# Seniors in eHealth: Challenges for Knowledge Acquisition During Information Retrieval

## Ilona Heldal, Ingebjørg Børsheim, Eva Haukeland Fredriksen and Tobba Therkildsen Sudmann

Western Norway University of Applied Sciences, Norway

ilona.heldal@hvl.no ingebjorg.treland.borsheim @hvl.no eva.haukeland.fredriksen@hvl.no tobba.sudmann@hvl.no DOI: 10.34190/EKM.20.177

Abstract: With more information on the Internet, all citizens who need digital information to manage their everyday life must be able to access it and trust it. They should have enough knowledge to use information and communication technologies (ICTs) and online health information (OHI) in an intended and purposeful way. This paper investigates e-Health literacy (eHL) amongst seniors aged 65-90. It presents a case study on how they use ICT and access, appraise, and apply OHI in comparison to the way they use face-to-face health-encounters. Data comes from 17 open-ended interviews. These are examined based on eHL concepts describing eHealth literacy as an interplay between individual and social. The results show how participants are engaging in self- and co-management of their own or others' health-related issues and illustrate the help that they get or give to understand OHI. By examining how they use ICT and do (not) trust OHI regarding "serious cases," this paper provides critical insight into ways seniors acquire information and how they appraise, understand or trust in it. Their information-seeking activities are performed mainly in private settings, seldom with professionals. They have lower levels of trust in their own, individual appraisal skills, compared to collective searches and appraisal skills. Norwegian seniors are cool and pragmatic, and emphatic on the "when needs must, see your GP!". By examining differences in ICT use, knowledge acquisition and support given or received, the results pinpoint how providers must affirm seniors' ICT use and individual and collective online health behaviour as assets for healthy ageing. A potential barrier for citizens' use of OHI and health technology is the built-in understanding of health as an individual capacity and ICT use as an individual activity, compared to a contemporary understanding of health and the Internet as social practices and collective resources. Designers of health technologies and OHI should critically consider built-in understandings of content and users to enhance accessibility and value for citizens of all ages.

Keywords: e-health, health literacy, health information, trust, knowledge acquisition, user characteristics

## 1. Introduction

This section introduces the background and aim of our study and offers a discussion of the contested e-health literacy concept and research field.

#### 1.1 E-Health literacy

In an ageing world, healthy ageing and longevity are related to how individuals and groups use available health related resources to make healthy decisions, to adapt, and co-manage or self-manage in the face of social, physical, and emotional challenges (Huber et al. 2011). All citizens should have the opportunity to make healthy choices and be knowledgeable about their own body, nutrition, physical activity, symptoms or diseases, and to know how health care services are organized and accessed (Levesque, Harris, and Russell 2013). However, todays seniors' knowledge about health or health care systems are a composite of what they learned through their lifetime, which may be outdated or no longer valid due to re-organisation of the healthcare systems. Acquisition and appreciation of current and valid health-related skills and knowledge presupposes lifelong learning and particular skills and competencies. Contemporary health resources are digitised, and seniors are expected to master health related technology, i.e. be e-health literate.

Knowledge acquisition in a digitised society is related to digital proficiency in online health information activities, access to digital technologies and the Internet, bodily capacities (e.g. cognition, hearing, sight, dexterity), and knowledge and functioning (understanding, analysing, decision-making). This paper builds on a study of how a selected group of Norwegian seniors between 65-90 years use ICT to access, appraise and apply online health information (OHI), and how they evaluate this information compared to face-to-face health-encounters.

The combination of longevity and digitisation of health services has raised concerns about evolving digital divides (WHO 2017, Friemel 2016, Hall et al. 2015, Rhoades et al. 2017) and digital exclusion in later life (Matthews, Nazroo, and Marshall 2019, Tennant et al. 2015, Kickbusch 2001, Silver 2015). Responding to this concern can be challenging: "Despite the significance of this phenomenon, the information systems (IS) literature lacks a comprehensive consideration and explanation of technology acceptance in general and, more specifically, Internet adoption by the elderly." (Niehaves and Plattfaut 2014). There are many influencing factors based on societal, individual, or technology differences. This divide may manifest differently in different countries (Nishijima, Ivanauskas, and Sarti 2017) based on individual characteristics (Van Deursen and Helsper 2015) or, for example, the national features of the used OHI system (Wang et al. 2008). Since OHI is beginning to be not only a right but also an opportunity to contact the healthcare services, exploring attitudes towards it is necessary both, in the end, for democracy, but also to achieve accessible healthcare for all. Citizens in western countries, as patients, are expected to use ICT and to find and engage with online health services, e.g. booking appointments, ordering prescriptions, or sharing electronic health records (EHRs). Hemsley et al. (2018) argue that electronic personal health records (e-PHR) exert new demands on patients and health care service providers e.g. cognitive capabilities, education, ICT literacy, and willingness to share health information. They warn that high literacy demands on e-PHR is a potential threat to health outcomes.

Contemporary framing of e-health literacy (eHL) departs from Nutbeam's (2008) seminal research, which showed a connection between literacy skills and health status, i.e. health outcomes. His Lily model, with 6 petals refer to different literacies: traditional (reading, writing, calculating), computer, media, science, information, and health and health services. The Lily model has been criticised for ignoring socio-economic factors, context and individual and group-based differences. Several scholars have attempted to amend or create a new model of eHL, making a plethora of definitions available (Gilstad 2014, Bautista 2015, Norgaard et al. 2015, Griebel et al. 2018).

Gilstad (2014) offers an amendment to Nutbeam's Lily model, and a new definition of eHL: *eHealth literacy is* the ability to identify and define a health problem, to communicate, seek, understand, appraise and apply *eHealth information and welfare technologies in the cultural, social and situational frame and to use the* knowledge critically in order to solve the health problem. (Gilstad 2014).

Norgaard et al. (Norgaard et al. 2015) proposes an eHL-framework, which focuses on individual's and population's capacity to understand, use and benefit from technology to promote and maintain their own health. The interaction between an individual's ability to process information and engage in their own, personal health and system requirements (accessible and suitable systems) gives the individual a sense of safety and control, and motivation to engage in digital services. Their framework is composed of seven domains:

"1. Ability to process information, 2. Engagement in own health, 3. Ability to engage actively with digital services, 4. Feeling safe and in control, 5. Motivation to engage with digital services, 6. Having access to systems that work, and 7. Digital services that suit individual needs." (Norgaard et al. 2015).

Bautista (2015) suggests that quality of life is added to an updated definition of eHL: "*eHealth literacy involves* the interplay of individual and social factