iceland, n.d.a). This difference in SRH is also reflected in a study conducted among 175 urban and rural community-dwelling adults 65–92 years old (mean *(M)* = 74.2, standard deviation *(SD)* ± 6.3), as SRH decreased with advanced age (Sigurdardottir et al., 2019).

1.4.2 The Icelandic environment

Iceland is an active volcanic island in the Arctic (Figure 1), covering an area of 103.492 km^2. The country is known for its rugged terrain and unpredictable weather and has one of the lowest population densities of any European country (Nordic Co-operation, n.d.). These factors, among others, influence organisational structures and the approachability and availability of resources needed for older adults to participate in tasks that promote and maintain good health and well-being, including accessing, understanding, appraising, and using health-related information.

Figure 2. The geographic location of Iceland in the Arctic region, viewed from the North Pole.

Source: Furian (2016).

More than 60% (around 233,000) of the Icelandic population lives in the Reykjavík greater capital area (CA) in the country's southern part. The remaining residents live along the coastline in rural areas, with small towns as urban centres (Statistics Iceland, n.d.b).

Iceland is a parliamentary democracy (Government of Iceland, n.d.). Neoliberalism has influenced the country's economy and the politics of health and welfare since the late 1970s, emphasising ideas of a globalised free market and people´s right and responsibility to choose (Ólafsson, 2016). It is a high-income country (OECD, 2023) and performs well in many aspects of well-being (OECD, n.d.b). The social and health sectors work towards the Nordic welfare model, which includes universal health coverage (European Observatory on Health Systems and Policies, 2019). While health care services are the responsibility of the Minister of Health, local authorities in municipalities arrange and provide social services. The country is divided into seven health districts, each of which must provide first- and second-level services, encompassing all general health services. Primary health care (PHC) should be individuals' first point of contact (Act on health care [Lög um heilbrigðisþjónustu nr. 40], 2007).

The Act on the Affairs of Older Adults in Iceland (1999) and The Act on Social Services of Municipalities (1991) state that those aged 67 and older should have access to the health and social services they require and receive them at the most reasonable level based on their needs, and for instance, ensure that they can live in their homes and remain connected with others for as long as possible. This can, however, be challenging, particularly in a sparsely populated country. Rural areas often face long distances, and weather and road conditions can be unpredictable; public transportation options and healthcare hours are limited. For instance, an accessibility analysis indicated that in east Iceland, travel time from a residence to the nearest healthcare facility ranges from 10 minutes to two hours, with a one-hour car ride serving 86.4% of the population and a visiting care worker may need to travel as far as 600 km. for a home visit. Furthermore, a continual challenge in rural areas is the absence of essential services like pharmacies and grocery stores, including many areas where older residents live (Penje et al., 2020).

The Act on Social Services of Municipalities (1991) further states that each municipality must establish a Senior Citizens Council to enhance empowerment and the perspective of service users. This council is a formal platform for consulting on services and development related to ageing and older adults. The National Association of Senior Citizens, a non-profit organisation promoting older adults' interests and welfare, is expected to nominate three older adults to serve on the council (The National Association of Senior Citizens [Landsamband eldri borgara], n.d.).

Private cars are the most common means of transport in Iceland, with most travelling as drivers or passengers in private cars, with limited differences between the CA and outside the CA (Government of Iceland [Stjórnarráð Íslands], 2023). Around 250,000 people hold a general driver's license, approximately 1500 (0.6%) of whom are aged 70 and 500 (0.2%) of whom are aged 80, with no gender differences (Ásta Þorleifsdóttir & Sigrún Birna Sigurðardóttir, 2021).

The digitalisation of all public services in one place in Iceland, Digital Iceland, has been building up on the website island.is. (Directorate of Health, 2016). This includes, for example, a particular web page with practical information dedicated to ageing (Digital Iceland, n.d.). Furthermore, the ICT system "Heilsuvera" is for booking doctor appointments, viewing drug prescriptions, communicating with doctors or other health professionals, and getting reliable health information (Directorate of Health and the PHC, 2017). By the end of 2026, all legal entities in all urban and rural areas in Iceland will have stable and high-speed electronic access. Approximately 82% of legal households in rural areas have access to this kind of electronic connection (Government of Iceland [Stjórnarráð Íslands], 2024). However, study findings indicate that although ICT systems are available, people have trouble getting the help needed when using technology (Pálsdóttir, 2020).

1.4.3 The interaction of various factors in Iceland

Although the Icelandic context for older adults' participation in HL is presented as personal and environmental factors, there is a dynamic interaction within and between those factors to be considered. For example, the interplay between age, education level and residency. Like in many other European countries (Augère-Granier & McEldowney, 2020), rural areas in Iceland have the highest proportion of older adults (Statistics Iceland, 2020a). Living in rural areas of Iceland has also been associated with, for example, worse SRH, inadequate perceived income and cohabitation (Arnadottir et al., 2009, 2011; Haraldsdóttir et al., 2014; Sigurdardottir et al., 2013). Furthermore, in urban areas, the percentage of older adults with tertiary education is over twice that of rural areas. This difference in educational levels between urban and rural areas is most evident in Iceland compared to other Nordic countries (Huynh et al., 2022).

1.5 Summary of and rationale for the study

Studying HL through the lens of the POJF provides a unique perspective for a better understanding of the concept in relation to older adults. This approach considers the complexities of older adults' participation in daily life. Healthy decisions based on accessing, understanding, appraising, and using health-related information and services are made through the interaction of various individuals' abilities and the available environmental resources. Furthermore, grounded on global indications of age-related inequalities, from a human rights perspective, occupational justice is explored to enhance the full citizen participation of older adults in everyday life.

HL is considered essential for health and well-being, although it remains an evolving concept. Health-literate people are viewed as resilient, empowered and capable of taking responsibility for their health and well-being. Over the past 15 years, growing awareness of the significance of HL for public health has placed it on the agenda in Europe with the aim of improving general HL among populations. Efforts have been made to develop instruments and assess levels of HL within populations to identify at-risk groups. The HLS-EU-Q-16 is a skill-based instrument translated, validated, and used to assess HL in various countries, demonstrating reasonable psychometric properties overall. However, being a relational concept, the demands and complexity of health information and healthcare systems' effect on HL has increasingly gained attention. Furthermore, a systematic transformation has been suggested by strengthening the HL system's capacity beyond organisational and individual behaviour change. This frames

HL as a political choice, calling for greater commitment and the implementation of effective policies to enhance HL.

The literature mostly reflects the emphasis on measuring HL levels among populations or specific population groups in various settings. Furthermore, to connect different personal and environmental factors with limited HL scores. There are indications that older adults measure with more limited levels of HL than younger adults. Limited HL levels have also been connected to those with worse social and economic life positions and worse health status. However, the complexity of HL is highlighted by the interaction between personal and environmental factors. For example, rural regions in Europe have the highest proportion of community-dwelling older adults and living rurally has been linked to poor health, lower education, and reduced income. HL research has faced criticism for often viewing the concept as an individual construct, which limits the understanding of people's social context. Qualitative findings describe that being health literate resembles navigating an obstacle course. Therefore, it is crucial to comprehend how people perform and participate with health information in their context.

Iceland is a high-income democratic country in the North Atlantic. This sparsely populated Arctic island, with less than 400,000 inhabitants, ages more slowly than other European nations. This presents an advanced opportunity to address the impending challenges of global ageing. Individuals aged 65 and older comprise about 15% of the country's population, with rural areas exhibiting the highest proportion of community-dwelling older adults. Although the country performs well in various well-being aspects and has health and wellness systems rooted in the Nordic welfare model, health inequalities exist. If HL is not addressed, there is a risk of unintentionally widening inequality gaps by developing information and services that do not meet the needs of those who would benefit the most. There is a lack of validated HL instruments in Icelandic, and information regarding HL in the country is scarce. By collecting quantitative data on the HL levels of older adults in Iceland, alongside qualitative information about their experiences and needs regarding health information, valuable insights can be gained to enhance older adults' participation in occupations essential for their health and well-being.

2 Aims

This thesis comprises three distinct, interconnected research projects presenting three original papers. The overall objective was to investigate HL from a participatory occupational justice perspective, focusing on community-dwelling adults aged 65 and older living in sparsely populated Arctic regions of northern Iceland and the interaction of personal and environmental factors. The three projects all have specific aims and methodologies. The **first project** aimed to establish a valid instrument of HL in the Icelandic language and assess levels of HL in the country using samples from the general population. The **second and third projects** focused on the same population of community-dwelling older adults in northern Iceland. The **second project** applied the translated and validated instrument from the first project to assess levels of HL, identify challenging dimensions, and examine the impact of various personal and environmental factors on HL levels of older adults. The **third project** explored the experiences and needs of older adults in relation to being health literate.

The aims of the individual research projects were:

I. To **(a)** translate the short version of the European Health Literacy Survey Questionnaire (HLS-EU-Q16) into Icelandic and adapt it to the culture and language as needed, **(b)** evaluate its psychometric properties, and **(c)** establish population-based norms, including to analyse problematic domains of HL, and explore associations between HL levels and various personal and environmental factors.

II. To gather data on HL levels among community-dwelling older adults in one urban town and two rural areas in northern Iceland using the HLS-EU-Q16-IS, analyse problematic domains of HL, and explore associations between HL levels and various personal and environmental factors.

III. To explore the experiences and needs of older adults in northern Iceland who participated in research project II on accessing, understanding, appraising, and using health-related information.

3 Materials and methods

3.1 Research design

The three research projects described in this thesis had different research designs, as shown in Table 2. **Project I** was based on a methodological and descriptive design. Using both qualitative and quantitative research approaches, the Icelandic version of the HLS-EU-Q16 was developed through a stepwise process that included translation (with cultural and linguistic adaptation), validation, and the establishment of population-based norms. **Project II** was population-based and cross-sectional, where the validated instrument from Project I was used among older adults in three distinct areas in northern Iceland, along with other internationally recognised measurements and single-item questions. **Project III** was qualitative and explorative, where semi-structured individual interviews were carried out on the experience and needs of purposefully sampled study participants in Project II.

Table 2. Description of the three research projects (continued on the next page)

	Project I	**Project II**	**Project III**
Aim	Translate and adapt the HLS-EU-Q16 to Icelandic, validate it, establish population-based norms, analyse problematic dimensions, and explore associations with contextual factors.	Measure the level of HL among community-dwelling older adults in northern Iceland with the HLS-EU-Q16-IS, analyse problematic dimensions, and explore associations with contextual factors.	Explore the experiences and needs of older community-dwelling adults in northern Iceland regarding accessing, understanding, appraising, and using health-related information.
Design	Methodological, cross-sectional, descriptive, and correlational.	Quantitative, cross-sectional, descriptive, and correlational.	Qualitative and explorative, with a social constructivist lens.
Method	Translation: translation-back-translation, specialist review. Pretesting I: cognitive interviewing ("think out loud" and probing). Pretesting II: psychometric validity testing. Questionnaire (administered electronically and on paper).	Questionnaire (administered in person).	Individual semi-structured interviews.
Participants	17 lay adults in Akureyri. 251 population-based adults.	175 older adults, community-dwelling in the north.	20 older adults, community-dwelling in the north.
Instruments and variables	Translation: original English European Health Literacy Survey Questionnaire short version (HLS-EU-Q16). Pretesting I: Version T-2.1 for understanding, comprehension of meaning, and interpretation. Pretesting II: Final version of the HLS-EU-Q16-IS and 11 single-item questions.	European Health Literacy Survey Questionnaire short version (HLS-EU-Q16-IS), Connor-Davidson Resilience Scale (CD-RISC), Geriatric Depression Scale (GDS), Self-rated health (SRH) single-item question on global health status, and 15 single-item questions.	Interview guide on a) most extended residence and primary profession, b) experiences and needs regarding accessing, understanding, appraising, and using health-related information, and c) open-ended on any additional information.

	Project I	**Project II**	**Project III**
Analysis	Translation and pretesting I: discrepancies, changes in wording, clarity, applicability. Pretesting II: internal consistency, Principal Component Analysis (PCA). Norms: Descriptive statistics, linear multivariate regression	Independent t-tests, chi-square tests, Univariate linear regression models, and multivariable linear regression model.	Qualitative content analysis: abstracting meaning units, comparing commonalities into subcategories and categories.
Product	Paper I Translation and cross-cultural adaptation of the Icelandic version of the European Health Literacy Survey Questionnaire, HLS-EU-Q16.	Paper II Making Europe Health literate: Including older adults in sparsely populated Arctic areas.	Paper III When great responsibility comes with limited options: Experiences and needs of older community-dwelling adults regarding accessing, understanding, appraising and using health-related information.

3.2 Research teams

In **Projects I** and **II**, the research team consisted of SSG and PhD committee members. Additionally, the team included a specialist group of six researchers from the University of Akureyri, Iceland and the University of Iceland. This specialist group collaborated on a population-based research project titled "Health and Well-being in northern Iceland among Community-dwelling Icelandic people aged 65 years and older," which Project II was part of. The group had diverse backgrounds; most were experienced researchers and experts in fields such as geriatrics and urban/rural studies. They contributed to the translation and adaptation process of the HLS-EU-Q16 instrument in Project I and collaboratively selected instruments and additional items for the survey in Project II. In **Project III**, the research team included SSG and PhD committee members, as well as an older adult living in Akureyri.

3.3 Research settings

The setting for **Project I** covered all of Iceland, including Akureyri town in northern Iceland, for the translation process, and for validating the HLS-EU-Q16 through pre-testing and establishing preliminary HL norms. **Projects II** and **III** are based on three areas in northern Iceland: Akureyri town, defined as an urban centre (Sindradóttir & Harðarson, 2012), and two distinct rural areas consisting of people living on farms in isolated houses or small villages with fewer than 200 inhabitants (Statistics Iceland, 2020b). Although the Akureyri municipality population is only around 20,000

(Akureyrarbær, n.d.), it is the largest town in Iceland outside the CA, with comprehensive infrastructure and high service levels, and the north's centre of trade and services (Akureyrarbær, n.d.; Bjarnason et al., 2021). This includes several important facilities and services related to education, health care, accommodation, environment, transport, sport and leisure, culture, and recreation. Akureyri municipality offers specific services to older adults, such as transportation, home delivery of food, social counselling, and retirement homes for those who can no longer live at home without appropriate support (Akureyrarbær, n.d.).

The rural areas near Akureyri, surrounded by mountains, include the municipalities of Skagafjordur in the west and Thingeyjarsveit, Langanesbyggd, Tjorneshreppur, and Nordurthing in the east (collectively forming the Thingeyjarsveit district). These two rural districts primarily consist of agricultural and fishing regions, characterised by more limited services and infrastructure compared to Akureyri and longer distances to access those services. For instance, small primary healthcare clinics operate only a few hours a week, public transportation is rare, and road maintenance is limited during winter. The combined population of these two rural areas was approximately 4,000, with around 19% being aged 65 and older. The average distance to healthcare services in rural areas exceeds 20 km (12.5 miles). To adhere to the established definitions for urban and rural areas, the most significant towns with populations of over 200 in these two rural districts, Saudarkrokur in the west and Husavik in the east, were excluded.

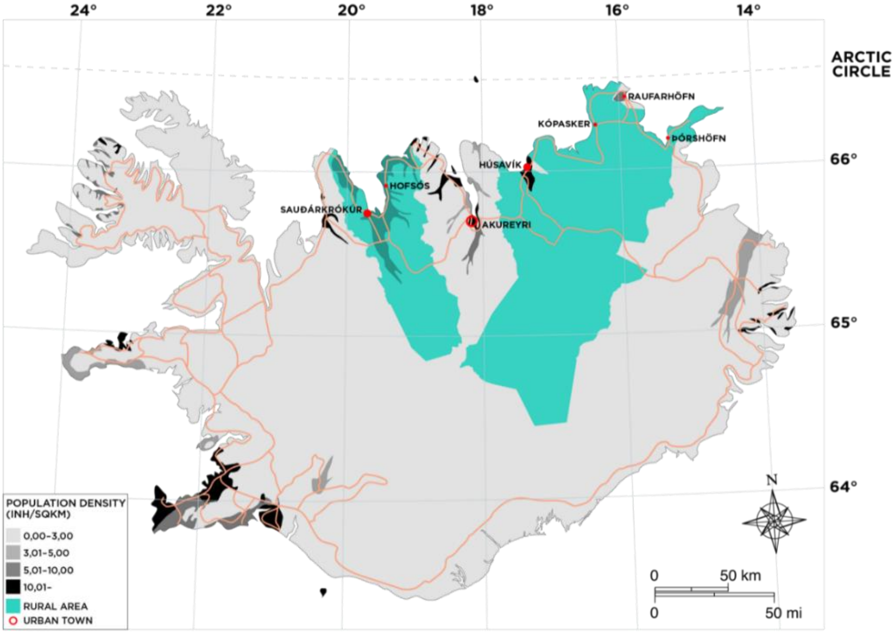

Figure 3. Research areas in northern Iceland and population density.

The green-coloured areas denote rural regions (by postcode). Akureyri, the urban town, is marked with the most prominent red circle. The next-largest red circles represent towns (Saudarkrokur, Husavik) in the study's rural areas that were excluded. The small red circles indicate the locations of health clinics in these rural areas. Population density is illustrated in shades of grey and black, with black denoting the most densely populated regions.

3.4 Participants selection

Participants in **Project I** were laypeople in Akureyri and a random sample of Iceland's general population. **Project II** was based on a random stratified sample of older adults, 65 and over, community-dwelling in the urban town of Akureyri and two rural areas, Skagafjordur and Thingeyjarsveit districts in northern Iceland. **Project III** involved a purposive selection from Project II.

3.4.1 Lay people in Akureyri and the general population in Iceland (Project I)

To explore potential cultural and linguistic adaptations, 17 individuals volunteered to participate in cognitive interviewing. They were purposefully selected from two public workplaces in Akureyri, representing the general adult public. The selected workplaces provided access to individuals of various ages, gender, and educational backgrounds. Additionally, snowball sampling was employed to incorporate retired employees, representing the older population.

A randomised stratified sample of the general population aged 18–85 with a registered home address in Iceland was selected for validity testing and establishing preliminary norms for HL levels in Iceland. In Iceland, children are legally defined as those under 18, and special permission is required to include them in a research sample. Thus, the minimum age limit was set at 18 for practical purposes. Given the life expectancy in Iceland, the chosen maximum age limit of 85 exceeds the average life expectancy for both women and men. The University of Akureyri Research Center advised on and provided a random sample size of 1,200, stratified by age, gender, and place of residence.

3.4.2 Older adults in northern Iceland (Project II and III)

A targeted random sample of 250 urban and 160 rural participants in **Project II** was determined, stratified by age, gender, and place of residency. This decision was based on the community size in Akureyri and the two other areas to achieve a statistically valid difference between urban and rural participants (Hulley et al., 2013). This sample size was selected to be sufficiently powered to identify potential differences between urban and rural participants. Inclusion criteria included living at home, communicating verbally in Icelandic, and arranging a time for data collection. Although Icelandic law defines older adults as those 67 and older, to ensure international comparability, the age limit was set at 65 (OECD, n.d.a). Of 302 potential participants, 175 (57.9%) agreed to participate. Those who declined did not differ significantly in age (*p* = 0.77) or residency (*p* = 0.55). More women (*n* = 73) declined to participate compared to men (*n* = 44) (*p* = 0.01). The most common reason for declining was being too busy or experiencing research fatigue, meaning they had recently participated in other studies.

The selection criteria for **Project III** were based on the study's aim to interview older adults from diverse backgrounds, including places of living, age, gender, education, modes of transport, and distance from services. Information on participants from the previous Project II was compiled into a selection matrix for the three research areas. Those without an ID or phone number on record were excluded. Since the richness of data was unknown in advance, one to two individuals were contacted in each age group across the three geographical areas. Twenty people were contacted for participation in the first round. Information on the participants and the interviews can be found in Appendix A.

3.5 Procedure

3.5.1 Translating, adapting, and validating the HLS-EU-Q16, and establishing norms (Project I)

This project included three steps: translation, adaptation, and validation. The HL norms were based on the same sample and procedure as the validation described in step 3. Translation and adaptation involve converting a questionnaire into a different language and culture while maintaining the same meaning as the original version. Cross-cultural adaptation (CCA) is commonly utilised in comparative studies to ensure the validity of a translated assessment tool (Beaton et al., 2000; Epstein et al., 2015; Hambleton et al., 2005). Prior to the translation process of the 16-item European Health Literacy questionnaire, the HLS-EU project manager, Kristine Sørensen, granted approval for the translation of the original English version of the instrument. In **step 1**, SSG and AKS, who were familiar with HL, translated the English version of the instrument separately and then combined the two versions into one. The specialist group reviewed the version before back-translations as part of the research team. Two experienced translators, whose first language was English and who were unfamiliar with HL as a relatively obscure term in Iceland, back-translated the version. All four translators had a strong understanding of English and Icelandic languages and their respective cultures and health sciences. Subsequently, SSG and AKS created an integrated version, which the specialist group reviewed prior to the pre-testing, including cognitive interviews in **step 2**. The semi-structured cognitive interviews (Beatty & Willis, 2007; Willis, 2005; Willis & Artino, 2013) employing pre-prepared questions were audio recorded, and a written summary was prepared after each interview to detail participants' responses and comments, such as their thoughts on wording and concepts. Following the first round of reflective conversations, a consultation meeting was convened to discuss changes to the instrument. An amended version underwent a second round of cognitive interviews in the same manner as previously described. A subsequent consultation meeting was held to discuss the results of the interviews, leading to adjustments in the wording of the instrument. The cognitive interviews lasted from 12–35 minutes, 25 minutes on average. **In step 3**, pre-testing II was conducted. All potential participants received an introductory letter, the HLS-EU-Q16 Icelandic version, and 11 background items. The 18–64 age group (*n* = 990) answered the questionnaire electronically, while the 65–85 age group (*n* = 210) filled out a paper questionnaire. The response rate after four weeks was low for the 18–64 age group (< 20%) but exceeded 60% for the 65–85 age group. As a result, every fifth participant in the 18–64 age group was approached and offered the opportunity to complete the questionnaire through a telephone interview.

3.5.2 HLS-EU-Q16-IS survey (Project II)

Potential participants in three areas of northern Iceland received an introductory letter about the study and a phone call from a research assistant. This project was part of a larger, population-based research project (Sigurdardottir et al., 2019). Four undergraduate nursing students specifically trained as research assistants conducted face-to-face interviews from September 2017 until February 2018 at the participants´ homes, their nearest healthcare centre, or the research centre in Akureyri town.

3.5.3 Individual interviews (Project III)

Potential participants in this project received an invitation letter by post and were contacted by telephone by SSG to invite them to take part. Data was collected over one year, from January 2022 to January 2023, at participants' homes or the University of Akureyri research centre. During an ongoing pandemic, the invitation letter described infection control measures implemented to ensure safety, such as social distancing, disinfectants, and masks. SSG conducted all interviews in Icelandic at the participants' preferred location. The interviews lasted from 30–65 minutes, 46 minutes on average, and were audio-recorded and transcribed verbatim.

3.6 Instruments and variables: Quantitative assessments and qualitative interview guides

In **Project I**, the original English version of the HLS-EU-Q16 instrument was translated into Icelandic and adapted. The HLS-EU-Q16 was selected for translation because it is short, easy to submit, and designed within the European context. It is also one of the few HL assessment tools designed to measure the general HL of the public rather than specific patient groups (Sørensen et al., 2012). Numerous integrated versions (T-versions) were created during the process and further developed. A preliminary Icelandic version (T-2.1) of HLS-EU-Q16 was utilised in cognitive interviews to test understanding, comprehension, interpretation, and the ease or difficulty of answering the items. See Table 3 for an example of the cognitive interview worksheet. The final Icelandic version of HLS-EU-Q16 (T-3) was utilised for validation and establishing preliminary norms. The survey also featured a set of background questions specifically selected to reflect characteristics commonly used in surveys related to levels of HL, such as age, education, income, and SRH.

Table 3. An example from the cognitive interview worksheet of verbal probe questions and comments

Item No.	Question	Cognitive interview questions	Comments
1	Find information on treatments of illnesses that concern you?	1. In your own words, what do you think is being asked about here? 2. What do you think is meant by "treatments"? 3. How did you feel (easy/difficult) answering the question?	Thought that treatment of illness applies to quite severe conditions and suggested using the word ailments instead

In **Project II**, the final Icelandic version (HLS-EU-Q16-IS) from Project I was used, along with the Connor-Davidson Resilience Scale (CD-RISC) (Connor & Davidson, 2003), the Geriatric Depression Scale (GDS) (Yesavage et al., 1982), and a single-item Self-Rated Health (SRH) question (Ware, 2000). These instruments and 15 additional single-item questions addressing various personal and environmental factors were selected because the literature connects them to potentially important roles related to HL and older adults in urban and rural settings.

The HLS-EU-Q16-IS consists of 16 items rated on a four-point scale: "very easy," "fairly easy," "fairly difficult," and "very difficult." The total points are calculated if at least 14 out of 16 questions are answered. Responses of "fairly easy" and "very easy" are combined into "easy" (scoring one point), while responses of "very difficult" and "fairly difficult" are combined into "difficult" (scoring zero). The total points range from 0–16, reflecting the level of health literacy skills, categorised as sufficient (13–16 points), problematic (9–12 points), and inadequate (0–8 points) (Pelikan et al., 2014; Röthlin & Ganahl, 2013). The CD-RISC contains 25 items scored from 0–4. Final points are calculated by summing the total of all items and range from 0–100, with the highest score indicating greater resilience (Connor & Davidson, 2003). The GDS consists of 30 items, each scored from 0–1. Final points are determined by adding the total of all items and range from 0–30, with a higher score indicating more severe depression (Yesavage et al., 1982). The standardised single-item SRH scale is scored from 1–5, where a higher score reflects better self-rated health (Ware, 2000).

In **Project III,** a three-part interview frame (Appendix B) was developed for this study to understand the experience of older adults when accessing, understanding, appraising, and using health-related information and to identify related needs. The first part consisted of introductory questions regarding the duration of their residency in the current area, primary occupation, and the pseudonyms they preferred for confidentiality. The second and central part invited participants to share their experiences regarding the accessibility, clarity, and usefulness of health-related information and services. In the final part, participants had the chance to provide additional information. The interview frame was piloted during the first three interviews. Participants were asked to reflect on the interview frame, for example, how easy/difficult it was to understand the questions and SSG as an interviewer.

3.7 Data analysis

3.7.1 Clarity, consistency, constructs, and norms (Project I)

In **steps 1 and 2** of the translation and adaptation process, discrepancies, changes in wording, clarity, and applicability of the instrument's items were sought through the research team and participants (lay people). Recorded discrepancies were addressed and reflected upon, and decisions were made based on consensus for integration. In **step 3** of the process, pretesting II was conducted among the general adult population. Data were analysed for internal consistency using Cronbach's α, and construct validity was evaluated through Exploratory Factor Analysis. PCA was used for structural analysis, an empirical technique particularly effective for examining cultural differences in item comprehension among populations (Bandalos, 2018). Descriptive statistics were used to calculate the HL score to set preliminary norms for Iceland. Following recommendations from Pelikan et al. (2014) and (2013), HL was divided into three levels: sufficient (13–16 points), problematic (9–12 points), and inadequate (0–8 points). Descriptive statistics were also used to analyse individual item ratings according to the dichotomised responses "easy" and "difficult", and linear multivariate regression was employed to examine the relationship between HL and various personal and environmental factors. The level of significance was set at $p < 0.05$ when appropriate. The IBM Statistical Product and Service Solutions (SPSS) software package v22 (IBM Corporation, 2013) was used for statistical analysis.

3.7.2 Health literacy score, item rating scale and associations (Project II)

Descriptive statistics and the three levels of HL were calculated using the same method to set the preliminary norms for Iceland in Project I and were categorised accordingly. Independent t-tests and chi-square tests were used to compare personal and environmental factors based on residency, and chi-square tests were used to compare missing answers to age, gender, education, and residency. Descriptive statistics were also used to analyse individual item ratings according to the dichotomised responses "easy" and "difficult". The association between HL and the selection of various personal and environmental factors was analysed using univariate and multivariable linear regression models. The level of significance was set at $p < 0.05$ when appropriate. The IBM SPSS v22 (IBM Corporation, 2013) was used for statistical analysis.

3.7.3 Meaning units, subcategories, and categories (Project III)

The transcribed interviews were analysed with qualitative content analysis (Graneheim & Lundman, 2004; Graneheim et al., 2017). An English-translated version of the interviews was also used, and the analysis was conducted in Icelandic and English. Initially, the data management software Non-Versioned Information, Versatile Outcomes (NVivo) (QSR International Pty Ltd, 2016) was used to identify meaning units; however, due to technical difficulties, the work was mainly carried out in Word.

In line with the method, meaning units were identified based on the study's aim, condensed, abstracted, and labelled as codes. Several codes made a subcategory, and several subcategories made a category. Each category describes a collection of similar data sorted into one place. Working through three analysis steps in a research team, the same logical and congruent level of abstraction and degree of interpretation was maintained while categorising based on direct content, minimal interpretation, and remaining close to the original text. The credibility was increased with regular reflections on the consistency of empirical data and the emerging categories. Table 4 provides an example of how meaning units are condensed and labelled with codes, creating a subcategory of a category.

The 20 interviews provided valuable data to fulfil the study's purpose, which was to explore the experiences and needs of older community-dwelling adults concerning their access to, understanding of, appraisal of, and use of health-related information and services. Therefore, no further interviews than those 20 in the first round were conducted.

Table 4. An example of a subcategory and how meaning units are condensed and coded

Category: Finding own ways		
Subcategory: Rely on spouse, family and friends		
Translated meaning units	**Condensed meaning units**	**Code**
Yes, yes. I ran into all kinds of such (computer problems) and I'm lucky enough to be able to get someone and our daughter .. is really good at helping. I don't know what we did if we lost touch with her I'm not much of a techie, I have a daughter who lives here and she's a techie so convenient that she just does it my daughter has only helped me in this way, it's been so short since I started this If I get into a lot of trouble, I'm calling a person I know knows what it is, just a friend I have a computer but I haven't mastered it, but my son is always here on weekends and he can inform us	To get necessary help from friends or children/grandchildren when having technical difficulties in accessing health related information	Necessary help (to work with the responsibility in the complex environment)

3.8 Ethical considerations

All three research projects were carried out following the guidelines of the Declaration of Helsinki (World Medical Association, 2013). According to information from the Icelandic National Bioethics Committee, **Project I** required no ethical approval after an inquiry. The Icelandic Data Protection Authority was notified about the study in January 2017. Written informed consent was obtained from participants in the cognitive interviews. Survey participants received an introductory letter detailing the purpose and nature of the study and provided consent for participation by completing the questionnaire. **Project II** received approval from the Icelandic National Bioethics Committee (VSNb2016060007/03.01) and was reported to the Icelandic Data Protection Authority. Written informed consent was obtained from all participants. The Icelandic National Bioethics Committee indicated that no further approval from the previous study (VSNb2016060007/03.01) was needed for **Project III** (VSN-21-009). The names and social security numbers of participants, along with the research numbers from the prior study, were kept separate and accessible only to the researchers with special permission from the file holder, the University of Akureyri Research Centre. Written informed consent was obtained from all participants. At the start of each interview, participants chose pseudonyms to ensure confidentiality and privacy, and recorded interviews were deleted following transcription.

4 Results

The main results of the three projects indicate that the HLS-EU-Q16-IS version used to assess general HL is a valid instrument. Based on the adult population, the preliminary norms for Iceland indicate that the majority has sufficient HL levels, and better SRH was an independent predictor of better HL. Results from using the instrument among older community-dwelling adults reveal a higher proportion of problematic HL levels than the norms and that higher education and driving a car as a means of transportation are independent predictors of better HL. Both the general adult population and older adults identified the domain of DP as the most challenging, related to information in the media. Moreover, older adults experience a personal responsibility for managing their health; however, they face limited environmental options to act on that responsibility, highlighting a critical tension that pushes them to adapt. The needs expressed are shared responsibility and manageable options. The results and findings from Projects I, II, and III are summarised below.

4.1 Validity of the HLS-EU-Q16-IS and preliminary norms (Project I)

The linguistic and cultural changes during the first step of the translation process included minor differences in wording and grammar noted in the Icelandic version of the HLS-EU-Q16. The specialist group made cultural choices regarding the phrasing of two concepts (found in items no. 8, 13, and 9) and determined that using "pharmacist" in item 10 was irrelevant. In the second step of the process, six men and six women aged 20–74 (*M* = 51, *SD* ± 19.55) took part in the first round of the cognitive interviews, and in the second round, four women and one man, aged 26–65 (*M* = 55, *SD* ± 11.12). Table 5 presents the age groups, gender, and education levels of the 17 participants (laypeople) in both rounds. The wording of 11 items changed during the cognitive interviews. The modifications were primarily minor (in nine items), while four considerable changes were noted (items no. 7, 8, 9, and 16), such as providing concrete examples for clarification. Appendix C provides further information about the wording changes during Icelandic's translation and adaptation process.

Table 5. Characteristics of participants in the cognitive interviews

First round	**Age group**	**Gender**	**Education**
1.	65-85	Woman	Secondary
2.	18-45	Woman	Elementary
3.	46-64	Woman	University
4.	18-45	Man	University
5.	46-64	Man	Secondary
6.	65-85	Man	University
7.	18-45	Woman	Elementary
8.	18-45	Man	University
9.	56-85	Woman	Secondary
10.	18-45	Man	Secondary
11.	46-64	Woman	Secondary
12.	65-85	Man	University
Second round	**Age group**	**Gender**	**Education**
13.	46-64	Woman	Elementary
14.	46-64	Woman	Elementary
15.	65-85	Man	Elementary
16.	18-45	Woman	University
17.	46-64	Woman	University

The psychometric properties of the HLS-EU-Q16-IS instrument were based on responses from 251 participants aged 18–85 (*M* = 55 ± *SD* 18.98). Among these, 52% were women, and 46% were men, with the majority speaking Icelandic as their first language (92.8%). An equal percentage (33.5%) had either completed secondary or trade school or held a university degree, while 22.3% had completed elementary school. Nearly 18% reported living alone, and 66.9% had sufficient income after tax to meet their needs. Additionally, 42.6% rated their health as excellent or very good, 25.5% as good, 21.1% as fair, and 6.4% as poor. The internal consistency of the instrument was 0.88. Eigenvalues of four components (5.94, 1.62, 1.38, and 1.05) explained 62.6% of the variance. Within the PCA and an Oblimin rotation, items clustered on factor components as follows: C1 with four items ($\alpha = 0.77$), C2 with four items ($\alpha = 0.85$), C3 with five items ($\alpha = 0.76$), and C4 with three items ($\alpha = 0.73$).

Establishing preliminary norms for HL levels in Iceland used the same participants as the psychometric analysis of the HLS-EU-Q16-IS. HL points and levels were analysed from 244 participants, while seven had more than two missing responses, and at least 14 of 16 questions had to be answered to calculate a total score. The points ranged from 2–16 (*M* = 13.52, *SD* ± 2.69), and the *median* was 14. The score and level distribution within gender and age groups is shown in Table 6. The difference between missing answers and, for example, age and gender could not be calculated due to limited scores.

The multivariable linear regression analysis revealed that better HL was independently associated with more education (p = 0.037), adequate income (p = 0.003), and increased self-rated health (p = 0.001). No association between HL and age was found. Lower self-rated health was an independent predictor of lower HL (β = −0.484, p = 0.008).

Table 6. Health literacy score and levels within the general population by gender and age groups

			HLS-EU-Q16-IS			
			Descriptives	**Categorical *n* (%)**		
	N	**Age-range**	***M* ± *SD* (Range)**	**Sufficient 13–16**	**Problematic 9–12**	**Inadequate 0–8**
Total	244	18–85	13.52 ± 2.69 (2–16)	174 (71.3)	54 (22.1)	16 (6.6)
Women	29	18–39	13.48 ± 2.98 (5–16)	19 (65.5)	8 (27.6)	2 (6.9)
	26	40–59	14.08± 2.43 (8–16)	19 (73.1)	5 (19.2)	2 (7.7)
	70	60–85	13.66 ± 2.63 (6–16)	53 (75.7)	13 (18.6)	4 (5.7)
Men	25	18–39	13.88 ± 2.01 (9–16)	20 (80)	5 (20)	0 (0)
	25	40–59	13.68 ± 2.90 (7–16)	18 (72)	4 (16)	3 (12)
	58	60–85	12.88 ± 3.00 (2–16)	77 (63.8)	16 (27.6)	5 (8.6)

Furthermore, Table 7 displays the three HLS-EU-Q16-IS items participants rated as the most difficult and their domains. These items are within the domain of HC and DP, related to a second opinion from a doctor and information in the media. The items most often rated as "easy" (by 95% of participants) were spread across all three domains: HC (items no. 3, 4, and 7), DP (items no. 9 and 10), and HP (item no. 16).

Table 7. Domains and items most frequently rated as difficult on the HLS-EU-Q16-IS among the general adult population

Item	**Domain***	***n* (%)**
5. judge when may need to get a second opinion from another doctor?	HC	77 (31)
11. judge if the information about health risks in the media is reliable?	DP	94 (38)
12. decide how you can protect yourself from illness based on information in the media?	DP	93 (37)
Domain*: HC Health Care, DP Disease Prevention Proportions (%) are based on valid responses to each item		

4.2 Older adults' health literacy levels, main challenges, and factor associations (Project II)

A total of 175 older adults participated in the survey: 105 (60%) from the urban town of Akureyri and 70 (40%) from the two rural areas. Participants' ages were comparable ($p = 0.550$) between the rural areas ($M = 73.9$, $SD \pm 6.2$, range 66–89) and the urban town ($M = 74.4$, $SD \pm 6.4$, range 66–92).

HL scores and levels were analysed from 134 participants, while 41 had more than two missing responses, and at least 14 of 16 questions had to be answered to calculate a total score. The score ranged from 6–16 points, with a mean of 13.25 (SD ± 2.41) and a median of 13. No difference in HL score was found between urban and rural participants ($p = 0.464$). Table 8 shows the HL score and levels for the whole group but also according to residency, gender, and age group. Among those with more than two missing responses (excluded lists), the difference between urban and rural residences was significant ($p < 0.001$), with individuals living in rural areas missing more responses; no difference was observed between missing answers and age, gender, and education.

Table 8. Health literacy score and levels according to age groups, gender, and residency among older adults

				HLS-EU-Q16-IS			
				Descriptives	**Categorical *n* (%)**		
			N	***M* ± *SD*** **(Range)**	**Sufficient 13–16**	**Problematic 9–12**	**Inadequate 0–8**
Total			134	13.25 ± 2.41 (6–16)	87 (65)	42 (31.3)	5 (3.7)
Residency	**Gender**	**Age-group**					
Rural	**Women**	65–74	19	13.58 ± 2.36 (6–16)	16 (84.2)	2 (10.5)	1 (5.3)
		75–92	4	10.50 ± 2.38 (8–13)	1 (25)	2 (50)	1 (25)
	Men	65–74	13	13.38 ± 2.22 (9–16)	8 (61.5)	5 (38.5)	0 (0)
		75–92	7	12.29 ± 2.5 (9–16)	2 (28.6)	5 (71.4)	0 (0)
Urban	**Women**	65–74	20	14.30 ± 2.05 (10–16)	16 (80)	4 (20)	0 (0)
		75–92	16	13.25 ± 1.61 (11–16)	11 (68.8)	5 (31.3)	0 (0)
	Men	65-74	31	13.48 ± 2.45 (7–16)	21 (67.7)	9 (29)	1 (3.2)
		75–92	24	12.46 ± 2.81 (7–16)	12 (50)	10 (41.7)	2 (8.3)

While many personal and environmental factors did not vary by residency, some significant differences were noted. Among personal factors, urban older adults, compared to their rural counterparts, had higher levels of education, were more likely to be retired, and exhibited greater resilience (p = < 0.001 – 0.044). In terms of environmental factors, urban residents used public transportation more frequently than those in rural areas. They also met friends and neighbours daily more often and had a more positive view of access to recreational centres and organised physical training. However, they rated access to medical services less favourably compared to rural residents (p = < 0.001 – 0.022). The univariate linear regression revealed that better HL was linked to several personal and environmental factors. Among the personal factors were being of younger age ($p = 0.005$), having higher levels of education ($p = 0.001$), having an adequate income ($p = 0.044$), increased resilience ($p = 0.001$), and lower levels of depression ($p = 0.006$). Among the environmental factors were driving a car ($p = 0.006$), good perceived access to healthcare ($p = 0.005$), and medical services (*p* = 0.027). The multivariable analysis identified more education (*p* = 0.014) and driving a car (*p* = 0.017) as independent predictors of better HL.

Table 9 shows the three items of the HLS-EU-Q16-IS within their domains that participants often rated "difficult". These items were related to information in the media in the domains of DP and HP. The items often rated "easy" (by 98%) were in the domains of HC (item no. 4) and DP (item no. 10), followed by items no. 3, 6, and 7 in the HC domain by 97% of participants.

Table 9. Items most frequently rated as difficult on the HLS-EU-Q16-IS among older adults

Item	**Domain***	***n* (%)**
11. judge if the information about health risks in the media is reliable?	DP	98 (57)
12. decide how you can protect yourself from illness based on information in the media?	DP	106 (63)
15. understand information in the media about how to get healthier?	HP	85 (49)
Domain*: DP Disease Prevention, HP Health Promotion Proportions (%) are based on valid responses to each item		

4.3 Older adults' experiences and needs (Project III)

All twenty individuals contacted first agreed to participate, provided their consent, and were interviewed. They were aged 70–96 (*M* = 77.3), 12 women and eight men, 10 from Akureyri and five from each rural area. Thirteen interviews were conducted at the older people's home, six at the University of Akureyri and one through Zoom.

The experiences and needs of older adults living in the community led to four categories based on the manifest content. Each category is independent yet interconnected, and two categories serve as the foundations, as shown in Figure 4. One foundational category, "Expectations for responsibility," includes two subcategories and describes the responsibility participants felt from themselves and their environment in managing their health, encompassing accessing, understanding, evaluating, and utilising information and services. The other foundational category, "A gap between expectancy and ability/context," outlines how, while acting on this expectation of responsibility, a gap emerged due to their skills or situations not aligning with the expectations described in three subcategories. As a result of this tension between the experience of bearing responsibility and the inability to do so, participants adapted, as described in a category named "Finding one's way," which includes three subcategories. The "Bridging the gap" category highlights experiences that require shared responsibility and more manageable options for making informed health-related decisions and navigating the healthcare system.

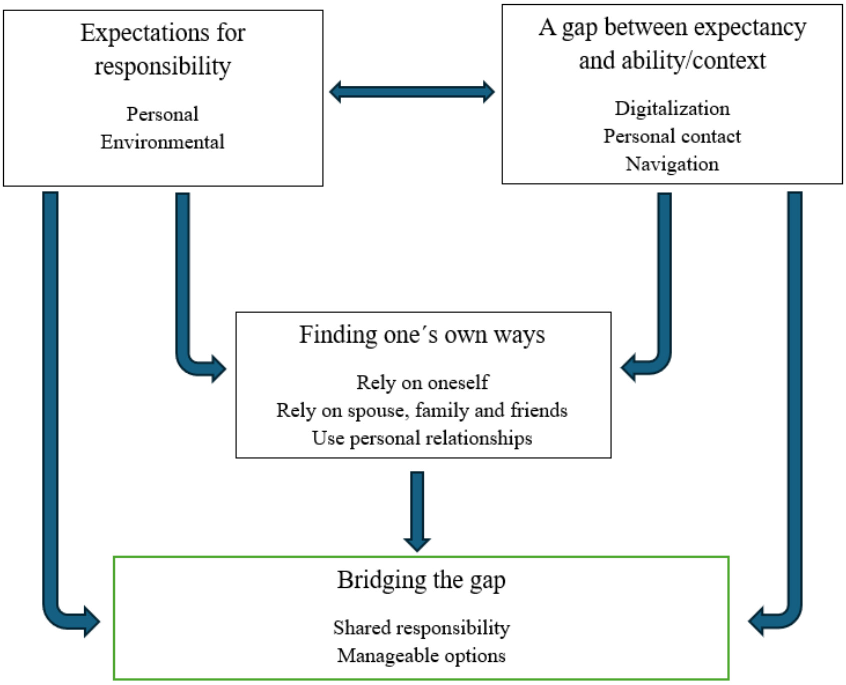

Figure 4. Categories and subcategories regarding older adults' experiences and needs concerning health literacy

The figure (Gustafsdottir et al., 2024) illustrates the interplay among the categories and the tension between "Expectations for Responsibility" and "A Gap Between Expectancy and Ability/Context," which often limits options for accessing, understanding, evaluating, and using health-related information and services. These two categories prompt individual action in "Finding One's Own Ways." Collectively, these three categories, including their subcategories, advocate for necessary actions in "Bridging the Gap".

5 Discussion

Establishing a valid instrument of HL in the Icelandic language and using quantitative and qualitative data to investigate HL among community-dwelling older adults through a participatory occupational justice lens contributes to the lack of instruments and information. The main findings of the three projects showed that the HLS-EU-Q16 is a valid instrument with a fairly clear factor structure that allows for the exploration of HL in Iceland and the comparison of results internationally. The established preliminary norms provided information that indicated sufficient HL levels among the general adult population, challenges with information in the media within the domain of disease prevention, and the association of lower levels of HL and worse SRH. The older adults in northern Iceland showed higher levels of problematic HL; however, the challenging domain and item resemble the general populations. Better HL was associated with personal factors (younger age, more education, adequate income, increased resilience, and lower rates of depression) and environmental factors (driving a car, good perceived access to healthcare and medical services). The independent predictors of better HL, being higher levels of education and driving a car, emphasise the significance of the influence of both environmental and personal factors in performing and participating in HL tasks. Furthermore, the four categories emerging from the interviews illustrated a tension between personal and environmental factors: the responsibilities of individuals regarding their health and the lack of options to fulfil those responsibilities, indicating occupational injustice. This tension works as a base and pushes older adults to adapt. Although they want to be responsible, older adults ask for occupational justice in shared responsibility and more inclusive, accessible service opportunities to bridge the information gap and enable participation in HL.

5.1 A valid instrument and information on health literacy levels in Iceland

The first project aimed to establish a valid measure of general HL in the Icelandic language and to gather information about HL scores in the country. Despite the increased emphasis on the important role of HL in public health within Europe, Icelandic officials have not been actively engaged (Frederiksen & Wångdahl, 2022). Consequently, valid instruments were unavailable in Icelandic, and limited information existed regarding HL in the country. By selecting a European and internationally recognised instrument and utilising a three-step translation process — which includes a specialist review, cognitive interview pretesting, and survey pretesting — a validated instrument was established, thereby enabling the country to enter the expanding field of HL research and policy setting.

The specialist review and cognitive interviews with laypeople in the three-step translation process were critical in the CCA needed for the Icelandic context. This included, for example, the specialist's decisions to leave out "pharmacist" (item no. 4) as their role in providing instruction on prescribed medication is not culturally relevant in Iceland. Furthermore, the laypeople suggested, for instance, in the cognitive interviews, reversing the response scale to start with “very easy” rather than “very difficult.” This emphasises the importance of including various stakeholders in the translation and adaptation process and cooperation and cocreations with target groups in the research development (Willis, 2005; Willis & Artino, 2013).

The Icelandic version of HLS-EU-Q16 exhibited high internal consistency, aligning with results from other research on several language versions of the instrument (Bergman et al., 2023; Eronen et al., 2019; Lorini et al., 2019; Rouquette et al., 2018; Tiller et al., 2015). Each component also showed acceptable internal consistency given a 16-item shortlist. The findings from the PCA indicate that items did not cluster together identically to the original English version (Sørensen et al., 2015). Results from other research, for example, on the psychometric properties of the Swedish shortlist (Bergman et al., 2023) indicate the same. These differences in factor loading from the PCA highlight certain cultural variations and indicate that the domains and/or competencies do not manifest in the same way across cultures. Therefore, the instrument's total score should be used for international comparison.

Iceland's first preliminary norms on HL levels indicate good individuals' ability to perform HL tasks with relatively high scores compared to the first (Sørensen et al., 2015a) and the second (Pelikan et al., 2021) European studies, although considerable variation in level values across countries occurred in those studies. In Iceland, 71% of the adult general population demonstrated sufficient HL levels compared to an average of 55% in the second HLS19 study, with sufficient and excellent HL levels ranging from 5% in Germany to 65% in Portugal. Additionally, 22% of individuals in Iceland exhibited problematic levels of HL, whereas the average in the HLS19 was 33%, with rates spanning from 18% in Slovenia to 48% in Germany. Furthermore, roughly 7% of the population in Iceland had inadequate HL levels compared to an average of 13% in the HLS19, with values ranging from 4% in Austria to 27% in Belgium (Pelikan et al., 2021). This might not be a surprise as Iceland is a democratic, high-income country with a universal healthcare and welfare system and relatively good living conditions.

However, when exploring associations with limited HL in Iceland, lower education and income levels showed a negative relationship, both factors that have been repeatedly reported in published national population surveys (Nutbeam & Lloyd, 2021). Health disparities by income group exist, and the inequality gap is increasing in Iceland (Haraldsd. Elínardóttir et al., 2021) as in the other Nordic countries (Grøholt et al., 2019). Furthermore, the findings from this first project indicate a negative relationship between SRH and HL, as SRH was an independent predictor of HL. Connections between limited HL and poorer health status have been found in numerous research (Fan et al., 2021; Niedorys et al., 2020). However, no association was discovered between age and HL in this project. Although there are strong indications that older people measure with more limited HL than younger (Niedorys et al., 2020; Sørensen et al., 2013; Zamora & Clingerman, 2011) (Zamora & Clingerman, 2011), the literature suggests some inconsistency between countries (Pelikan et al., 2021) like research from, for example, Denmark indicates (Svendsen et al., 2020).

The general adult population in Iceland rated items in the HC and DP domains as most challenging, with 38% rating item no. 11, "judging if information about health risks in the media is reliable" as difficult and 37% of item no. 12 "to decide how to protect themselves from illness based on information in the media". Although international comparison of domains and competencies should be made cautiously because of indications of cultural differences, a study among Danish adults 25 years and older (Svendsen et al., 2020), found that the item "Judge if the information on health risks in the media is reliable" was perceived as the most difficult. Furthermore, the most difficult tasks identified in the HLS19 study based on the average overall percentage of respondents were related to "judging different treatment options" (42%), "protecting oneself from illness using information from the mass media" (40%), and "finding information on how to handle mental problems" (36%) (Pelikan et al., 2021). This might indicate a global issue regarding the challenges of deciding on the reliability of health-related information in the media.

5.2 Older adults' ability to perform health literacy tasks within their environment- indications of occupational injustice

Building on the foundation of Project I, Projects II and III aimed to investigate the influence of personal and environmental factors on HL, specifically among community-dwelling older adults in one urban town and two rural areas in northern Iceland. In Project II, the translated and validated HLS-EU-Q16-IS instrument was used to quantify HL levels as an individual's ability, identify challenging dimensions of HL and explore influencing factors; Project III added depth by capturing older adults' experiences and needs regarding being health literate.

The results indicate higher levels of problematic HL among older adults in northern Iceland than the general adult population and that HL levels decrease with advanced age. This is what numerous studies from other countries have found (Kamal et al., 2018; Pelikan & Ganahl, 2017; Sørensen et al., 2015). However, some inconsistency regarding advanced age and lower HL scores has also been reported (Pelikan et al., 2021; Svendsen et al., 2020; Tiller et al., 2015). Project I also revealed this among the general adult population in Iceland, where the oldest group was 60 years and older, and no correlation was found between age and HL score. Although this inconsistency could, to some extent, be explained by different research methods and statistics, this could also reflect the complexity and differences in older adults' competencies, situations, and how healthcare services are organised and structured and that HL is based on an interaction with the socioeconomic and cultural contexts (Mårtensson & Hensing, 2012). Older adults should, therefore, not be viewed as a homogeneous group, and chronological age alone does not influence the ability to perform HL tasks.

No difference in HL was found between participants in the urban town and the two rural areas in northern Iceland. Findings from a literature review (Aljassim & Ostini, 2020) indicate that the urban population has better HL than rural residents, echoed in results from Southeast Europe, where older urban residents had higher HL scores than those living rurally (Toçi, 2013). Some inconsistencies have, however, also been noted. For instance, research conducted in rural Berlin, Germany, among people 35 years and older, found that HL levels were higher among people in rural regions (Haeger et al., 2023). The authors point out that rural areas can vary in terms of infrastructure and those who choose to live there, as in the case of rural Berlin, where financially secure and educated people move for a quieter life (Haeger et al., 2023). Therefore, rurality seems not to be an influencing factor on its own. Moreover, this indicates the complexity of the interplay between HL and various people in different environmental settings. Differences in HL might depend more on sociodemographic factors than place of residency. For instance, residents of the urban town in northern Iceland had higher education levels, exhibited greater resilience, used public transport more frequently, met friends and neighbours more often, and rated their access to recreational centres and organised physical training more positively than the residents of rural areas. Living in rural areas in Europe has been associated, for example, with advanced age, poorer health, less education, and lower income (Augère-Granier & McEldowney, 2020). In Iceland, the percentage of older adults who have completed tertiary education is more than double in urban areas compared to rural areas. This disparity in educational attainment between urban and rural regions is more pronounced than in other Nordic countries (Huynh et al., 2022). The difference in missing answers in the HLS-EU-Q16-IS among the older adults in northern Iceland was connected to residency, as those living in rural areas had more missing responses. There was no difference between missing answers and age, gender, and education. Although choosing not to answer items in questionnaires is always an option for respondents, this might need to be investigated further as being related to the instrument items and other personal or environmental factors.

The dynamic interaction between the individual, the task, and the environment is further supported by findings indicating that the HL score of older adults in northern Iceland is associated with both personal factors such as education, income, resilience, and mental health issues, as well as environmental factors related to access to services. This suggests that health disparities among older adults are multidimensional (Cohen et al., 2018). As seen in Project I, having adequate income and higher levels of education was associated with better HL. This reflects the factors repeatedly associated with limited HL levels internationally (Nutbeam & Lloyd, 2021) and the increasing health inequality by income groups in Iceland (Haraldsd. Elínardóttir et al., 2021). Findings from Project II showed that better resilience and lower levels of depression were associated with better HL. It has been stated that HL builds resilience (Kickbusch et al., 2013). Whether resilience increases HL has, however, mainly been studied in relation to mental health literacy rather than general HL, although based on similar concepts. The association between better HL and driving a car as a means of transport and good self-perceived access to healthcare and medical services indicates that environmental factors might play an essential role regarding HL. Although driving a car could be linked to education level or cognitive ability, it should also be reflected in the Icelandic context. With the country's 103.492 km^2 division into seven health districts providing general health services, travel time can be substantial in rural areas (Penje et al., 2020). With limited public transport, driving a car might be the only way to stay mobile and gain physical access to various necessary services beyond medical care, like pharmacies and grocery stores. These findings indicate that HL is positively and negatively influenced by various societal and environmental factors beyond an individual's behaviour and direct control (WHO, 2021b).

The most challenging domains of older adults in Iceland were DP and HP, related to items on information in the media (items no. 11, 12, and 15). Although interpreted with caution, these items have also been acknowledged as problematic in a Finnish study among 75-year-olds (Eronen et al., 2019). Item no. 11, "Judge if the information on health risks in the media is reliable", in the domain of DP, was also perceived as the most difficult in a study among Danish adults 25 years and older (Svendsen et al., 2020) as well as among the general adult population in Iceland in Project I. Furthermore, protecting oneself from illness using information from the mass media was among the three items most often rated as difficult in the HLS19 study (Pelikan et al., 2021). Although it can be assumed that younger people use media differently regarding health-related information than older adults, for example, in frequency and sources, this indicates not only a global issue but also non-age-specific in terms of younger people facing the same challenge regarding health-related information in the media.

Following up on the information from Projects I and II, with no identification of occupation injustice, the experience and needs of older adults in northern Iceland were explored. Findings revealed a tension between personal and environmental factors as the expected responsibility participants experienced and accepted often did not match their abilities and/or situations. In other words, they wanted to perform HL-related tasks and be responsible for their health but faced information gaps while trying. These information gaps emerged because of increased digitalisation, limited personal contact, and complicated navigation systems. The heightened emphasis on individuals' autonomy and responsibility in health self-management has faced criticism for neglecting the systemic role in creating healthy environments (de Souza, 2011; Verweij

& Dawson, 2019). For example, the conditions for obtaining digital health information in Iceland can be considered excellent because of the of all governmental information in one place (Directorate of Health, 2016) and the high-speed internet connection in the majority of Icelandic homes (Government of Iceland [Stjórnarráð Íslands], 2024); however, it should be noted that access to the internet does not necessarily lead to the use of digital health information (Pálsdóttir, 2020). The journey from "having" a high-speed internet connection to "doing", that is, participating in and performing HL-related tasks, can be long and influenced by many factors. This is what the participants in the Stormacq et al. (2023) study described; being health literate was like running an obstacle course.

The "Finding One's Ways" category describes this long and sometimes troublesome journey from wanting or needing to "do" a task and not having the ability or options to use the official or general ways and highlights how older adults adapt to get the information or services needed. This adaptation might be interpreted as resilience created by the tension between expected responsibility and not being able to act on the responsibility in the official ways to get the needed information or service. Resilience seems, therefore, to be needed for HL when "official" options are limited. The important role relatives play as part of people's social networks and essential resources has been pointed out (Stormacq et al., 2023). However, this requires people to have a social network and for someone in that network to assist.

The tension identified between older adults in northern Iceland's responsibility for their health and their limited options to fulfil this responsibility indicates occupational injustice and power imbalance. The participants expressed their need for shared responsibility in health matters and manageable options to close the information gap. From the participatory occupational justice perspective, they are asking for occupational justice and inclusion.

5.3 Health literacy from a Participatory Occupational Justice Perspective

The purpose of the POJF is to promote social inclusion. By raising awareness of and addressing occupational injustice, social inclusion is facilitated. Participation in chosen and valued occupations so that people can contribute to the society in which they live is based on occupational justice, as in having real opportunities to perform or "do" (Whiteford et al., 2018).

Older adults in northern Iceland express signs of occupational injustice. They wish to take responsibility for and care for their health; however, their options to do so are often limited, for example, in accessing fundamental health information. This limits their possibility of participating in valued and chosen occupations essential for making healthy choices and sustaining well-being in daily life. Therefore, power dynamics within and between personal and environmental factors must be addressed to facilitate the social inclusion of older adults related to HL. The term "health literacy" indicates a personal skill, causing challenges in how the lay public, the health sector, and politicians understand and work with it. The environmental side of HL gets limited attention, which pushes further for individual responsibility. By focusing on occupational participation, both these important sides are considered, as well as the differences of various people living in different social contexts. Occupational justice is enhanced by power sharing, coproduction, and collaboration of different stakeholders in all aspects of all processes, all the time, driven by a vision to enhance systems that better serve those confronting occupational injustice.

5.4 Strengths and limitations

This thesis addresses HL from a novice perspective through the lens of the POJF. Therefore, the focus is on the interaction between older adults' abilities to perform HL tasks and environmental opportunities. Furthermore, power relations and justice are connected to HL and older adults. In a globally ageing world, prioritising the health and well-being of older adults has become increasingly important. Projects II and III specifically address older adults and HL using quantitative and qualitative research methods. Moreover, no valid instruments for measuring HL are available in Iceland, and there is a limited understanding of HL in the region. The growing interest in HL among the general population worldwide and across Europe underscores the demand for HL measurements in Icelandic. The strength of this thesis lies in the selection of a European instrument to measure HL in Project I and the use of internationally standardised measurements in Project II. Additionally, the cognitive interviews bolstered the validation process of the HLS-EU-Q16 in Project I. In Project III, having an older adult on the research team with a lived experience was important. In content analysis, it is crucial for researchers to understand the context. Involving four interdisciplinary researchers in Project III, each with specialised expertise in data analysis, enhanced the study's credibility. While two researchers conducted the primary analysis, regular meetings with all authors at each step of the process facilitated reflection on potential biases and ensured consistency between the empirical data and the emerging categories as well as their content.

The generalisability of the findings from Projects I-III is somewhat limited by the relatively small sample sizes and the focus on residents of northern Iceland with similar cultural backgrounds in Projects II and III. However, it should be noted that there may be significant similarities between Iceland and other northern regions of the world where the culture is classified as western. Furthermore, within a nation of approximately 390,000 inhabitants, the samples represent a relatively large proportion compared to counties with larger populations. Both samples in Project I and II were random and stratified. In Project I, the mean intraclass coefficient indicated that the sample was not more homogeneous than if it had been drawn from a non-stratified sample. One potential limitation of Project III is the dual-language nature of the study, which may lead to the misrepresentation of participants’ expressions during the translation from Icelandic to English. Nevertheless, the fact that three out of four researchers are fluent in both languages should help mitigate this issue. A thorough evaluation of the meaning and usage of words during the translation process provides an advantage in terms of reliability and accuracy.

6 Conclusions

6.1 Responsibility must be balanced with real options

Older community-dwelling adults' HL is influenced by various personal and environmental factors acting as enablers or barriers in a complex interaction. The ability of older adults to access, understand, appraise and use health-related information and services, measured with the valid HLS-EU-Q16-IS, is more limited than the population-based norms in Iceland and decreases with age. This might indicate that chronological age influences HL. However, other personal factors also seem to influence HL, like education, income, resilience and depression. Additionally, environmental factors connected to access to services, such as driving a car and having good perceived access to healthcare and medical services, also influence HL. Furthermore, information in the media seems to be challenging both for the general adult public and the older adults in Iceland.

The role of environmental factors in HL is further highlighted in older adults' experiences, where a tension between a person's responsibility for health and limited environmental options to act on that responsibility was identified. This tension indicates occupational injustice that limits options to act on expected and wanted responsibilities to make healthy choices, excluding older adults from full participation as citizens. The older adults ask for shared responsibility and inclusion so they can more easily participate in meaningful and valued occupations central to their everyday lives, health, and well-being.

Individual ability is a necessary part of the complex interaction of various factors jointly influencing HL. Therefore, measuring people's abilities is important. However, to foster a just society and equity, there is a need to critically address HL from a justice perspective and how existing services are meeting the needs of older adults for a balance in responsibility and real options.

6.2 Advancing health literacy in research, policy, and practice

The findings of Projects I to III support the importance of creating a balance between responsibility in health and real options to act on in relation to HL and community-dwelling older adults in northern Iceland. However, further research, practice, and policy implementation are needed to advance HL and ensure occupational justice.

Although the HLS-EU-Q16-IS instrument is valid, the factor loadings from the PCA suggest that the domains and competencies do not manifest as they do in the original instrument. This indicates certain cross-cultural variations. Cross-country comparisons could be explored to determine whether the factors loading among countries with similar cultures and service systems demonstrate similar factor loadings. Additionally, a confirmatory factor analysis of the HLS-EU-Q16-IS version is recommended using a large cross-population sample for further psychometric evaluation of the instrument. Furthermore, the HLS-EU-Q12 instrument is currently attracting increased attention in health literacy research in Europe as it is considered to address the criticism that the Q16 instrument has faced for lacking an item concerning the use of health information in the domain of health promotion. Therefore, validating an Icelandic Q12 version for future studies on health literacy is advised.

A discourse analysis of strategic public documents related to the health and well-being of older adults would provide information on power balance and, for example, if ageist attitudes, practices, and policies are present. Furthermore, a case study on processes related to public decision-making could shed light on how decisions are made and the stakeholders partaking in the process. Although a Senior Citizens Council is mandatory by law in each municipality in Iceland, and the National Association of Senior Citizens actively represents the interests and welfare of older adults towards governmental officials, there is a need to know to what extent their influence holds.

An ideology representing more power-sharing could be implemented in the service system. Based on the coproduction and collaboration of different stakeholders, including older adults, health-related interventions would be driven by a vision to enhance systems that better serve those confronting occupational injustices. This would create more manageable options, improve communication, and reduce complexity so people can more easily make informed decisions about health and effectively navigate healthcare services.

Human rights and justice should be integrated into all research, interventions, and policies related to HL. Policymakers in Iceland should, therefore, advocate internationally for a specific human rights act that explicitly addresses the rights of older adults. Such an act, establishing what the older population values the most, would be a step towards tackling age-related health inequalities by setting a guiding framework for officials on developing services for older adults and, therefore, sharing the responsibility for health.

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Translation and cross-cultural adaptation of the European Health Literacy Survey Questionnaire, HLS-EU-Q16: the Icelandic version

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Abstract

Background: Health literacy (HL) is defined as the knowledge and competences of people to meet the complex demands of health in modern society. It is an important factor in ensuring positive health outcomes, yet Iceland is one of many countries with limited knowledge of HL and no valid HL measurement. The aim of this study was to translate the European Health Literacy Survey Questionnaire- short version (HLS-EU-Q16) into Icelandic, adapt the version, explore its psychometric properties and establish preliminary norms.

Methods: The HLS-EU-Q16 translation model included three steps: 1) translation-back-translation of HLS-EU-Q16 including specialists' review ($n = 6$); 2) cognitive interviewing of lay people ($n = 17$); and 3) psychometric analysis with survey participants. The HLS-EU-Q16 includes 16 items, with scores ranges from zero (low/no HL) to 16 (high HL). Statistics included were descriptive, internal consistency measured by Cronbach's α, exploratory factor analysis, and multivariate linear regression.

Results: After the translation and cognitive interviewing, 11 of the HLS-EU-Q16 items were reworded to adapt the instrument to Icelandic culture while maintaining their conceptual objectives. Survey participants were 251. Internal consistency of the translated and adapted instrument was $\alpha = .88$. Four factors with eigenvalues > 1.0 explained 62.6% of variance. Principal component analysis with Oblimin rotation presented four latent constructs, "Processing and Using Information from the Doctor" (4 items, $\alpha = .77$), "Processing and Using Information from the Family and Media" (4 items, $\alpha = .85$), "Processing Information in Connection to Healthy Lifestyle" (5 items, $\alpha = .76$), and "Finding Information about Health Problems/Illnesses" (3 items, $\alpha = .73$). Lower self-rated health was an independent predictor of lower HL ($\beta = -.484$, $p = .008$). Preliminary norms for HL ranged from five to 16 (M 13.7, SD ± 2.6) with 72.5% with sufficient HL (score 13–16), 22% with problematic HL (score 9–12) and 5.5% with inadequate HL (score 0–8).

Conclusions: The Icelandic version of HLS-EU-Q16 is psychometrically sound, with reasonably clear factor structure, and comparable to the original model. This opens possibilities to study HL in Iceland and compare the results internationally. The translation model introduced might be helpful for other countries where information on HL is missing based on lack of validated tools.

Keywords: Health literacy, HLS-EU-Q16, Translation and adaptation, Cognitive interviewing, Validation, Instrument

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Background

Health literacy (HL), as a construct, was introduced within public health research almost 45 years ago [1] and since that time has become an increasingly relevant issue for global public health [2]. It has a broad and inclusive definition referring to "personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health, or to have implications on health" [3]. HL represents a strong connection to social determinants of health and has been recognised as an important factor in ensuring positive health outcomes [4]. Although high HL does not entail empowerment [5], it is argued that that HL is critical to empowerment of people [6]. Based on this there is a need to improve public access to health information and people's capacity to use it effectively.

Whereas HL has been researched for decades in native English-speaking countries, the field is still in its early stages in non-English speaking parts of Europe and is only marginally integrated in health research, policy and practice [7, 8]. However, HL gained relevance on the European Commission's (EC) health agenda [9], and a working group, called the European Health Literacy (HLS-EU) Consortium, was established [10]. Based on content analysis, the HLS-EU Consortium developed an integrated conceptual model, capturing comprehensive evidence-based dimensions of HL, with definition of HL as "... people's knowledge, motivation and competences to access, understand, appraise and apply health information ..." [11]. The design and developmental process of the European Health Literacy Survey Questionnaire (HLS-EU-Q) was described in Sørensen et al. [10]. The Consortium's work resulted in four versions of the questionnaire: [1] the core version (HLS-EU-Q47) [2]; the extended version Q86 (including additional 39 items relating to selected HL determinants and outcomes) [3]; the short version Q16 [12]; and short-short version Q6 [13]. Using the HLS-EU-Q86, in a survey of HL in eight countries in Europe ($N = 8000$), results indicated that subgroups within the population, defined by financial deprivation, low social status, low education, or old age, had higher proportions of people with limited HL [14]. The results demonstrated that the questionnaire was useful for identifying strengths and weaknesses in HL levels, both within and between countries [14]. In a critical review of population HL assessments, it was noted that the HLS-EU-Q differs from most others HL assessment tools as it is designed to measure HL of general populations rather than specific patient groups. However, an acknowledged limitation of the HLS-EU-Q is a continued emphasis on healthcare and disease prevention and less on health promotion [15].

The number of self-report questionnaires has increased rapidly [16] as has the growth in adapting health status measures to other languages and cultures [17]. Due to Iceland's population of only 350,000 people, approximately [18], assessment tools are not commonly developed specifically for Icelandic circumstances. A more common approach is to translate and adapt foreign tools to the Icelandic context with a translation-back-translation procedure or with a specialist's review [19]. Both methods have been criticised, mostly for leaving out the process where lay people respond to the instrument [20]. The term Cross-Cultural Adaptation (CCA) describes the process of viewing both language and cultural issues in preparing a questionnaire for use in another setting [17, 21]. A review of 31 different CCA methods [16] demonstrated that many different recommendations do exist, but a formal standard has not been established, and universal consensus on all aspects of the process has not been reached. As HL has been defined in an inclusive way, meaning it is more than transmitting information and is related to empowerment of lay people, the translation and adaptation of HL instruments should emphasise participation by the people they are intended for. As a part of the cross-cultural adaptation procedure, cognitive interviews are becoming increasingly important [20]. Cognitive interviews are methods to identify problematic survey items by asking research participants to report what is going through their mind, either during or after responding to the survey. The technique helps analyse the manner in which respondents understand, mentally process, and ultimately respond to the presented materials [20, 22]. The cognitive interview technique is reported to be useful when translating questionnaires to other languages [23], and the validity of the technique has been supported when identifying linguistic problems in the questionnaire's items [24].

There is limited knowledge on HL in Iceland and no validated instruments are available. The increasing interest in HL in the general population worldwide and across Europe supports the demand for HL measurements in Icelandic. Thus, the aim of our study is to translate the European Health Literacy Survey Questionnaire- short version (HLS-EU-Q16) into Icelandic, adapt the version, explore its psychometric properties and establish preliminary norms.

Methods

Study design and setting

The HLS-EU-Q16 translation model included three basic steps. In step one, the questionnaire was translated and back- translated with a specialists' committee review. In step two, 17 lay people responded to the questionnaire in cognitive interviews. In step three, the final Icelandic version of the questionnaire (HLS-EU-Q16-IS) was validated in a stratified random sample, drawn from the Icelandic national registry, including 11 background questions added by the researchers. This same general sample of Icelandic adults was used to establish preliminary norms for health literacy based on HLS-EU-Q16-IS. A permission for the translation was obtained from the HLS-EU-Q project leader and the Icelandic Data Protection Authority was informed about the study.

Instrument

The HLS-EU-Q16 is one of four questionnaires that resulted from analysis of HLS-EU-Q data from a large, cross-national survey of EU citizens using Eurobarometer methodology [10, 12] where data was collected by using either computer-assisted personal interviews or paper-assisted personal interviews [14]. The original HLS-EU-Q item selection was guided by a conceptual model of HL, which identifies four competencies related to managing health information (find, understand, appraise, and apply) in three domains (health care, disease prevention, and health promotion). These four competencies in three domains were used to create a four by three HL-EU matrix, including 12 cells with unique content for HL [10, 12, 14]. The 16 items in the HLS-EU-Q16 questionnaire were selected as they represent well 11 out of the 12 cells in this HL-EU matrix and at the same time present good psychometric properties. The construct validity of this 16-item scale has been established in all eight HLS-EU study participating countries, based on Rasch modelling for content- and face validity criteria [25]. In Italy e.g. computer-assisted telephone interviews were used in the validation process of the Q16 version [26]. All four HLS-EU-Q questionnaires use the same four response categories for each item. However, when scoring the HLS-EU-Q16, the categories; “very difficult”, “fairly difficult”, “fairly easy” and “very easy” are dichotomized into “easy” (scored with 1) and “difficult” (scored with 0). Summing these responses gives a HLS-EU-Q16 final score that can range from 0 (low/no HL) to 16 (high HL). Missing responses are replaced with 0, given that no more than two responses are missing. For interpretation of the final score on the scale, three levels have been defined: Inadequate HL (0–8), Problematic HL [9–12], and Sufficient HL [13–16] [13, 25]. The HLS-EU-Q16 was selected for translation and adaptation because it is short, easy to administer and is one of few HL instruments designed to measure HL of general populations rather than specific patient groups.

Participants and sampling method

For the first step of the research, four people were selected for the translation of the questionnaire and six people to create a specialist committee to review translations of the questionnaire twice in the process. Two of those participating in the translations came from the specialists committee and two were hired from outside because of their experience in health related translations. Members of the specialist committee were selected based on their field of specialty to create a multidisciplinary group within health and social sciences.

To access lay people, for the cognitive interviewing in the second step of this research, administrators of two public institutions, each with 70–80 employers, were contacted in January and February 2017. The institutions were chosen, as they were not in the field of health-related service but in education and social welfare, and were known to have employers with various educational levels. The administrators forwarded, by e-mail, an introduction letter provided by the researchers to their respective employees with general information about the study and information about the right not to participate or to withdraw from the study at any time. Those willing to participate were asked to contact the administrator who forwarded the information on to the researchers. Initially, only one round was planned with 12 people. Because of new information received after the first round, it was decided to add another round. For the first round, 15 were willing to participate and 12 were selected according to the criteria for equal gender, age groups (18–45, 46–64, and 65–85) and educational level distribution (elementary, secondary or university degree). For the second round, five were willing to participate and were selected.

Participants in the validation process (step three) were a part of a stratified random sample of 1200 Icelanders, drawn from the Icelandic National Registry. The sample was stratified according to age, gender and place of living. Inclusion criteria was to be between 18 and 85 years old and registered with a home address in Iceland. People living in nursing homes were excluded. Due to name and address not matching, 91 questionnaires were returned. Therefore, the intended sample size was 1109.

The translation model

Translation of the instrument

The translation and adaptation process are described in Table 1. The original validated English version of the HLS-EU-Q16 was translated into Icelandic by authors 1 and 2, based on recommendations from Beaton et al. [17]. The two authors are fluent (which includes knowing colloquial phrases, jargon, idiomatic expressions, etc.) in the source language, and the target language is their native tongue. Both are familiar with source and target cultures, both have lived and studied in an English speaking country, and both have some knowledge in the content of the instrument. After discussion between the researchers, and with a review from the specialists’ committee, the two versions were combined into one Icelandic version that was translated back into English by two translators. The two back translators are native speakers of the source language and are fluent in the target language. Both back translators have lived and worked in both source and target cultures but are unfamiliar with the content of the instrument. The English back-

Table 1 Translation and adaptation process of the instrument

Original HLS-EU-Q16 English version
STEP 1 TRANSLATION
Forward translation: April 2016 Two translators, fluent in both source and target language with the target language as their native tongue, familiar with both cultures, and having some knowledge in the content of the instrument made two independent forward translations, *versions T-1 and T-2.*
Integration I: April 2016 Versions T-1 and T-2 were merged into a single version by authors 1 and 2, *version T-1.2.*
Specialists´ committee review I: May 2016 The multi-disciplinary specialist committee consisted of six members with a PhD in health or social sciences at two public universities in Iceland and most were experienced researchers. Review of the committee reflected on translations and critical decisions. Authors 1 and 2 reached a consensus on any discrepancy and *versions T-1.2.1* was made.
Back translation: June–July 2016 Two translators, fluent in both source and target language with the source language as their native tongue, familiar with both cultures but unfamiliar with the content of the instrument made two independent back translations, working with T-1.2.1 version.
Integration II: August 2016 Two independent back translations were merged into a single *version T-2* by authors 1 and 2.
Specialists´ committee review II: December 2016 Review of all translations by the specialists' committee and critical decisions. Authors 1 and 2 made a *Pre-final version T-2.1* to be used for cognitive interviewing.
STEP 2 PRE-TESTING I
Cognitive interviewing I: January–February 2017 Twelve interviews taken by author 1 and a research assistant (RA) with the pre-final version T-2.1. Comments made on nine questions.
Consultation and integration I: February 2017 Summary of all item comments reviewed. Authors 1, 2 and RA made *version T-2.2.*
Cognitive interviewing II: February 2017 Five interviews conducted by RA with people that volunteered participation with the pre-final version T-2.2. Comments made on five questions.
Consultation and integration II: February 2017 Summary of all item comments reviewed. Authors 1, 2 and RA made *version T-3 for use in pre-testing II.*
STEP 3 PRE-TESTING II
HLS-EU-Q16-IS questionnaire: March 2017 An intended cross-sectional sample of 1200 people provided by the Icelandic national registry was sent an introduction letter, the HLS-EU-Q16-IS and 11 background questions by mail. The actual sample consisted of 251 individuals who completed the HLS-EU-Q16-IS. Data was analysed for internal consistency using Cronbach's α, and construct validity was examined using exploratory factor analysis.
Final version of the HLS-EU-Q16-IS

translated versions were combined into one by the researchers and compared with the original HLS-EU-Q16. Minor discrepancies were addressed based on consensus. Based on these differences, another consultation with the specialists´ committee took place before the final version, for the cognitive interview process, was made.

Cognitive interviewing

The cognitive interviews took place at the workplace or at a given participant's home, depending on their preference. The interviews lasted from 12 to 35 min (average – 25 min), were tape-recorded, and a written summary was made after each interview. Both the think-aloud interview method and the verbal-probing technique were used [20, 22]. The think-aloud part involved participants responding to the questionnaire in writing, while being asked to think out loud about what was going through their mind while responding to each item. This was to help the researcher capture participants' understanding of each item, and to determine if they were struggling to understand the wording or comprehend the meaning of each item. As a follow-up to the think-aloud procedure, participants were also given verbal probes about: [1] their understanding and interpretation of specific items or ideas [2]; how they would rephrase items [3]; why they answered them the way they did; and [4], generally speaking, how easy or difficult it was to answer the items. After the first and second round of cognitive interviews, authors 1, 2 and the research assistant held a consultation meeting where summaries from the interviews were reviewed and the questionnaire changed accordingly. The goal of the second round of interviews was to get an opinion from individuals who had not seen the questionnaire, to confirm that there were no additional issues or comments on wording.

Validity testing of instrument

For the instrument validation, mode of data collection varied depending on the participant's age. The intention was to maximise the response rate, by targeting each generation in the most user friendly way, yet within the surveys budget and timeframe. All intended participants were mailed an introduction letter along with the HLS-EU-Q16 Icelandic version and 11 background items. The background items were on age, gender, education, income and perception of own general health. For participants in the 18–64 age group ($n = 990$), the introduction letter included a QR code and a web URL so they could answer the questionnaire by computer-assisted (electronic) self-administration method. In the 65–85 age group ($n = 210$), the introduction letter included a questionnaire for a traditional paper and pencil self-administration and a prepaid response envelope. In addition, the information letter stated that they would receive a phone call from the researcher if the researcher had not received their answers in three weeks, so they would have the opportunity to answer the list by phone, a computer-assisted telephone interview. For that purpose, questionnaires for this age group were numbered. After four weeks, the response rate in the 18–64 years age group was low (< 20%) compared to over 60% in the 65–85 age group. Therefore, every fifth participant in the 18–64 age group was phoned and offered to answer the questionnaire by computer-assisted telephone interview or by computer-assisted (electronic) self-administration method (web-URL).

Analysis of survey data

Descriptive statistics for the background of all survey participants ($n = 251$) included mean (M) and standard deviation (SD) for continuous variables and counts and proportions for categorical variables. Descriptive statistics were also used to present the preliminary norms on HLS-EU-Q16-IS by gender and age group.

A Principal Component Analysis (PCA) was conducted for structural analysis of the HLS-EU-Q16-IS, using an Oblimin rotation. In addition, a linear multivariate regression model was used to analyse the association between HL (dependent variable) and potential influencing factors (independent variables). The independent variables were selected for the model based on a significant bivariate correlation with HL. Statistical analyses were run with the IBM SPSS software package, v. 22 [27].

Results

Translation and adaptation based on cognitive interviewing

In the translation process, small differences were found in syntax and grammar between the forward and back translations of the questionnaire. The items were, however, semantically equivalent. The specialists´ committee reflected and reviewed translations and made critical decisions on "mental health" in item 8 and 13, "health warnings" in item 9 and "health screenings" in item 10 and about the role of pharmacist in different cultures connected to item four.

The translation process was followed by the first round of cognitive interviews with lay people including six women and six men, age range from 20 to 74 (*Mean* = 51 and *SD* ± 19.55) years. For the second round, four women and one man, age range 26 to 65 (*Mean* = 55 and *SD* ± 11.12) years participated. Eleven items of 16 in the HLS-EU-Q16-IS were changed after the two rounds of analyses following the cognitive interviews. The items appeared to become simpler and clearer as well as becoming more applicable to lay Icelandic language. After the analysis of responses, we also changed the appearance of the instructions for the questionnaire, switching the order of the responses to the scale's items, starting with "very easy" instead of "very difficult". Participants felt it important to have the most positive response the first one. A comprehensive overview of changes in the items of the questionnaire after the two rounds and consultation of researchers are shown in Table 2. As an example of minor changes in wording; in item 1, we replaced the medical term for "treatment" with a more general term which expresses wider variety of interventions. An example of a considerable change in wording is found in item 7, "… follow instructions from your doctor or pharmacist". In the Icelandic version, the "pharmacist" was dropped because of cultural differences.

Survey participants

A total of 268 participants completed the survey form (response rate 24%), 119 on paper, 28 per phone and 121 per web URL. However, 17 participants had to be excluded because of more than two missing items on HLS-EU-Q16-IS. A total of 251 participants completed the questionnaire, age 18 to 85 years (*Mean* = 55, ±*SD* 18.98) and 52% women. The response rate was higher in the 65–85 age group compared to the 18–64 age group. Icelandic was the first language of 92.8% (233/251) of participants and the majority (72.5%; 182/251) lived in South Iceland, including the capital area. To gauge for potential hidden nesting effects due to response rates, sampling methods and geographic location of respondents, an intraclass coefficient (ICC) was calculated. The mean ICC for single measures was .322, indicating that the sample was not more homogeneous than if it had been drawn from a non-stratified sample. See Table 3 for characteristics of survey participants.

Validity testing of instrument

Table 4 shows responses to individual items by response options on the HLS-EU-Q16-IS, including missing values and skewness/kurtosis values for each item. Overall, missing values were few, the highest count of which was nine, on item 8.

Internal consistency for the HLS-EU-Q16-IS questionnaire was $\alpha = .88$. The KMO value was .86, supporting the sampling adequacy for the analysis [28, 29]. Bartlett's test of sphericity ($\chi^2 = 1436.930$, df = 120, $p < 0.001$) indicated that correlations in the correlation matrix did not occur by chance, and that correlation between items were sufficient for the analysis. The final data reduction model chosen for the current analysis was a Principal Component Analysis (PCA) with an Oblimin rotation. An initial analysis was run to obtain eigenvalues for each

Table 2 Changes in wording of items due to cognitive interviewing

	Items with no changes	Items with minor changes	Items with considerable changes
First round	1, 2, 3, 4, 13, 14 and 15	5, 6, 10, 11, 12 and 16	7, 8 and 9
Second round	2, 3, 4, 5, 6, 7, 8, 11, 12, 13 and 15	1, 9, 10 and 14	16

Table 3 Characteristics of the instrument testing sample ($n = 251$)

	Frequencies (n)	%
Age:		
18–39	55	21.9
40–59	52	20.7
60–85	137	54.6
Missing	7	2.8
Gender:		
Female	131	52
Male	115	46
Missing	5	2
Education level:		
Elementary	56	22.3
Secondary/Trade school	93	37
University degree	84	33.5
Other (e.g. professional pilot program, musical education)	7	2.8
Missing	11	4.4
Number of people in the household:		
1	45	17.9
2 or more	193	76.9
Missing	13	5.2
Income per month for the home after tax:		
< 1.440 EUR	14	5.6
1.440–2.885 EUR	87	34.6
> 2.885 EUR	134	53.4
Missing	16	6.4
Enough income after tax to fulfil needs:		
Yes	168	66.9
No	64	25.5
Missing	19	7.6
Self-rated health:		
Excellent	23	9.1
Very good	84	33.5
Good	64	25.5
Fair	53	21.1
Bad	16	6.4
Missing	11	4.4

component in the data. Four components (eigenvalues 5.94, 1.62, 1.38 and 1.05) explained 62.6% of the variance. The scree plot indicated that the optimal solution consists of two to four components depending on how the plot is interpreted. The items´ loadings after rotation are illustrated in Table 5 with Cronbach's alpha for each subscale. The items that cluster on the same factor suggest that component 1 (items: 3, 5, 6, 7 and $\alpha = .77$) represents "Processing and Using Information from the Doctor"; component 2 (items: 11, 12, 14, 15 and $\alpha = .85$) represents "Processing and Using Information from the Family and Media"; component 3 (items: 4, 9, 10, 13, 16 and $\alpha = .76$) represents "Processing Information in Connection to Healthy Lifestyle"; and component 4 (items: 1, 2, 8 and $\alpha = .73$) represents "Finding Information about Health Problems/Illnesses". Component 1, "Processing and Using Information from the Doctor" had the highest internal consistency of the subscales that appeared in the current PCA. The corrected item-total correlation in each subscale was high as all items received correlation of .40 or higher, with a range from .47 to .85. Deleting items from subscales did not affect the internal consistency of the subscales.

There were positive relationships among HL score and [1] education ($r = .144$, $p = 0.037$), [2] income per month ($r = .167$, $p = 0.016$), [3] having enough income after tax to fulfil needs ($r = .205$, $p = 0.003$), and a negative relationship between HL score and self-rated health ($r = -.263$, $p = 0.001$). No correlation between HL and age was found. A multivariate linear regression was conducted to analyse association between HL (dependent variable) and education level, income per month, having enough income to fulfil needs, and self-rated health (independent variables). A statistically significant regression relationship was found ($F(4, 193) = 5.484$, $p < .001$), with an R^2 of .102. Self-rated health was the only statistically significant predictor of HL ($\beta = -.484$, $p = .008$.).

Preliminary norms

Preliminary norms for HL were established in a general population of Icelanders. In this sample the scores ranged from 5 to 16, the mean was 13.7 ($SD = \pm 2.6$) and the median 14. In Table 6, descriptive findings on HL score divided by gender and age groups are shown. There were 182 individuals (72.5%) that scored from 13 to 16 indicating sufficient HL, 55 (22%) scored from 9 to 12, which has been defined as problematic HL, and 14 (5.5%) scored from 0 to 8, indicating inadequate HL.

Discussion

Our results indicate that, after translating and adapting the HLS-EU-Q16 to Icelandic, the HLS-EU-Q16-IS is a valid instrument, ready to be used in Iceland, and opening possibilities to study HL in Iceland and compare the results internationally.

In our view, to be consistent with the broad and inclusive definition of HL, we felt that lay people should be participants in the process. The cognitive interviewing using lay people was an important step in the translation

Table 4 Responses to individual items on the HLS-EU-Q16-IS (*n* = 251)

Item nr.	Very easy	Fairly easy	Fairly difficult	Very difficult	Missing	Skewness	Kurtosis
1	70	141	32	7	1	.61	.53
2	108	110	25	5	3	.83	.42
3	139	99	8	1	4	.89	.50
4	190	60	0	0	1	1,22	−.50
5	63	108	68	9	3	.23	−.66
6	107	117	20	4	3	.81	.61
7	152	92	5	0	2	.77	−.59
8	76	107	49	10	9	.50	−.38
9	185	55	10	1	0	1.79	2,92
10	171	70	8	0	2	1.26	.62
11	59	92	77	17	6	.17	−.81
12	47	105	72	21	6	.23	−.61
13	106	111	25	4	5	.78	.30
14	106	108	29	3	5	.69	−.05
15	80	99	48	16	8	.57	−.45
16	166	73	7	2	3	1.55	2.62

process, which eventually led to the Icelandic version of HLS-EU-Q16. Although the specialist review turned out to be essential regarding accepted language within the health- and social setting, the cognitive interviewing gave vital information about the understanding of actual people who might answer the questionnaire. It also provided lay people an opportunity to influence the adaptation process. This was, for example, useful in the wording of items connected to culturally sensitive things, such as mental health and illness. Not only did the wording of items change with cognitive interviewing, but it also prompted the researchers to reverse the response scale, starting with "very easy" instead of "very difficult" as in the Swedish version [30]. Epstein et al. [16] has pointed out that currently there is no consensus on cross-cultural adaptation procedure. However, researchers suggest [24], the importance of including the target audience when translating questionnaires to another language.

The Icelandic version of HLS-EU-Q16 exhibited high internal consistency, with Cronbach's $\alpha = .88$, which is in line with results from the German version of the instrument [31]. The four components yielded by the PCA (Table 5) had internal consistency from $\alpha = .73$ for component 4 to $\alpha = .85$ for component 2. It should be noted that with a list of 16 items, lower internal consistency could be expected, so these results are quite acceptable. The PCA yielded a reasonably defined structure, and only item 4 loaded on more than one component (Table 5) ("… understand your doctor's or pharmacist's instruction on how to take prescribed medicine?" loaded on components 1 and 3). This is possibly because participants perceived taking one's prescribed medicine as a part of a healthy lifestyle, in addition to reflecting their interaction with the doctor. Another explanation could be that the word "pharmacist" was removed from item 7 in the Icelandic version but not in item 4. In the Icelandic culture, doctors and nurses play a dominant role in instructing people on how to take their medicine, whereas pharmacists play a negligible one.

In our principal component analysis, the fourth component includes items representing the competency to find health related information (Table 5). The other three components represented more than one competency in the original Sørensen's et al. [10] model. This might indicate that finding health-related information is more salient for the Icelandic sample than, for example, understanding and appraising health-related information. The three domains of health care, disease prevention and health promotion are not indistinct in the current analysis. Component 1 includes only items within the health care domain and component 4 includes two of three items within that domain. Component 2 includes items from two domains and component 3 includes items within every three domains. This indicates subtle differences in how the Icelandic samples responds to those items and the original model. As previously reported, the HLS-EU-Q instrument has received critique for its continued emphasis on healthcare and disease prevention over health promotion [15]. The findings from our current PCA indicate that the four health promotion domain items do not cluster together as they did in the original version [10]. Considering the above, it is reasonable to conclude that the domains do not manifest in the same way across the cultures, comparing our study and the work of Sørensen et al. [10]. Our approach of using PCA seems

Table 5 Component loadings of the HLS-EU-Q16-IS, after Oblimin rotation (*n* = 251)

Item	Component				*α*	Subscales
	1	2	3	4		
3. understand what your doctor says to you?	**.696**	−.075	−.016	.172	.77	Processing and Using Information from the Doctor
6. use information the doctor gives you to make decisions about your illness?	**.629**	−.267	−.020	.166		
7. follow instructions from your doctor?	**.626**	−.112	.219	−.136		
5. judge when may need to get a second opinion from another doctor?	**.503**	−.140	−.026	.376		
12. decide how you can protect yourself from illness based on information in the media?	−.019	**−.921**	−.067	.031	.85	Processing and Using Information from the Family and Media
11. judge if the information on health risks in the media is reliable?	−.004	**−.815**	.038	.059		
15. understand information in the media on how to get healthier?	.215	**−.801**	−.059	−.059		
14. understand advice on health from family members or friends?	.140	**−.505**	.269	.013		
16. judge which everyday behaviour is related to your health?	−.140	−.241	**.701**	−.043	.76	Processing Information in Connection to Healthy Lifestyle
9. understand health warnings about behaviour such as smoking, low physical activity and drinking too much?	.110	.112	**.685**	.009		
10. understand why you need health screenings?	.253	.004	**.621**	.022		
13. find out about activities that are good for your mental well-being?	−.229	−.345	**.531**	.367		
4. understand your doctor's or pharmacist's instructions on how to take a prescribed medicine?	.432	.130	**.457**	.120		
1. find information on treatments of illnesses that concern you?	.031	−.071	−.177	**.819**	.73	Finding Information about Health Problems/Illnesses
2. find out where to get professional help when you are ill?	.199	.137	.032	**.744**		
8. find information on how to manage mental health problems like stress or depression?	−.111	−.099	.278	**.715**		

α = Cronbach's alpha
Loadings in bold represent items that loaded on each component

relatively unique, yet, as PCA is an empirical technique, it should be well suited for analysis of cultural differences in item understanding of populations. While Confirmatory Factor Analysis seems more commonly used than a PCA or Exploratory Factor Analysis for validation of the HLS-EU-Q (e.g. [32–34]), exploratory techniques such as an EFA or PCA are nevertheless used in the field. For example, Sukys et al. [35] used an EFA to assess the factor structure of the healthcare, disease prevention, and health promotion domains for the HLS-EU-Q47.

Table 6 HL score distribution within gender and age groups

Gender	Age	N	Mean (SD)	Median (min-max)
Women	18–39	30	13.48 (2.98)	15 (5–16)
	40–59	26	14.32 (2.13)	15 (8–16)
	60–85	74	13.74 (2.58)	14 (6–16)
Men	18–39	25	13.90 (2.13)	15 (9–16)
	40–59	26	13.84 (2.91)	15 (7–16)
	60–85	63	13.29 (2.59)	14 (6–16)

The results from the current study demonstrated a relative high score in HL, compared to the European study [14], and limited HL was connected to people with lower education and income, while a negative correlation was seen between self-rated health as predictor of HL. People with lower education have been found to have lower health literacy in comparison to people with higher education [14, 36]. Interestingly, no negative correlation was discovered between age and HL in the current study, as previous studies from Europe, Australia and Asia have reported [14, 34, 37]. In a Danish national study [38], results indicated that people age 45–65 have less difficulty in understanding and engaging actively with healthcare providers, than those between the ages of 25 and 45. Attention is drawn to the necessity to look at HL also in connection to what kind of health care systems are provided in each country, and that, for example, Nordic counties with similar universal health care systems could more easily be compared together than counties with different systems. The current research is based on a sample of 251 people within a nation with approximately 350,000 inhabitants, a relatively large proportion compared to counties with larger populations. In addition, our sample was stratified according to age, gender and place of living and socio-demographic data of the respondents did not indicate difference from the general population. Therefore, our results may offer preliminary norms or benchmarks that can inform future surveys in countries with comparable health systems.

Limitations

The low participation rate, 24%, (step three of the validation process of the instrument) is of some concern and a limitation to this study. However, the overall number of participants reached is acceptable within the frame of the statistical analysis used, and an intraclass correlation of .322 indicated that the assumption of independence was not violated. The reasons for the low participation rate can only be speculated upon, especially among people between the ages of 18 and 59. This age group had a participation rate of 40% (Table 3), compared to almost 55% in the 60–85 age group. We used diverse administration modes, a traditional paper and pencil self-administration by post, computer-assisted telephone interviews and computer-assisted electronic self-administration method (web URL). The impact of administration mode on response effects has been reported as well as the difficulty to separate out such effects [39, 40]. Although self-administered questionnaires are considered to have many benefits the mode has also been criticised for, among other things, to have a high cognitive burden and not offering additional explanations [39, 40]. The different administration modes in our study can be regarded as a limitation for between-studies comparison. However, by conducting cognitive interviews among lay people a step was taken to limit this effect.

Survey response rates have been declining over the past decade and there are indications that web-based questionnaires could be an alternative platform to reach higher participation rates in population surveys, compared to paper questionnaires [41]. An attempt was made to make answering more appealing or acceptable to people by offering a QR code. However, that option might be more used by younger people, under the age of 30.

Conclusions

The findings indicated that the Icelandic version of HLS-EU-Q16 is psychometrically sound, with a reasonably clear factor structure, and comparable to the original model. This opens possibilities to study HL in Iceland, gradually add to a database, which now includes preliminary norms, and compare the results internationally. The specialist review and cognitive interviewing provided essential additional information to the translation-back-translation procedure. This translation model might be helpful for other countries where information on HL is missing based on lack of validated tools. We believe that this instrument will become valuable in a future cross-cultural research on HL among the public.

Abbreviations

CCA: Cross-Cultural Adaptation; EC: European Commission; HL: Health literacy; HLS-EU-Q: The European Health Literacy Survey Questionnaire; HLS-EU-Q16: The European Health Literacy Survey Questionnaire- short version; ICC: Intraclass correlation coefficient; PCA: Principal Component Analysis

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Authors' contributions

SSG analysed, interpreted the data, and wrote the manuscript. AKS was the study guarantor, a grant holder and a senior statistician, contributed to interpretation of data, drafting and revising the manuscript. SAA contributed to interpretation of data, drafting and revising the manuscript. GTH contributed statistical analysis and revising the manuscript. LM contributed to drafting and revising the manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study and the Icelandic version of the questionnaire are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

According to information from The Icelandic National Bioethics Committee, after an inquiry, no part of this project needed ethical approval in Iceland. The Icelandic Data Protection Authority needed however to be notified about the project. Formal notification was sent to The Icelandic Data Protection Authority in January 2017, which processed the notification without any remarks. Written informed consent was obtained from participants in the cognitive interviews. Survey participants in the third part of the project, received an introduction letter about the purpose and nature of study and provided consent for participation by answering the questionnaire.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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RESEARCH

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Making Europe health literate: including older adults in sparsely populated Arctic areas

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Abstract

Background: Older people have been identified as having lower health literacy (HL) than the general population average. Living in sparsely populated Arctic regions involves unique health challenges that may influence HL. The research aim was to explore the level of HL, its problematic dimensions, and its association with the selection of contextual factors among older adults living in sparsely populated areas in Northern Iceland.

Method: This was a cross-sectional study based on a stratified random sample from the national register of one urban town and two rural areas. The study included 175 participants (57.9% participation rate) who were community-dwelling (40% rural) and aged 65–92 years (*M* 74.2 ± *SD* 6.3), 43% of whom were women. Data were collected in 2017-2018 via face-to-face interviews, which included the standardised European Health Literacy Survey Questionnaire-short version (HLS-EU-Q16) with a score range from 0 to 16 (low-high HL).

Results: The level of HL ranged from 6–16 (*M* 13.25, *SD* ± 2.41) with 65% having sufficient HL (score 13–16), 31.3% problematic HL (score 9–12) and 3.7% inadequate HL (score 0–8). Most problematic dimension of HL was within the domains of disease prevention and health promotion related to information in the media. Univariate linear regression revealed that better HL was associated with more education (p=0.001), more resiliency (p=0.001), driving a car (p=0.006), good access to health care- (p=0.005) and medical service (p=0.027), younger age (p=0.005), adequate income (p=0.044) and less depression (p=0.006). Multivariable analysis showed that more education (p=0.014) and driving a car (p=0.017) were independent predictors of better HL.

Conclusion: Difficulties in HL concern information in the media. HL was strongly associated with education and driving a car however, not with urban-rural residency. Mobility and access should be considered for improving HL of older people.

Keywords: Ageing, Arctic region, Environment, Health literacy, Residence characteristics

Background

Health literacy (HL) has been recognised as a critical determinant and moderator of health [1]. It has a broad and inclusive definition, referring to personal skills and social resources needed for individuals and communities to achieve, understand, appraise and use information and services to make well-founded decisions about health [2]. Limited HL is considered to reinforce existing inequalities in health [1].

Older people are of specific concern when it comes to HL [1], as this group has been prominently connected to limited HL [3, 4], which is in turn linked to an increased use of health services and higher mortality rates [5, 6].

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Better HL, conversely, is considered a predictive factor for older people's use of preventive health care [7].

To investigate HL among the older population, the conceptual model behind the International Classification of Functioning, Disability and Health (ICF) can be used [8]. Accordingly, the main aspects of HL are reflected in an individual's functioning, which indicates the positive attributes of interaction between an individual's health condition and contextual (environmental and personal) factors. Although 'health condition' is commonly used as a term for diseases or disorders, it also includes other circumstances, such as ageing [9]. Therefore, HL among older adults can be viewed as resulting from dynamic interactions between the process of ageing (health condition) and a collection of contextual factors that 'represent the complete background of people's life and living' ([10] p16). Environmental (e.g. various settings, services, support, attitudes and policies) and personal (e.g. gender, age in years, education and other health conditions) contextual factors can act and interact as barriers to or facilitators of HL in old age.

Personal contextual factors that have been prominently linked with low HL are lower education and income [3, 4]. Other personal factors linked with low HL are, for example, lower self-rated health [11] and health conditions like depression [12].

Environmental contextual factors may also play an important role in facilitating or hindering HL in old age. Such factors include where one lives and the surrounding social structure. In the European Union, the proportion of older people living in rural areas is typically higher compared to urban areas [13]. Studies have demonstrated health inequities between urban and rural populations [14, 15], and living in rural areas has been associated with factors such as poor health and disability, less education and lower income [13, 14]. The results from a systematic review indicated that urban populations have better HL than those living in rural areas [15]. In Arctic regions, the demanding environment can also act as a barrier to ideal neighbourhood characteristics for active ageing [16] and ageing in place [17], such as outdoor spaces and buildings, transportation, and social and civic participation. However, some potential facilitators of HL should not be overlooked, as research findings have indicated that the level of resilience in older people in rural settings is high [18].

Another environmental factor that should be considered is ageism in the form of systematic stereotyping of older people and viewing them as a homogeneous group [19] by creating literacy-related barriers to information, services and care [8]. Old-age exclusion has been declared a remaining fundamental challenge for ageing communities in Europe with, for example, exclusion from health services [19]. Programmes aiming to promote better health among older people have been criticised for focusing too much on individual behaviours and ignoring environmental factors like social structures, services, societal attitudes and ideologies [20].

According to population projections, it is expected that by 2037, 20% of all Icelanders will be 65 years of age or older compared to 14% in 2020, and by 2064, over 25%, with the greatest increase in the oldest group [21]. Moreover, a greater proportion of residents are 65 years or older in rural areas compared to urban areas in Iceland [21]. With about 370,000 inhabitants in an area of 103.000 km^2, Iceland, which is near the Arctic Circle, is one of the most sparsely populated countries in Europe [22]. The capital area in the south of the country is home to about two-thirds of the population, whereas the remaining third live mostly along the coastline (see Fig. 1). Importantly, in recent years, Icelanders have received more limited health services due to both depopulation in rural municipalities and changes to the public healthcare system following the economic crisis in 2008, which was reorganised to create fewer – yet stronger – healthcare regions [23]. Previous studies have shown that residents in rural areas in Iceland have less education, are more likely to cohabitate, perceive their income as inadequate, and have worse self-rated health and more depressive symptoms compared to urban residents [24–27]; however, they rated their access to medical care as good [28].

There is limited information on levels of HL among older people in sparsely populated areas in Europe and the factors that influence these levels. Therefore, the aim of this study was to (a) collect information about HL levels among an understudied group of older people living in Iceland, a relatively sparsely populated Arctic European region, (b) analyse problematic dimensions of HL, and (c) explore associations between HL levels and contextual factors, including age, gender, education, income, self-evaluated health condition, resilience, urban/rural residency, perceived access and distance to different services, means of transportation, and social participation.

Methods

This study was part of a larger, population-based research project, which has previously been described in detail [29]. In brief, a stratified random sample from the national register that considered place of residency (by zip codes), age and gender was used in three areas in Northern Iceland. Data were collected from September 2017 until February 2018 via face-to-face interviews. A research group, including multi-disciplinary faculty from two universities in Iceland, conducted the study. The data collection tools included an international standardised

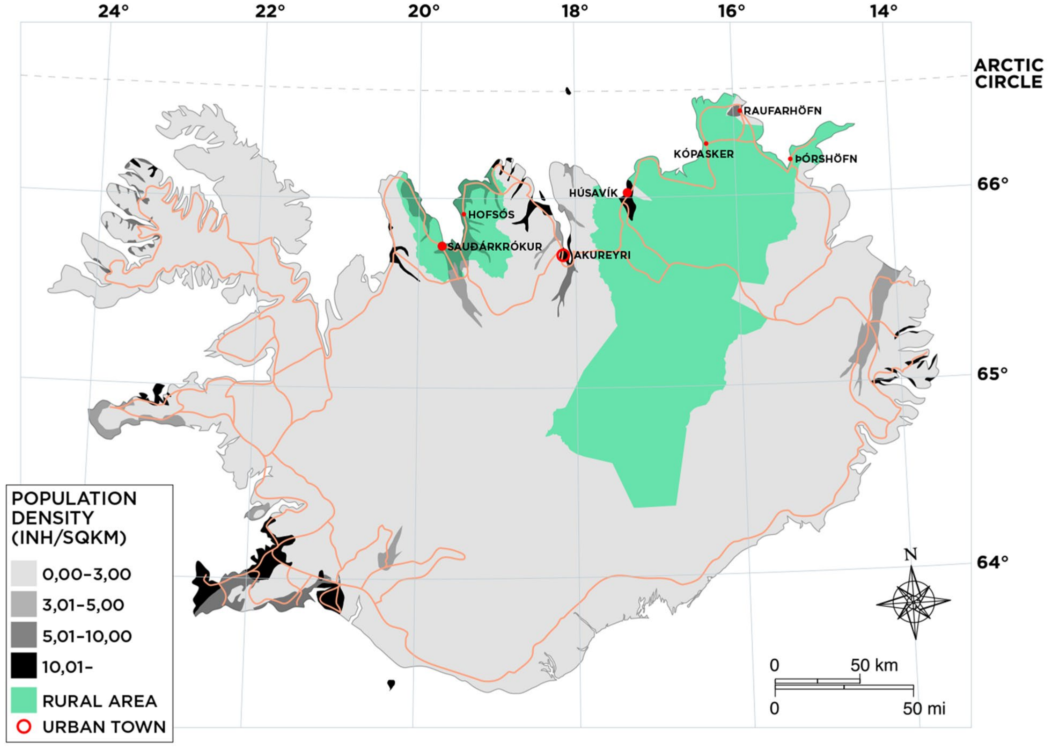

Fig. 1. Research areas and population density of Iceland. The green areas represent rural areas (by zip code). The urban town of Akureyri is marked with the largest red circle. The next-largest red circles represent towns (Saudarkrokur, Husavik) in both rural areas of the study that were excluded. The small red circles mark the locations of health clinics in rural areas. Areas shaded in grey and black indicate the population density, with black indicating the most densely populated areas

instrument for HL, three international standardised instruments for selected contextual factors, and a collection of single-item questions for additional contextual factors.

Participants and the research area

The study included people 65 years of age and older living in their own homes in three distinct geographical areas in Northern Iceland closest to the Arctic Circle (see Fig. 1). One urban town and two nearest rural districts were included: (a) Akureyri, the largest urban town outside of the capital area and, with 19,000 inhabitants, a university, a secondary national hospital and diverse services; (b) Skagafjordur district, with around 4000 inhabitants, a primary healthcare centre and a small hospital in the town of Saudarkrokur (not included in the study); and (c) Thingeyjarsyslur district, with around 4000 inhabitants, a primary healthcare centre and a small hospital in the town of Husavik (not included in the study). These three areas were selected as they represent parts of Iceland with understudied older populations and because they fulfilled predetermined definitions for urban/rural residency in Iceland [30]. Power analyses based on a study by Arnadottir [24] showed that at least 250 participants are needed to obtain a statistically valid difference between urban/rural participants. Therefore, a stratified random sample from the national registry (N=400) based on community size was taken, with 240 from the urban town and 160 from the two rural areas, with equal gender ratio. The rural group was oversampled in order to optimize reliable estimates for that part of the total sample and to have the two sub-samples as similar in size as possible. Moreover, to be included, residents had to be able to verbally communicate in Icelandic and to determine a time for a face-to-face interview. Twenty residents did not meet the inclusion criteria, five had passed away and 73 could not be reached, resulting in a sample of 302 potential participants.

Participant selection

An introduction letter, with information about the study, was sent to all potential participants. Two weeks later, they received a telephone call from a research assistant (four third-year nursing students specifically trained for data collection) asking whether they would be willing to participate in the study. If they decided to participate, they were asked to determine a time and date for a face-to-face interview. The participants could choose to meet with the research assistant at their own home, at the research centre (based in Akureyri) or at the nearest healthcare centre. Of the 302 potential participants, 175 (57.9%) agreed to participate. Those who declined to participate did not differ significantly from the study sample in terms of age (p=0.77) or residency (p=0.55) – more women or 73, however, declined to participate compared to 44 men (p=0.01). Those who declined to participate were asked to provide an explanation for their decision. The most common explanation was that they were too busy to participate or had recently taken part in other studies.

Assessment of health literacy and contextual factors

To measure HL, the 16-item validated Icelandic version of the European Health Literacy Survey Questionnaire-short version (HLS-EU-Q16-IS) which presents sound psychometric properties, with Cronbach´s alpha 0.88 [31] was used. The instrument was developed by a consortium of eight European countries [32] and is based on a conceptual model of HL outlining its main dimensions. The core of the model conceives the key processes of accessing, understanding, appraising and applying health-related information within three domains: health care, disease prevention and health promotion. The domain of health care refers to medical or clinical issues; the domain of disease prevention includes information on risk factors for poor health; and the domain of health promotion includes determinants of health in the social and physical environment. Each of the items on the HLS-EU-Q16-IS is rated on a four-point scale: 'very difficult', 'fairly difficult', 'fairly easy' and 'very easy'. Each response is then dichotomised into 'easy' (scored with 1) and 'difficult' (scored with 0) [33]. Summing these responses gives the final score of the HLS-EU-Q16, which can range from 0 (low/no HL) to 16 (high HL). Missing responses, on one or two items, are replaced with 0 before calculating the total. If there are more than two missing responses, the total score cannot be calculated. The HLS-EU-Q16 was selected as it is one of the few HL instruments designed to measure HL levels among the general population rather than specific patient groups, is internationally recognised [4, 32] and available in the Icelandic language.

Resilience was measured with the Connor-Davidson Resilience Scale (CD-RISC), which contains 25 items scored from 0 to 4 [34]. The scoring of the scale is based on summing the total of all items. Final scores range from 0 to 100, with higher scores reflecting greater resilience. The original version of the scale has presented sound psychometric properties [34] also in the settings of measuring resilience in older adults [35] the psychometric properties of the Icelandic translation have not been published.

Depression was measured with the Geriatric Depression Scale (GDS), which contains 30 items scored from 0 to 1 [36]. The scoring of the scale is based on summing the total of all items. Final scores range from 0 to 30, with higher scores indicating more severe depression. The original version of GDS [37] and the Icelandic translation [38] have demonstrated sound psychometric properties within older community-dwelling populations

Self-rated health (SRH) was measured using a standardised single-item question on global health status: 'How would you rate your overall health?' [39]. Response options were as follows: 5 – very good, 4 – good, 3 – fair, 2 – bad and 1 – very bad. The scores range from 1 to 5, with a higher score reflecting higher self-rated health. The measurement is considered valid and reliable at the population level among people without cognitive impairment, is critically used internationally [40, 41] and in Iceland [29].

In addition to measures based on standardised instruments, participants answered singe-item questions on personal and environmental contextual factors. Personal factors were age in years, age group (65 to 74 and 75 to 92 years old), gender, educational level and years in school, monthly income, and whether income was adequate. Environmental factors were urban/rural residency, distance and perceived access to healthcare services, recreational centres and organised physical training, perceived access to medical services, distance to a store, means of transportation, and social connections in the form of cohabitating or living alone, having someone to ask for assistance, frequency of meeting children or other relatives, and frequency of meeting friends or neighbours.

Statistical analysis

Descriptive statistics for the contextual factors, describing the background of all study participants, included mean (M) and standard deviation (SD) for continuous variables and counts and proportions for categorical variables. Descriptive statistics were also used to present HL levels. To interpret the final score on the HL scale, three HL levels have been defined: inadequate HL (0 to 8), problematic HL (9 to 12) and sufficient HL (13 to 16) [33]. To compare personal and environmental factors by residency, independent t-tests were used for continuous variables and chi-square tests were used for categorical variables. A few univariate linear regression models were used to analyse the association between HL (dependent variable) and contextual factors (independent variables). In addition, one multivariable linear regression model was used to describe the association between HL (dependent variable) and a selection of both personal and environmental contextual factors (independent variable) with significant (p-value <0.05) bivariate associations from the univariate linear regression. For statistical purposes and to avoid collinearity, the independent variables age in years and education in years (interval-ratio scale) were used in the multivariable mode rather than age groups and education level (ordinal scale). Statistical analysis was run with the IBM SPSS software package, v22 [42].

Ethical approval

The study was approved by the Icelandic National Bioethics Committee (VSNb2016060007/03.01) and reported to the Icelandic Data Protection Authority. Written informed consent was obtained from all participants.

Results

Participants

Participants' contextual factors, personal and environmental, are shown in Table 1. Compared to participants in rural areas, residents in the urban town had higher education levels, showed more resilience, used public transportation more often, met friends and neighbours daily more often and rated access to recreational centres and organised physical training better. Interestingly, however, they rated access to medical services worse than those living in rural areas.

Health literacy

Of the total 175 participants, 134 completed the questionnaire with less than two missing answers. Scores ranged from 6 to 16, with a mean of 13.25 ($SD \pm 2.41$) and a median of 13. Eighty-seven (65%) scored from 13 to 16, indicating sufficient HL, 42 (31.3%) scored from 9 to 12, which has been defined as problematic HL, and 5 (3.7%) scored from 0 to 8, indicating inadequate HL. See Table 2 for more information about each item. The items most often rated as difficult by participants were in the domain of disease prevention and health promotion, related to information in the media. Conversely, the items most often rated as easy were predominantly in the domain of health care.

Health literacy and contextual factors

The results from the univariate linear regression are shown in Table 3. A negative significant difference in HL was found within five personal factors: age in years $F(1.132)=8.3$; age groups $F(1.132)=7.6$; education level $F(1.131)=12.5$; having adequate income to fulfil needs $F(1.132)=4.1$; depression $F(1.131)=7.8$. A positive significant difference in HL levels was found within two personal factors: education in years $F(1.112)=11.4$; resilience $F(1.127)=10.9$. A positive significant difference in HL levels was found within three environmental factors: transportation by driving a car on one's own $F(1.132)=7.9$; perceived access to healthcare services $F(1.132)=8.0$; perceived access to medical services $F(1.132)=4.9$.

In multivariable linear regression, years in school and the ability to drive a car on one's own were independent predictors of HL. The model was significant $F(10.100)=5.0$, $p<0.001$, R^2 0.289, explaining 29% of the HL variable.

Discussion

This study contributes to the currently limited literature on the HL of older people in sparsely populated Arctic regions – in this case, one urban town and two rural areas in Iceland. Our results indicated that HL levels were lower among the population in this study compared to the general population of Icelanders [31]. Of the study participants, 35% demonstrated problematic or inadequate HL in contrast to 27.5% of the general public [31]. Therefore, the importance of addressing HL specifically among older people is emphasized. The results revealed that HL decreased with advanced age, supporting the heterogeneity of older people, and that HL becomes more problematic with increased age. The reason for this could be multidimensional and complex, including barriers associated with the process of ageing and a decline in body function. However, ageism in the form of societal attitudes should be considered. For example, increased use of technology and a limited consideration of various environmental factors, like culture, natural environment and services can result in exclusion from information and services.

The findings indicate that the most problematic dimension of HL is within the domains of disease prevention and health promotion rather than that of health care. The role of the general practitioner (GP) and the primary healthcare system seems to be well recognised. People know where to look for assistance in the case of illness or disease however, this is not the case regarding how to maintain or promote one's own health. In a Danish study, Bo et al. [43] reported fewer difficulties engaging with healthcare providers and understanding health

Table 1 Participants' contextual factors according to residency

Personal factors		**Total** ***N*=175**	**Rural** ***n*=70**	**Urban** ***n*=105**	***p*-value***
Age in years, mean (*SD*), [min-max]		74.2 (6.3) [66–92]	73.9 (6.2) [66–89]	74.4 (6.4) [66–92]	0.550
Age groups, *n* (%)	65–74 years	104 (59.4)	43 (61.4)	61 (58.1)	0.660
	75–92 years	71 (40.6)	27 (38.6)	44 (41.9)	
Gender, *n* (%)	Female	75 (43)	33 (47)	42 (40)	0.350
	Male	100 (57)	37 (53)	63 (60)	
Years in school, mean (*SD*), [min-max]		11.1 (5.3) [0–30]	9.0 (4.7) [0–24]	12.5 (5.2) [1–30]	<0.001**
Education level, *n* (%)	Elementary	78 (45.1)	38 (55.9)	40 (38.1)	0.044**
	Secondary/trade school	66 (38.2)	23 (33.8)	43 (41)	
	University degree	29 (16.8)	7 (10.3)	22 (21)	
Income per month, *n* (%)	<1.440 EUR	8 (5)	4 (6.9)	4 (4)	0.627
	1.440–2.885 EUR	74 (46.5)	28 (48.3)	46 (45.5)	
	>2.885 EUR	77 (48.4)	26 (44.8)	51 (50.5)	
Adequate income, *n* (%)	Yes	132 (75.4)	53 (75.7)	79 (75.2)	0.943
	No	43 (24.6)	17 (24.3)	26 (24.8)	
Working or retired, *n* (%)	Working	57 (32.6)	36 (51.4)	21 (20)	<0.001**
	Retired	118 (67.4)	34 (48.6)	84 (80)	
HLS-EU-Q16, mean (*SD*), [min-max]		13.2 (2.4) [6–16]	13.0 (2.4) [6–16]	13.4 (2.4) [7–16]	0.464
GDS, mean (*SD*), [min-max]		4.9 (3.8) [0–20]	4.9 (4.1) [0–20]	4.9 (3.7) [0–18]	0.978
CD-RISC, mean (*SD*), [min-max]		75.9 (12.4) [39–100]	70.4 (10.9) [39–94]	79.3 (12.0) [50–100]	<0.001**
SRH, mean (*SD*), [min-max]		3.0 (0.9) [1–5]	3.0 (0.8) [2–5]	3.0 (0.9) [1–5]	0.833
Environmental factors		**Total** ***N*=175**	**Rural** ***n*=70**	**Urban** ***n*=105**	***p*-value***
Way of living, *n* (%)	Cohabitating	135 (77.1)	59 (84.3)	76 (72.4)	0.066
	Living alone	40 (22.9)	11 (15.7)	29 (27.6)	
Means of transportation, *n* (%)	Walk	118 (67.4)	47 (67.1)	71 (67.6)	0.947
	Drive on own	162 (92.6)	64 (91.4)	98 (93.3)	0.638
	Driven by others	39 (22.3)	13 (18.5)	26 (24.7)	0.749
	Public transport	21 (12)	3 (4.3)	18 (17.1)	0.010**
Have someone to ask for assistance, *n* (%)	Yes	170 (97.1)	69 (98.6)	101 (96.2)	***
	No	5 (2.9)	1 (1.4)	4 (3.8)	
How often meet children or other relatives, *n* (%)	Daily	69 (39.7)	30 (43.5)	39 (37.1)	0.481
	Weekly	70 (40.2)	19 (27.5)	51 (48.6)	
	Monthly	26 (14.9)	16 (23.2)	10 (9.5)	
	Yearly	9 (5.2)	4 (5.8)	5 (4.8)	
How often meet friends or neighbours, *n* (%)	Daily	60 (34.3)	16 (22.9)	44 (41.9)	0.003**
	Weekly	97 (55.4)	43 (61.4)	54 (51.4)	
	Monthly	15 (8.6)	9 (12.9)	6 (5,7)	
	Yearly	3 (1.7)	2 (2.9)	1 (1)	
Perceived access to healthcare services, *n* (%)	Good	99 (56.6)	38 (54.3)	61 (58.1)	0.156
	Rather good	47 (26.9)	26 (37.1)	21 (20)	
	Neither nor	7 (4)	2 (2.9)	5 (4.8)	
	Rather bad	16 (9.1)	3 (4.3)	13 (12.4)	
	Bad	6 (3.4)	1 (1.4)	5 (4.8)	

Table 1 (continued)

Personal factors		**Total** ***N*=175**	**Rural** ***n*=70**	**Urban** ***n*=105**	***p*-value***
Perceived access to medical services, *n* (%)	Good	104 (59.4)	41 (58.6)	63 (60)	0.022**
	Rather good	41 (23.4)	22 (31.4)	19 (18.1)	
	Neither nor	8 (4.6)	3 (4.3)	5 (4.8)	
	Rather bad	16 (9.1)	2 (2.9)	14 (13.3)	
	Bad	6 (3.4)	2 (2.9)	4 (3.8)	
Perceived access to recreational centres, *n* (%)	Good	89 (50.9)	23 (32.9)	66 (62.9)	<0.001**
	Rather good	23 (13.1)	11 (15.7)	12 (11.4)	
	Neither nor	56 (32)	31 (44.3)	25 (23.8)	
	Rather bad	6 (3.4)	4 (5.7)	2 (1.9%)	
	Bad	1 (0.6)	1 (1.4)	0 (0)	
Perceived access to organised physical training, *n* (%)	Good	69 (39.4)	16 (22.9)	53 (50.5)	<0.001**
	Rather good	24 (13.7)	10 (14.3)	14 (13.3)	
	Neither nor	69 (39.4)	32 (45.7)	37 (35.2)	
	Rather bad	9 (5.1)	8 (11.4)	1 (1)	
	Bad	4 (2.3)	4 (5.7)	0 (0)	
Distance from healthcare services, *n* (%)	0–5 km	107 (61.1)	4 (5.7)	103 (98.1)	<0.001**
	5–20 km	21 (12)	19 (27.1)	2 (1.9)	
	20 km+	47 (26.9)	47 (67.1)	0 (0)	
Distance from recreational centres, *n* (%)	0–5 km	123 (72.4)	18 (27.7)	105 (100)	<0.001**
	5–20 km	32 (18.8)	32 (49.2)	0 (0)	
	20 km+	15 (8.8)	15 (23.1)	0 (0)	
Distance from a store, *n* (%)	0–5 km	119 (68)	14 (20)	105 (100)	<0.001**
	5–20 km	29 (16.6)	29 (41.4)	0 (0)	
	20 km+	27 (15.4)	27 (38.6)	0 (0)	
Distance from organised physical training, *n* (%)	0–5 km	124 (73.8)	19 (30.2)	105 (100)	<0.001**
	5–20 km	20 (11.9)	20 (31.7)	0 (0)	
	20 km+	24 (14.3)	24 (38.1)	0 (0)	

HLS-EU-Q16 European Health Literacy Survey Questionnaire-short version, *GDS* Geriatric Depression Scale, *CR-RISC* Connor-Davidson Resilience Scale, *SRH* Self-rated health-single item question. *Differences between rural/urban residents were based on *t*-test for continuous variables and a chi-square test for categorical variables. **Statistical difference, $p<0.05$. ***Differences between rural/urban residents could not be calculated due to the homogeneity of responses

information with increased age. This could be explained with the established relationship between people and their GP, as part of the countries public healthcare system is provision of GP´s to all citizens in their geographical regions. Previous findings from rural Iceland are corresponding [28], which might be related to the fact that Nordic countries have similar healthcare systems. The results of this study also revealed specific difficulties in HL concerning understanding, appraising and using health-related information in the media. Most participants found it difficult to determine how to protect themselves from illnesses based on information in the media. This accords with findings from a study on HL among older people in Finland [12]. At present, in the context of the ongoing COVID-19 pandemic, older adults may experience being excluded from precautionary measures which are extensively presented via technology.

The findings from this study found no difference in HL in terms of urban-rural residency. According to Aljassim and Ostini [15], rurality alone may not be a determinant of HL, as other personal and environmental factors might play important roles in a complex interplay within both HL and rurality. HL, in this study, increases with younger age, more education, having adequate income, less depression, increased resilience, driving a car and good self-reported access to medical and healthcare services. Multivariable analysis revealed that driving a car and having more years of education were independent predictors of better HL. It should not be overlooked, that driving a car may largely influence HL, as it is directly linked to physical access to health-related information and services. This ability may afford older people more independence and enhance their inclusion in sparsely populated Arctic regions. Good perceived access to

Table 2 Distribution of answers to the HLS-EU-Q16 items

Item	Domain*	*n*	Easy *n* (%)	Difficult *n* (%)	Missing *n* (%)
1. find information about treatments for illnesses that concern you?	HC	170	148 (87)	22 (13)	5 (3)
2. find out where to get professional help when you are ill?	HC	174	163 (93)	11 (7)	1 (0.5)
3. understand what your doctor says to you?	HC	175	170 (97)	5 (3)	0 (0)
4. understand your doctor´s or pharmacist's instructions on how to take a prescribed medicine?	HC	174	171 (98)	3 (2)	1 (0.5)
5. judge when you may need to get a second opinion from another doctor?	HC	157	127 (80)	30 (20)	18 (10)
6. use information the doctor gives you to make decisions about your illness?	HC	168	163 (97)	5 (3)	7 (4)
7. follow instructions from your doctor?	HC	174	169 (97)	5(3)	1 (0,5)
8. find information about how to manage mental health problems like stress or depression?	DP	145	110 (76)	35 (24)	30 (17)
9. understand health warnings about behaviour such as smoking, low physical activity and drinking too much?	DP	174	168 (96)	6 (4)	1 (0.5)
10. understand why you need health screenings?	DP	175	171 (98)	4 (2)	0 (0)
11. judge if the information about health risks in the media is reliable?	DP	171	73 (43)	98 (57)	4 (2)
12. decide how can protect yourself from illness based on information in the media?	DP	168	62 (37)	106 (63)	7 (4)
13. find out about activities that are good for your mental well-being?	HP	172	146 (85)	26 (15)	3 (1,5)
14. understand advice on health from family members or friends?	HP	171	144 (84)	27 (16)	4 (2)
15. understand information in the media about how to get healthier?	HP	172	87 (51)	85 (49)	3 (1,5)
16. judge which everyday behaviour is related to your health?	HP	175	162 (93)	12 (7)	0 (0)

Domain*: *HC* Health care, *DP* Disease prevention, *HP* Health promotion

healthcare and medical services were also related to a higher HL score. Access to medical services was perceived to be better in the two rural areas than in the urban town, which aligns with findings from other rural areas in Iceland [28]. Access might, therefore, not only be limited to ground distance but may also refer to social access, costs, waiting time and knowing where to seek or access information. Although sparsely populated rural communities might lack public transport, they may also have less complex communication pathways and more personal connections between healthcare staff and residents than in urban areas [28].

In this study while significant in the univariate analysis, income level was not independently associated with HL in the multivariable analysis like years of education. However, higher education is generally linked to higher income. The importance of education and income to HL is particularly interesting considering that Iceland is a high-income country [44] with comparatively high equity in education [45]. Older people with higher levels of education and income have better HL [1] – both factors, yet, are not represented among those living rurally, internationally [13–15] and in Iceland [24–27] thereby, indicating that there are vulnerable groups within every country, regardless of the economy.

In this study, overall, resilience can be considered relatively high and depression symptoms limited, although HL increased with higher resilience and decreased with more depression symptoms. Resilience was, however, higher in the urban town in this study, compared to previous findings that indicated higher resilience related to older people living rurally [18]. Better HL is considered to increase resilience if combined with, for example, better access to health information and services [46]. The link and interactions between HL, resilience and contextual factors need to be investigated further, specifically in rural areas.

Strengths and limitations

The strength of this research was its use of an international standardised instrument to measure HL as well as three other international standardised instruments. Yet, it might be considered a limitation that the psychometric properties of the Icelandic translation of the CD-RISC have not been published. The face-to-face interviews used for data collection generally minimised non-responses and maximised the quality of the collected data, for example, the interviewer could clarify items to the respondent if needed. However, having described the HLS-EU-Q16-IS instrument in the methods section and the four- point response scale that does not include options like "I don't know/I don't want to answer" and the fact that participants signed an informed consent stating voluntary participation could explain the missing answers for some items. The study sample was relatively small, yet reasonable compared to the size of the general population and the population-level random sampling approach used. For unknown reasons, women were more

Table 3 Health literacy and its association with personal and environmental contextual factors

Contextual factors	**Univariate associations**			**A multivariable model**		
Personal factors	***β*** **(*t*-value)**	**95% CI Lower Upper**	***p*-value**	***β*** **(*t*-value)**	**95% CI Lower Upper**	***p*-value**
Age in years	-0.244 (-2.887)	-0.157 -0.029	0.005*	-0.155 (-1.672)	-0.144 0.012	0.098
Age group (75–92 years)	-0.234 (-2.765)	-1.985 -0.329	0.007*			
Gender (male)	-0.103 (-1.191)	-1.327 0.330	0.236			
Years in school	0.304 (3.378)	0.057 0.221	0.001*	0.236 (2.508)	0.022 0.186	0.014*
Education level (secondary/trade school)	0.129 (1.488)	-0.208 1.470	0.139			
Education level (elementary)	-0.295 (-3.540)	-2.254 -0.638	0.001*			
Income per month (<1.440 EUR)	-0.051 (-0.567)	-2.828 1.569	0.572			
Income per month (1.440–2885 EUR)	-0.118 (-1.329)	-1.425 0.280	0.186			
Adequate income (no)	-0.174 (-2.030)	-1.915 -0.025	0.044*	-0.061 (-0.650)	-1.330 0.673	0.517
Working or retired (retired)	-0.112 (-1.297)	-1.498 0.312	0.197			
GDS	-0.237 (-2.794)	-0.248 -0.042	0.006*	-0.113 (-1.125)	-0.187 0.052	0.263
CD-RISC	0.281 (3.305)	0.022 0.087	0.001*	0.119 (1.203)	-0.015 0.061	0.232
SRH	-0.165 (-1.922)	-0.876 0.013	0.057			
Environmental factors	***β*** **(*t*-value)**	**95% CI Lower Upper**	***p*-value**	***β*** **(*t*-value)**	**95% CI Lower Upper**	***p*-value**
Residency (urban)	0.064 (0.735)	-0.556 1.212	0.464			
Way of living (living alone)	-0.036 (-0.409)	-1.170 0.769	0.683			
Means of transportation:						
Walking	-0.041 (-0.469)	-1.088 0.671	0.640			
Driving a car	0.239 (2.822)	0.685 3.893	0.006*	0.213 (2.424)	0.489 4.906	0.017*
Public transport	0.069 (0.794)	-0.724 1.695	0.429			
Driven by others	-0.054 (-0.619)	-1.464 0.766	0.537			
How often meet children or other relatives	-0.113 (-1.300)	-0.803 0.166	0.196			
How often meet friends or neighbours	0.039 (0.449)	-0.509 0.808	0.654			
Perceived access to healthcare services	0.239 (2.830)	0.155 0.875	0.005*	0.252 (1.734)	-0.076 1.131	0.086
Perceived access to medical services	0.191 (2.231)	0.045 0.748	0.027*	0.036 (0.253)	-0.492 0.636	0.801
Perceived access to recreational centres	0.088 1.020)	-0.204 0.638	0.310			
Perceived access to organised physical training	0.164 1.914)	-0.013 0.761	0.058			

Table 3 (continued)

Contextual factors	Univariate associations			A multivariable model		
Personal factors	**β** **(*t*-value)**	**95% CI** **Lower** **Upper**	***p*-value**	**β** **(*t*-value)**	**95% CI** **Lower** **Upper**	***p*-value**
Distance from healthcare services	-0.116 (-1.343)	-0.874 0.167	0.181			
Distance from recreational centres	0.095 (1.086)	-0.338 1.162	0.280			
Distance from a store	0.020 (0.231)	-0.567 0.717	0.818			
Distance from organised physical training	-0.072 (-0.822)	-0.951 0.393	0.413			

GDS Geriatric Depression Scale, *CD-RISC* Connor-Davidson Resilience Scale, *SRH* Self-rated health-single item question. *Statistical significance $p<0.05$

likely to decline participation than men and were therefore slightly underrepresented compared to the general population.

Conclusion

In a dynamic and complex interaction, HL among older adults is a result of the process of aging and contextual factors that act and interact as barriers or facilitators. Although urban/rural residency does not seem to influence HL, other factors do, like age, education and income, depression, resilience, driving a car and access to medical and healthcare services, with more education and driving a car being the strongest associated factors. Thus, a one-size-fits-all approach does not apply to measures taken to increase HL, and we therefore need to consider and respond to the ways in which older people are being excluded from information and services by, for example, increased use of technology and the need for better strategies to improve the health literacy of those who may be less mobile. Particular attention should be paid to disease prevention and health promotion and to the role of the media in providing reliable health-related information. In a call for action within the European Union to improve HL, identifying specific barriers among population groups that need more support was highlighted. This study did so by providing information on HL levels among an understudied group of older people in sparsely populated Arctic regions and demonstrating the importance of associations with various contextual factors.

Abbreviations

HL: Health Literacy; HLS-EU-Q16: The European Health Literacy Survey Questionnaire- short version; HLS-EU-Q16-IS: Icelandic version of the European Health Literacy Survey Questionnaire-short version; CD-RISC: Connor-Davidson Resilience Scale; GDS: Geriatric Depression Scale; SRH: Self-rated health-single item question; HC: Health care; DP: Disease prevention; HP: Health promotion; GP: General practitioner.

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Authors' contributions

SSG analysed, interpreted the data, and wrote the manuscript. AKS was the study guarantor and a grant holder, contributed to interpretation of data, drafting and revising the manuscript. LM contributed to drafting and revising the manuscript. SAA contributed to interpretation of data, coordinating, drafting and revising the manuscript. All authors read and approved the final manuscript. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study and the Icelandic version of the questionnaire are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the Icelandic National Bioethics Committee (VSNb2016060007/03.01), reported to the Icelandic Data Protection Authority and, written informed consent was obtained from all participants. This study was carried out in accordance with the relevant guidelines and regulations (Declaration of Helsinki).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interest.

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RESEARCH

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When great responsibility comes with limited options: experiences and needs of older community-dwelling adults regarding accessing, understanding, appraising and using health-related information

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Abstract

Background In previous research, older adults have been associated with reduced levels of health literacy (HL) influenced by a range of contextual factors. To optimise HL, it is essential to better understand the interactions between the ageing process and both personal and environmental factors as perceived by older adults. This study aimed to explore the experiences and needs of older community-dwelling adults when accessing, understanding, appraising and using health-related information.

Methods An explorative, qualitative design was used within the social constructivism framework. Semi-structured individual interviews were conducted with 20 adults aged 70–96 living at home in three areas in Northern Iceland. The transcribed interviews were constructed into categories and subcategories using qualitative content analysis.

Findings.

Four categories emerged. "Expectations for responsibility" describes the experience that individuals are responsible for taking care of their health, including accessing, understanding, appraising and using information and services, showing initiative and keeping needed communications active. "A gap between expectancy and ability/context" includes experiences while taking responsibility for expectations not aligning with skills/situations, creating information gaps. "Finding one's own ways" comprises various adapted ways to access, understand, and use information and services. "Bridging the gap" describes experiences of needing shared responsibility and more manageable options to enable reasoned health-related decisions and navigation in the healthcare system.

Conclusions The participants valued and took full responsibility for accessing, understanding, appraising and using information and services as part of a social norm; however, they experience information gaps. They request shared responsibility by being provided with fundamental health-related information as a vital step in making reasoned health-related decisions and navigating the healthcare system. They also request more inclusive and accessible service opportunities to bridge the gaps and facilitate HL. It is necessary to critically address, at a systematic level, the conflict between expected individual responsibility and the existence of options to act upon this responsibility.

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In matters of health, health services and HL, the need to analyse and confront structural disadvantages experienced by older adults is highlighted.

Keywords Access to health care, Access to information, Ageing, Health literacy, Health promotion, Information seeking behaviour, Qualitative research

Introduction

Health literacy (HL) refers to both the personal skills and social resources needed for individuals and communities to access, understand, appraise and use information and services to make reasoned health-related decisions and to navigate in the healthcare system [1, 2]. HL is therefore considered essential to maintaining and improving quality of life throughout the life course [3]. With advancing age, older adults may require more frequent interactions with health-related information. Consequently, the importance of addressing HL concerning older adults has been emphasised [4], particularly because of population projections that indicate a global increase in the number of older adults in the future and the need to enhance health promotion for this group [5].

In Europe, an effort has been made to measure HL levels, for example, with the European Health Literacy Survey Questionnaire (HLS-EU-Q), among the general population. Limited HL is associated with social and socioeconomic conditions, particularly lower levels of education, income, low social status and older age [4, 6–8].

Acknowledging HL as an interaction of individual skills within a social context, it is essential to look beyond the personal level and include the social structures in which people live. That is, to better understand the influence of the situations in which people are required to use their HL skills and capabilities [9, 10]. There is, for example, a heightened focus on the organisational context of HL, the health system's demands and the complicated information environment in a modern world [11, 12]. However, at the same time, it is essential to recognise the complexity of the social context of HL [9, 10]. This has, for example, been addressed in research focusing on experiences related to health information among socioeconomically disadvantaged adults in Switzerland [13], among refugees in Sweden [2] and as part of information literacy in everyday life among people aged 47–64 [14] and 57–70 in Australia [15].

Research findings concerning older adults in Iceland echo this complex interaction between the ageing process, HL and both personal and environmental factors. Notably, HL has been connected to the personal factors of age in years, education level, income, resilience and depression and the environmental factors of means of transport and perceived access to healthcare and medical service [16]. These factors seem to play an important role in HL; however, further information is needed to comprehensively understand this dynamic interaction between older adults, HL and their context. In contrast to using quantitative measurements in relation to HL as is prominent, a qualitative perspective is needed to gain a deeper understanding of the matter. Therefore, this study aimed to explore the experiences and needs of older community-dwelling adults concerning accessing, understanding, appraising and using health-related information.

Methods

Study design

This qualitative study within the social constructivism framework sought to understand the specific contexts in which people live [17, 18]. An explorative design was used to find and create knowledge of the focused and little-studied phenomena [19]. We conducted individual semi-structured interviews to generate qualitative data, get insights into the lives of older adults and establish knowledge [20].

The research group consisted of three Icelandic researchers (SSG, SAA and AKS), a Swedish (LM) researcher and an Icelandic senior citizen (AS). The four researchers created an interdisciplinary team of occupational therapists (SSG and LM), a physiotherapist (SAA) and a nurse (AKS) as professors/researchers (LM, SAA and AKS) and a PhD student (SSG). The group's expertise, research and lived experience lie within ageing, daily living, gerontology, HL, health promotion, qualitative research and urban/rural settings.

This study is reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [21]. An application for ethical approval was sent to the Icelandic National Bioethics Committee. The committee deemed permission not necessary according to Icelandic law on scientific research in health (VSN-21–009 based on VSNb2016060007/03.01).

Participants and setting

Participants in this study were purposefully selected from 175 partakers in a previous quantitative cross-sectional study on HL. That study was based on a stratified random sample from the national register of community-dwelling people 65 years and older in one urban town and two rural areas in Northern Iceland [16, 22].

To get as broad a perspective as possible, the selection criteria for this study were based on the aim of interviewing older people with various backgrounds regarding place of living, age, gender, education, means of transport and distance from services. The selection procedure was conducted in three steps, as shown in Table 1. In the first step, potential participants were sorted by partakers' numbers from the previous quantitative research. They were placed into a matrix list based on five to six determining factors, with a sixth factor being considered for those living in rural areas. Considering the amount of needed information, that some people might not be reached and some might decline participation, the matrix list included 69 from 175 previous partakers, with many categorised with the same factors. In the second step, previous partakers' numbers and the names of potential participants were connected. Information recorded at the Register Iceland database on a) social security number, b) place of living and c) a registered telephone number accessible through an open website were matched. This information could not be paired for 21 persons, leaving 48 on the potential participants' list. In the third and last step, 20 people on the list were contacted for participation. They all agreed, consented, and were subsequently interviewed.

All participants, 11 women and nine men were born and raised in Iceland except for one individual who, despite not being native, had resided in the country for decades. Their birth years ranged from 1926 to 1952, and the median age was 76,6 years. Seven had elementary education, eight a secondary or trade school education and five a university degree. Agriculture, education, trade, healthcare and homemakers were the main occupation fields.

In three interviews, the spouse was present. In one case, the participant had early-stage Alzheimer's, so in cooperation with the couple, it was decided that the spouse would play the roles of support, memory and voice. In the other two cases, both in rural settings, the spouse of the participant was present in the kitchen, where the interview was conducted as a part of the culture in place. The spouses were not direct participants in the interview; however, they added information when, for example, asked to recall a process, names or times.

Procedure

Potential participants were sent an invitational letter by mail and subsequently contacted (by SSG) by telephone and invited to participate. Data were collected over one year, from January 2022 to January 2023. SSG conducted all of the interviews in Icelandic at the participants' chosen place. The interviews were audio-recorded and lasted from 30 to 65 min, with an average of 46 min. The recordings were deleted after transcription. An interview frame designed for this study was used, which included a) opening questions about the length of time living in their current area, main occupation and preferred pseudonyms for confidentiality; b) questions about HL, which asked the participants to describe their experience of accessibility, clarity and usefulness of health-related information and services; and c) an opportunity to add any information.

Data analysis

The interviews were transcribed verbatim and analysed using content analysis as described by Graneheim and Lundman [23] and Graneheim, Lindgren and Lundman [24]. The method offers researchers different epistemological positionings with various levels of abstraction and degrees of interpretation, depending on the study aim and data quality. It is, for example, applicable when knowledge is believed to be socially constructed [24]. As reflexivity was considered an essential part of the whole process, the analysis was conducted with a team of all authors. Although SSG and LM mostly did the main work because of their pre-understanding of the research

Table 1 Participants' main selection procedure

		Urban town	Rural area 1	Rural area 2	Total
Previous study partakers:		**105**	**33**	**37**	**175**
Step 1	Matrix factor list:[a]				
	Selected	33	18	18	69
Step 2	Necessary contact information:				
	Available	20	15	13	48
Step 3	Contacted:				
	Accepted and interviewed	10	5	5	20

[a] Matrix list included the following factors: 1) urban/rural place of living (by zip codes), 2) age groups (70–74, 75–84, 85–89, 90 +), 3) gender (female, male), 4) education (elementary, secondary/trade school, university degree), 5) means of transport (walk, drive on own, driven by others, public transport) and 6) distance from healthcare service in rural areas (0–5, 5–20, 20 + km)

area and the method used for analysis, all the authors met in working meetings at each step of the analysis process, as described below. These meetings were used for reflection on the empirical data, the potential influence of preconceptions and the emerging findings from SSG and LM. In addition, a reflection from AS with a lived experience of the matter was sought in each step. Throughout the analysis process, work was carried out in Icelandic and English. Transcriptions were entered into the data management software NVivo 11 [25] for data storage, organisation, and coding. However, the team encountered difficulties in sharing information using the software, which resulted in the analysis being conducted manually in a Word document.

In the first step, all the authors read the interviews several times to understand the content. The three Icelandic researchers read the material in their native tongue, and the Swedish researcher used an English Google-translated version. The interviews were discussed both as a whole and in specific parts, where meaning units and potential content areas in consideration of the study's objective were identified.

In the second step, meaning units were identified according to the aim of the study and condensed into descriptions close to the text, preserving the core meaning, abstracted and labelled with codes. Further abstraction occurred as subcategories and categories emerged from the condensed content based on patterns or commonalities. Similarities, differences and connections between and within the content were reflected upon and sorted. Constant comparison was used to clarify meanings, comparing data with codes and codes with codes.

In the third and last step, further analysis took place when the descriptive content of the preliminary categories was formulated by going back and forth and checking consistency between the categories, their content and the empirical data. The emerged core meanings were validated by contextualizing the meaning units in the individual interviews and the data as a whole. The 20 interviews provided insightful data to answer the purpose of the study, which was to explore the experiences and needs of older community-dwelling adults concerning accessing, understanding, appraising and using health-related information.

Findings

Based on manifest content, four qualitative categories emerged from the experiences and needs of older community-dwelling adults. Each category is independent, yet interconnected with the others, as shown in Fig. 1. "Expectations for responsibility" describe the experience that the individual should be responsible for taking care of their own health, including accessing, understanding, appraising and using information and services, as well as showing initiative and keeping needed communications active. "A gap between expectancy and ability/context" includes experiences while taking responsibility for expectations not aligning with one's own skills/situations. "Finding one's own ways" comprises various adapted ways to access, understand, appraise and use information and services due to a misalignment between expectations for responsibility and the individual's ability or context. "Bridging the gap" describes experiences of needing shared responsibility and more manageable options to optimise reasoned health-related decisions and navigation through the healthcare system. Significant quotations are provided to illustrate the empirical foundations of the subcategories. Table 2 provides information about the manifest content from the analysis.

Expectations for responsibility

This category describes participants' experiences regarding the predominant expectation that each individual should carry the responsibility of taking care of their own health, including accessing, understanding, appraising and using health-related information as well as showing initiative and keeping needed communications active. The category is divided into two subcategories based on how this expectation is described: directly from the person and indirectly from the information providers. The subcategories were named "Personal expectations" and "Environmental expectations".

Personal expectations

This subcategory describes the experience that the person was expected to be responsible for their health and health-related matters—that is, to be their own health manager. The person should know best what they need and therefore be responsible for achieving, understanding, appraising and using information. This expectation was accepted as part of being independent and acknowledging the increase in general knowledge, making people more educated about health matters. By not taking responsibility as one's health manager, opportunities for health and welfare information might be lost, and then the person would be the only one to blame.

> *"You get the information you need, you just look for it... so you have nothing to complain about but yourself" (if you have missed information) (Thorunn, 76-year- old woman).*

Environmental expectations

The responsibility for taking care of one's own health was also experienced as an unspoken expectation from health-related information and service providers, who

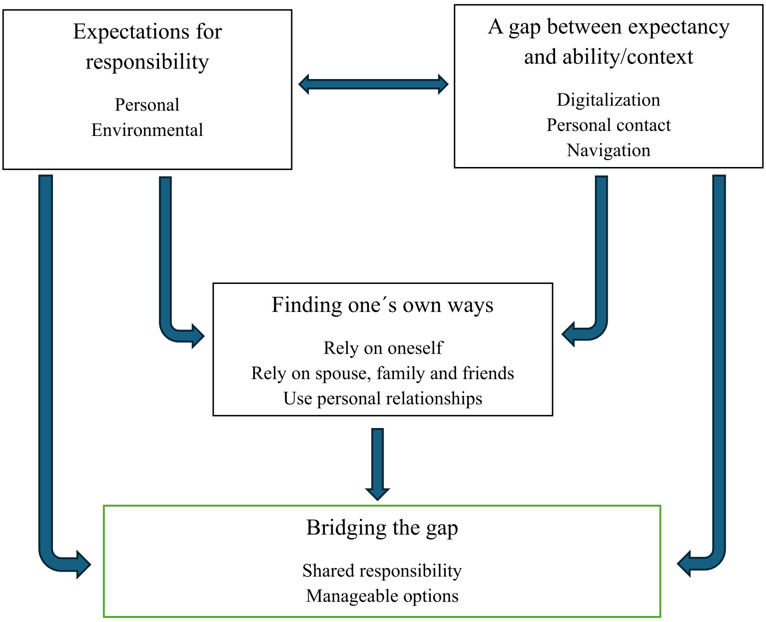

Fig. 1 Interplay of categories and subcategories for older adults' experiences and needs related to health literacy. The figure shows the interaction and tension between the categories "Expectations for responsibility" and "A gap between expectancy and ability/context" that together create limited options and push for individual action in "Finding one's own ways" when accessing, understanding, appraising, and using health-related information. Jointly, these three categories, including their subcategories, call for needed actions in "Bridging the gap", presented in the green box

Table 2 Participants' main selection procedure

Category	**Expectations for responsibility**		
Subcategory	Personal expectations	**Codes**	Own health manager, My responsibility, I should know, Missing information is my fault
	Environmental expectations		Have to request, Seek and ask, Not receive, Show initiative, Information is out there
Category	**A gap between expectancy and ability/context**		
Subcategory	Digitalisation gap	**Codes**	Technology skill wall, No access, Information gets lost, Lack of instructions and support, Equipment, Maintenance, Expensive
	Personal contact gap		On my own, No one knows me, Unsafe, Lost
	Navigation gap		Complicated, Disconnection, Give up, Tiering, Service not for me
Category	**Finding one's own ways**		
Subcategory	Rely on oneself	**Codes**	Prior experience, Former work, Taking care of own parents
	Rely on support from spouse, family and friends		Spouse essential as manager, Necessary help from children and grandchildren, Support from friends
	Use personal relationships within welfare systems		No other way, Easier and more effective, Staff decision, Informal way
Category	**Bridging the gap**		
Subcategory	Shared responsibility	**Codes**	First I need to know, What is valid, My rights
	Manageable options		Don't just tell me – enable me, Overview of service, Things important to me, More possibilities and choice, In-person support, Quality guarantee

often only deliver information if requested. In these circumstances, the individual needs to take the initiative to look for the information and services that are needed and relevant on each such occasion. If opportunities to manage one's own health were lost, this was because of a lack of responsibility of the persons rather than the information provider.

> *"I did not know... usually it is the case that you have to look for information" (Kara, 70-year-old woman).*

A gap between expectancy and ability/context

This category describes participants' experiences of being unable to live up to the expectations of being responsible for accessing, understanding, appraising and using health-related information to manage their health. The category is divided into three subcategories based on descriptions of different kinds of gaps between the expectancy and one's own ability/context, although often interlinked, which are named "Digitalisation gap", "Personal contact gap", and "Navigation gap".

Digitalisation gap

This subcategory describes the experiences of being unable to access and use information as expected and navigating within and between the health and welfare systems because of the increased use of computers and the internet, that is, digitalisation. Although digital development was generally viewed positively, it was expressed that all the changes were happening so fast, leaving many unable to keep up. For those needing more than general information or not having all the proper equipment or the ability, digital technologies were creating a significant gap in information and services.

> *"You know, I am back from ancient times. I have no computer and no phone to Google and nothing, so I am completely... so many things that you cannot do unless you have a computer... all the information" (Dora, 96-year-old woman).*

Personal contact gap

With the increased use of digital technology, there was also the experience of a decrease in personal and direct contact. This combination created an even wider gap between expectations of taking responsibility and one's own ability/context. This gap consisted of being unable to use entirely the formal digital ways to access, understand, appraise and use information and, simultaneously, the conventional and valued forms of person-to-person contact being limited. Being without a key person within the health and welfare systems to contact was described as being lost and not knowing what information to look for, where and what options were current or applied to them. This contact with a key healthcare person was significant in the case of illnesses. Although generally satisfied with hands-on service, with no one knowing the health history and situation of the older person or the possibilities in the service system, there was no way to safely navigate or coordinate the necessary information and actions when needed.

> *"... I need to get someone I trust. I do not want to end up with a new person in every conversation and say the same thing over and over and over again. After the fifth time, you think 100 times over whether to call again... Everyone wants to assist you, but can't because they do not know you" (Hanna, 80-year-old woman).*

Navigation gap

A gap in navigation while taking responsibility for accessing, understanding, appraising and using health-related information was experienced as a result of the general complexity within and between health-related services, particularly in knowing what information to find and where. This gap in navigation was fuelled by the digitalisation gap and the personal contact gap. The existence of long, complicated, and unclear communication channels, disconnection between organisations, and unclear service provision or division between entities, such as the local municipality and the state, often result in difficulties finding information or some information getting lost along the way. These were expressed as daunting, never sure of being on the right navigation course, always showing initiative and only relying on persistence not to give up. Perceived by participants as confusing, health-related service systems were described as not being made for the older service user and made to drive them away.

> *"...this is uncomfortable because you sometimes get the impression that the system does not care... and then you think you are somehow alone if something happens. Why isn't it better? Maybe that is why senior citizens get the impression that you are a bit set aside. It is tiring always to have to push yourself somehow through" (Sigrun, 78-year-old woman).*

Finding one's own ways

This category describes the experiences of finding one's own ways to live up to the expectancy of being responsible for accessing, understanding, appraising and using health-related information. It is divided into three subcategories based on descriptions of the different ways used to adapt: "Rely on oneself", "Rely on spouse, family and friends", and "Using personal relationships".

Rely on oneself

This subcategory describes the experience of relying on oneself while managing health-related information. It was described as using knowledge through former work experience from the health and welfare service, watching parents age or even taking care of them and building on information and service from that time. Having some idea about what service is available and where to start looking for further information was expressed. This includes having enough knowledge to know where to look for information and how the services operate, given that little has changed.

> *"I know the operation (at the former workplace) well enough that I would look for the service, if I needed home care or something like that, I know how to do it" (Nina, 80-year-old woman).*

Rely on spouse, family and friends

Finding one's own ways based on the experience of relying on the spouse, family and friends regarding health-related information was described. In situations in which the participant could not use computer technology fully or at all, but the spouse could, he or she was valued as essential and even the reason for being able to live in place. Help from grown-up children or acquaintances was also mentioned, and they considered themselves lucky to have people around to help, stating that this was not the case for everyone.

> *"Our daughter … is extremely good at helping. I do not know what we would do if we lost touch with her" (Fannar, 72-year-old man).*

Experiences of getting information about available services and where to turn in need at gatherings organized by local senior non-governmental organisations (NGOs) were also described. Also, when getting together, friends shared information on where to turn in need and hands-on experiences.

Use personal relationships

Finding one's own ways by using personal relationships or acquaintances with health and welfare professionals was described by some as being, at times, necessary to access information or services by using this kind of relationship. This required using informal methods rather than formal ones when no other means seemed possible.

> *"He (the general practitioner) was always on vacation or busy or not reachable … so I called my son (who is a medical doctor) and said now you have to help me" (Dora, 96-year-old woman).*

Others described it as a common way to use personal connections regarding health-related information, especially in rural areas where "everybody knows everyone". Considerations of being very lucky to have this kind of relationship and being able to use this informal way were expressed.

Bridging the gap

This category describes the experience of what is needed to access, understand, appraise and use health-related information to be more able to take care of one's own health. It is divided into two subcategories based on descriptions of different needs: "Shared responsibility" and "Manageable options".

Shared responsibility

This subcategory describes the experience of needing shared responsibility by being provided with the necessary fundamental health-related information. Although accepting the expectations of being responsible for achieving information as a part of taking care of their own health (category "Expectations for responsibility") the experience also revealed that to do so, fundamental knowledge of what information and services exist and are current is required. To find information about services, the person first needs to know what opportunities and resources are available.

> *" I really expect this (information) to be handed to me when I reach the age, but not that I have to run after it" (Hanna, 80 year-old woman).*

Some of the fundamental information on health-related matters was described as being provided by local senior NGOs and highly valued as such; however, at the same time, it was questioned who should be responsible for providing older adults with this information.

Manageable options

In addition to needing the provision of fundamental health-related information to bridge the gap, this subcategory describes the experience of what kind of information access is required and in what way accessed. Manageable options refer to an accessible overview of opportunities and resources that are available and current, both locally and nationwide. A clear venue for quality and reliable information is necessary, which was possible during the COVID-19 pandemic, so there is a precedent. Also, getting valuable and more relevant information is needed.

> *"Why do you always have to be in such a terrible shape to get information and service? … I think there needs to be a little more about everyday things. If*

> *you're taking care of yourself, advice is needed on the best way to do this" (Nina, 80-year-old woman).*

Access to information and services must align with diverse abilities/contexts. More options than mainstream digitalisation to access information and navigate through service systems need to be available. In rural areas, experiences of information being delivered more according to the ability and context of people were described, however, as being more the personal decisions of the staff rather than an embedded system ideology. Manageable options also include offering in-person support for those who require more introduction, instructions or assistance when accessing, understanding, appraising and using information.

Discussion

The findings of this study among community-dwelling older adults revealed four separate, but interconnected, qualitative categories. The category "Expectations for responsibility" describes the experience that the person, the individual, should be responsible for taking care of their health, including accessing, understanding, appraising and using information and services. However, difficulties in doing so are revealed in the category "A gap between expectancy and ability/context" and include experiences, while taking the responsibility of expectations to do so are not in line with skills/situations. The consequences are information gaps that arise. The category "Finding one's own ways" comprises various adapted ways to access, understand, appraise and use information and services. Although accepting the expectations that the individual should be responsible for taking care of their health, the category "Bridging the gap" describes experiences of needing responsibility to be shared and more manageable options to optimise reasoned health-related decisions and navigation in the healthcare system.

The category "Expectations for responsibility" is the base for the categories "A gap between expectancy and ability/context" and "Finding one´s own ways". It describes the responsibility that participants experience in accessing, understanding, appraising and using health-related information and services as part of being their own health managers. This view is fuelled by and intertwined with personal expectations and messages from the environment that seem to be a part of social norms. This experience echoes, in a way, neoliberal ideology, with its economic and political focus on individualism and autonomy. It includes the idea that people should have the right and responsibility to make their own choices, which inevitably shapes healthcare delivery systems [26, 27]. Reflecting this upon Iceland, although generally considered a part of the Nordic welfare states, the rise and promotion of neoliberalism in the country has shaped the economy and politics of health and welfare since the late 1970s [28].

Although the findings from this study indicated that the participants accept the expectation of being responsible for their health and value being their own health managers, they also revealed that this expectation was often not in line with their skills/situations. The result was the emergence of information gaps limiting their options to be responsible and make informed health decisions. The "A gap between expectancy and ability/context" category describes three interlinked subcategories: digitalisation, personal contact and navigation gaps. Numerous studies have reported challenges among older adults to participate in or benefit from the growing digitalisation, known as the "digital divide" or "grey digital divide" [29, 30]. Research findings from Iceland also highlight this information gap. Palsdottir [31] has reported an increased frequency of online health information seeking among people 68 years and older from 2002 to 2012. However, the usefulness of that information, including websites by the health care system or health specialists, did not increase. A study on perceived barriers to health information among people 60 years and older also reveals hindrances in the availability of information and the ability to seek and find it [32]. This divide is considered to marginalise older adults, among other groups, who are most likely to become excluded from the benefits of digital technologies [30]One solution to the digital transformation that healthcare is undergoing [29], and in line with the expectation of individual responsibility, would be to modify HL by interventions aimed at strengthening the digital skills or competencies of individuals through education. However, Bittlingmayer and Sahrai [33] drew attention to what might happen if increased education is challenging to manage – for example, in the case of disability. Although older adults are a heterogeneous group, this perspective could be reflected, for instance, in the normal ageing process. Lifelong learning [5] should always be an option; however, how health services meet the complex needs of people as their own health managers needs to be addressed. Another angle regarding these experienced information gaps is that limited HL has generally been related to lower levels of education [4, 6, 16]. In this study, however, the community-dwelling participants' education level is relatively high, with most having a secondary or a university degree. Perhaps this echoes the dynamic and complex interaction between various personal and environmental contextual factors acting and interacting as barriers or facilitators of HL.

Because of the gaps experienced in health-related information, the participants need to adapt and find other ways to manage. They do this by, for example, relying on people close to them like spouses, children, grandchildren and friends, as described in the category "Finding one's own ways". Concerning this adaptation, the resilience and resourcefulness of the participants seem to play an important role; it also identifies the importance of social connections or networks. Making reasoned health-related decisions and navigating the healthcare system can, therefore, build on if you have someone in your life willing and able to help. Findings from this research indicated that, in some cases, this support is provided by healthcare staff, even when not on the job. ers. The importance of relatives as an adapted or alternative strategy while dealing with health information was one of four main themes in a study among socioeconomically disadvantaged adults in Switzerland [13]. This supports the importance of social connection and support for those experiencing health-related information gaps. Although matters of caregiving and the share of informal/unpaid carers, often female family members or friends [34], are beyond the scope of this research and will not be addressed further, the effects of individualism and healthcare delivery systems' expectations of responsibility cannot be underestimated. The local senior NGOs in Iceland also seem to play an important role in providing relevant health-related information, for example about rights and available services. However, to participate in gatherings these organisations provide or to receive most of the information, people must become members and pay an annual fee [35].

In the category "Bridging the gap", the participants ask for two things to make the passing of the experienced information gaps easier, presented in the subcategories "Shared responsibility" and "Manageable options". Although the findings from this study indicated that the participants accept the expectation of responsibility for their own health, they also revealed a contradiction. Namely, without knowing what information and services exist and are current, this expectation can sometimes be hard to live up to, or even be impossible. Shared responsibility in providing older adults with more fundamental health-related information seems a vital preliminary step for them to access, understand, appraise and use information. Access to healthcare is generally considered a multifaceted concept consisting of the interaction between the accessibility of services and the abilities of people [36]. One of the five identified dimensions of accessibility is the approachability of services. This dimension includes making services known and reachable to individuals, along with the necessary individual skills to identify the need for these services [36]. Yet again, the complexity of HL is brought to light, and the question is raised where this line between individual versus service responsibility is drawn and, more importantly, who decides. Organisational health literacy (OHL) is an evolving concept [11], especially in the wake of COVID-19, which has transformed the healthcare service [37]. It is described as an effort to transform health-related services to make it easier for people to navigate, understand and use information and services to look after their own health and address the implementation of policies, practices and systems. This concept underpins the idea that HL does not merely depend on the abilities of individuals [11, 38]. Neoliberal policies, with their emphasis on economic value, have often been criticised for negatively impacting access to healthcare by not addressing the structural disadvantages experienced by certain population groups [39]. Furthermore, these policies are considered to contribute to the negative viewing of individuals who are not in the workforce, perceiving them as potentially financially burdensome [39].

Also, older adults may experience decreased functioning over time due to the natural ageing process. This decline can affect their ability and capacity to access, understand, appraise and use health-related information. Focusing on individual responsibility can lead to compromised access to and use of information and services. Therefore, the effect of these policies on fuelling ageism in viewing older adults as a burden must be considered. Ageism has been estimated to cost societies vast amounts [40], and in the United Nations action plan Decade of Healthy Ageing 2021–2030 [5], one of the identified areas for action is connected to changing negative views and actions towards age and ageing.

The findings from this study indicated that the participants not only require shared responsibility in the form of being provided with fundamental health-related information in the category of "Bridging the gap". The subcategory "Manageable options" reflects the request for information that is approachable, acceptable, appropriate, and available. For example, this study indicates that older adults have a generally positive view of digital development as a part of the future. This finding is also reflected in a study on technology use for health information based on a randomized sample of older Icelanders [41]. However, it seems to be an issue of design, delivery, instructions and support, bringing us to service user participation and inclusion. One of the identified areas for action in the United Nations action plan, Decade of Healthy Ageing 2021–2030 [5], aims at enabling older people to continue to do the things that they value and support the inclusion of their voices not only as service beneficiaries but also as agents of change. The focus is on the abilities of older people and person-centred integrated care and primary health services. Brach et al. [42] introduced the 10 attributes of a health-literate healthcare organisation (HLHCO). The attributes are based on the OHL concept [11] to deliver person-centred healthcare and tackle system-level factors enabling people to access, understand, appraise and use health-related information. One of the 10 attributes emphasises the importance of including the voices of consumers in the design process, implementation and evaluation of health information and services [42]. This specific attribute, engagement and support of service users, has been recognized as one of the most prevalent topics of OHL [38].

Furthermore, in a framework for strengthening the health system's capacity regarding HL, one of the eight suggested action areas focuses on people-centred services based on user engagement and enabling environments [43]. In this study, the participants indicated that they value being their own health managers and take full responsibility for accessing, understanding, appraising and using health-related information, as expected, as part of social norms. However, the lack of options to fulfil this expectation implies that healthcare delivery systems do not always meet the needs of older adults to act on it.

Strengths and limitations

This qualitative exploratory study aimed to gather information about the experiences and needs of older community-dwelling adults concerning accessing, understanding, appraising and using health-related information. One of the strengths of this study is that it gives older adults living at home a platform to be heard. By selecting potential participants purposefully with different backgrounds regarding the place of living, age, gender, education, means of transport and distance from services, variations in experiences were sought. The generalisability of the results was affected by participants being restricted to living in Northern Iceland and including individuals with similar cultural backgrounds. It should, however, be kept in mind that close similarities may exist between Iceland and other northern geographical areas of the world where the culture is labelled Western.

The possible effects of having a spouse present during three of the 20 interviews must be mentioned. Their presence was considered culturally relevant in rural areas in the sense of greeting visitors at home. The spouses also acted as a support and facilitated communication, such as for one participant with early-stage Alzheimer's disease. Memory loss is most often a reason for exclusion from research. However, gender roles and the power balance between couples must be considered, which might have affected the conversations. One interview took place via Zoom. While this may not align with our main findings, older adults' technological skills vary. In times of often hard confinement and isolation of older people during the COVID-19 pandemic, by preparing the interview setting well, the wishes of this participant to meet on Zoom could be met.

Clear categories emerged based on evident patterns, consisting of direct content, minimal interpretation and remaining close to the original text. In content analysis, the researcher must know the context. Having four interdisciplinary researchers with stated expertise partaking in the data analysis process contributed to the credibility of this research. Although two researchers conducted the primary analysis, regular meetings with all authors at every step of the process were used for reflection on possible preconceptions and consistency between empirical data and the emerging categories and their content. Including a senior citizen with lived experience on the research team further enhanced the credibility of this research. However, the involvement of an older adult in the earlier stages of the research is an aspect for consideration in future studies.

Working on data in Icelandic and English can be both a strength and a limitation. A strength regarding reasonability and accuracy as a thorough evaluation of the meaning and use of words during the translation process took place. A limitation in the sense of possibly misrepresenting the participants' expression in the translation process from Icelandic to English, although three of four researchers are fluent in both languages, should minimise that risk.

Conclusions

The participants in this study experienced expectations of being responsible for accessing, understanding, appraising and using health-related information as part of acting as their own health managers. Although valuing and accepting these expectations, limitations regarding living up to them were revealed because such expectations were often not in line with their skills/situations, despite having a relatively high education level. Information gaps, therefore, arise due to digitalisation, limited personal contact and general navigation complexity within and between health-related services. Therefore, approachable fundamental health-related information, current and quality checked, and inclusive service opportunities are needed to bridge the resulting gaps. It is necessary to critically address the possible influences of politics regarding the views on individual responsibility at a systematic level in matters of health and HL. Such action should analyse if and how those principles shape attitudes, social norms and health services and confront structural disadvantages experienced by population groups. Access to information and services must be viewed beyond availability and include the approachability, acceptability and appropriateness of service users with various abilities and contexts. The findings from this study reflect participants' experiences of bearing most of the responsibility as their own health managers, while simultaneously having limited choices in acting on it. Policymakers are therefore encouraged to develop services that enable older adults to make reasoned decisions about health and navigate healthcare services in an effective way.

Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
COVID-19	Coronavirus disease 2019
HL	Health literacy
HLHCO	Health literate health care organisation
HLS-EU-Q	European Health Literacy Survey Questionnaire
NGOs	Non-governmental organisations
OHL	Organisational health literacy

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Authors' contributions

SSG collected, analysed and interpreted the data, drafted the manuscript and was the grant holder. LM contributed to analysing and interpreting the data and drafting and revising the manuscript. SAA and AKS contributed to the data interpretation and revising the manuscript. AKS was also a grant holder. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

According to the Icelandic National Bioethics Committee, no further approval from the previous study (VSNb2016060007/03.01) was needed for this continued research (VSN-21–009). Information about the names and social numbers of participants and research numbers from the previous study were kept separate and accessible only to the researchers through special permission from the file holder, University of Akureyri Research Centre. Written informed consent was obtained from all participants. Participants chose pseudonyms at the beginning of each interview, which were used to ensure confidentiality and privacy, and recorded interviews were deleted after transcriptions. This study is not a registered clinical trial.

Consent for publication

Consent for publication was not applicable.

Competing interests

The authors declare no competing interests.

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Publisher's Note

Appendix A

Information about participants and the individual interviews

Pseudonym	Birthyear (age)	Gender	Place of interview	Interview duration
Sigrun	1944 (78)	Woman	UNAK	50 min
Nina	1942 (80)	Woman	Home	55 min.
Hanna	1942 (80)	Woman	Zoom	41 min
Bara	1928 (94)	Woman	Home	42 min
Sverrir	1945 (77)	Man	UNAK	38 min
Sunna	1949 (73)	Woman	Home	53 min
Dora	1926 (96)	Woman	Home	39 min
Petur	1948 (74)	Man	UNAK	48 min
Magnus (and Sigurbjorg)	1951 (71)	Man	Home	30 min
Gunnar	1951 (71)	Man	UNAK	30 min
Fannar	1950 (72)	Man	Home	60 min
Gulla	1936 (86)	Woman	Home	57 min
Lisa	1950 (72)	Woman	UNAK	34 min
Finnur	1952 (70)	Man	Home	51 min
Kara	1952 (70)	Woman	Home	42 min
Runa	1944 (78)	Woman	Home	43 min
Katrin	1952 (70)	Woman	Home	65 min
Thorunn	1946 (76)	Woman	Home	50 min
Thorolfur	1952 (71)	Man	UNAK	47 min
Sigurpall	1936 (87)	Man	Home	46 min
UNAK = University of Akureyri				

Appendix B

The English and the Icelandic version of the interview frame

Opening of interview

How long have you lived here, what have you worked on the longest and what pseudonyms do you want to choose?

Tell me about your experience as a senior citizen with access to health-related information.

Access/find/get information that concerns your health both when you are ill and also to maintain or improve your overall health. Can you give me an example where you had to get information about something health-related? Examples of health-related information received? Examples of when you did not get the needed information?

How does access to health-related information need to be in order for it to suit your needs?

For you to get the information you need.

Tell me about your experience of how clear/easy to understand the information you have found or been given.

In what form were they provided? Can you give me an example where you found it easy/difficult to understand the information given to you? What is difficult/easy to understand?

How does health-related information need to be presented/provided to suit your needs?

How, when.

Tell me, what is your experience with how useful the information is?

How useful or relevant to your life and circumstances? How to use/use this information. Examples where you could / could not use information or services?

How do you need information to be able to use it?

End of interview

Is there something you want to add on the matter of health-related information and service?

Upphaf viðtals
Hversu lengi þú hefur búið hérna, við hvað þú hefur lengst af starfað og hvaða dulnefni vilt þú velja þér.

Segðu mér frá því hver reynsla þín, sem eldri borgari, er af aðgengi að heilsutengdum upplýsingum.
Nálgast/finna/fá upplýsingar sem varða heilsuna þína bæði þegar þú ert lasin en líka til að viðhalda eða bæta almennt heilsuna. Getur þú gefið mér dæmi þar sem þú þurftir að afla þér upplýsinga um eitthvað heilsutengt? Dæmi um upplýsingar sem þú fékkst? Dæmi þar sem þú fékkst ekki upplýsingar sem þig vantaði?

Hvernig þarf aðgengi að heilsutengdum upplýsingum að vera til að það henti þínum þörfum best?
Til að þú fáir þær upplýsingar sem þú þarfnast.

Segðu mér frá reynslu þinni af hversu skýrar/auðskiljanlegar upplýsingarnar eru sem þú hefur fundið eða þér verið veittar.
Á hvaða formi voru þær veittar? Getur þú gefið mér dæmi um þar sem þú áttir auðvelt/erfitt með að skilja upplýsingar sem þér voru veittar? Hvað er sem torfveldur/auðveldar skilning?

Hvernig þurfa heilsutengdar upplýsingar að vera framsettar/veittar til að þær henti þínum þörfum?
Hvernig, hvenær.

Segðu mér hver reynsla þín er af því hversu gagnlegar upplýsingarnar eru?
Hversu nothæfar eða viðeigandi við líf og aðstæður þínar? Hvernig gengur að nýta/nota þessar upplýsingar. Dæmi þar sem þú gast/ekki nýtt þér upplýsingar eða þjónustu?

Hvernig þurfa upplýsingar að vera svo þú getir nýtt þær?

Lok viðtals
Eitthvað sem þú vilt bæta við í tengslum við heilsutengdar upplýsingar og þjónustu?

Appendix C

Changes in the wording of the HLS-EU-Q16-IS during its Icelandic translation and adaptation process

	HLS-EU-Q16 original English version	After translation and specialist review integration	After the first round of interviews and integration	The final version after the second round of interviews and integration
1 AC	find information on **treatments** of illnesses that concern you?	finna upplýsingar um **meðferð** veikinda sem varða þig?	að finna upplýsingar um **meðferð** veikinda sem varða þig?	að finna upplýsingar um **meðhöndlun** veikinda sem varða þig?
2 AC	find out where to get professional help when you are ill?	finna hvar þú getur fengið faglega aðstoð þegar að þú ert veik(ur)?	að finna hvar þú getur fengið faglega aðstoð þegar þú ert veik(ur)?	að finna hvar þú getur fengið faglega aðstoð þegar þú ert veik(ur)?
3 US	understand what your doctor says to you?	skilja hvað læknirinn þinn segir við þig?	að skilja hvað læknirinn þinn segir við þig?	að skilja hvað læknirinn þinn segir við þig?
4 US	understand your doctor´s or pharmacist´s instruction on how to take a prescibed medicine?	skilja leiðbeiningar læknis þíns eða lyfjafræðings um hvernig á að taka ávísuð lyf?	að skilja leiðbeiningar læknis þíns eða lyfjafræðings um hvernig á að taka ávísuð lyf?	að skilja leiðbeiningar læknis þíns eða lyfjafræðings um hvernig á að taka ávísuð lyf?
5 AP	judge when you may need to get a second opinion from another doctor?	meta hvenær þú **getur** þurft að fá álit frá öðrum lækni?	að meta hvenær þú **gætir** þurft að fá álit frá öðrum lækni?	að meta hvenær þú **gætir** þurft að fá álit frá öðrum lækni?
6 U	use information the doctor gives you to make decisions about your illness?	nota upplýsingar frá lækni til að taka ákvarðanir um veikindi þín?	að nota upplýsingar frá lækni til að taka ákvarðanir um veikindi þín? **(t.d. meðferð)**	að nota upplýsingar frá lækni til að taka ákvarðanir um veikindi þín **(t.d. meðferð)?**
7 U	follow instructions from your doctor or **pharmacist**?	fylgja leiðbeiningum frá lækni þínum eða **lyfjafræðingi**?	að fylgja leiðbeiningum frá lækni þínum eða **lyfjafræðingi**?	að fylgja leiðbeiningum frá lækni þínum?
8 AC	find information on how to manage **mental health problems** like stress or depression?	finna upplýsingar um hvernig er hægt að takast á við **geðræn vandamál** eins og streitu eða þunglyndi?	að finna upplýsingar um hvernig hægt er að takast á við **andlega vanlíðan** eins og streitu eða þunglyndi?	að finna upplýsingar um hvernig hægt er að takast á við **andlega vanlíðan** eins og streitu eða þunglyndi?

9 US	understand health warnings about **behaviour** such as smoking, low physical activity and drinking too much?	skilja viðvaranir um **hegðun** sem hefur slæm áhrif á heilsuna svo sem að reykja, hreyfa sig lítið og drekka of mikið?	að skilja viðvaranir um **lífsstíl** sem hefur slæm áhrif á heilsuna? **(svo sem að reykja, hreyfa sig lítið og drekka of mikið)**	að skilja viðvaranir um **lífsstíl** sem hefur slæm áhrif á heilsuna **(svo sem að reykja, hreyfa sig lítið og drekka of mikið)?**
10 US	understand why you need health **screenings**?	skilja hvers vegna þú þarfnast **eftirlits (skimunar)** með heilsufari þínu?	að skilja hvers vegna þú þarfnast **reglulegs eftirlits** með heilsufari þínu?	að skilja hvers vegna þú þarft **reglulegt eftirlit** með heilsufari þínu?
11 AP	judge if the information on health risks in the media is reliable?	meta hvort upplýsingar úr fjölmiðlum um það sem er hættulegt heilsunni séu áreiðanlegar?	að meta áreiðanleika upplýsinga úr fjölmiðlum um það sem er hættulegt heilsunni?	að meta áreiðanleika upplýsinga úr fjölmiðlum um það sem er hættulegt heilsunni?
12 U	**decide** how you can **protect yourself** from illness based on information in the media?	**ákveða** hvernig þú getur **komið í veg** fyrir veikindi byggt á upplýsingum úr fjölmiðlum?	að **nota** upplýsingar úr fjölmiðlum til að **fyrirbyggja** veikindi?	að **nota** upplýsingar úr fjölmiðlum til að **fyrirbyggja** veikindi?
13 AC	find out about activities that are good for your mental well-being?	finna út hvaða athafnir eru góðar fyrir geðheilsu þína?	að finna út hvaða athafnir eru góðar fyrir geðheilsu þína?	að finna út hvaða athafnir eru góðar fyrir geðheilsu þína?
14 US	understand advice on **health** from family members or friends?	skilja ráðleggingar um **heilsu** frá fjölskyldumeðlimum eða vinum?	að skilja ráðleggingar um **heilsu** frá fjölskyldumeðlimum eða vinum?	að skilja ráðleggingar varðandi **heilsufar** frá fjölskyldumeðlimum eða vinum?
15 US	understand information in the media on how to get healthier?	skilja upplýsingar úr fjölmiðlum um hvernig hægt er að bæta heilsuna?	að skilja upplýsingar úr fjölmiðlum um hvernig hægt er að bæta heilsuna?	að skilja upplýsingar úr fjölmiðlum um hvernig hægt er að bæta heilsuna?
16 AP	judge which **everyday behaviour** is related to your health?	meta hvað í þinni **daglegri hegðun** tengist heilsunni?	að meta hvað í þínum **daglega lífsstíl** tengist heilsunni?	að meta hvernig **lífsstíl** þinn tengist heilsunni **(t.d. hreyfing, mataræði og áfengisneysla)?**

Competences: AC= Access; US= understand; AP=appraise; U=use
Domains: Health Care; Health Prevention; Health Promotion
BOLD: changes in wording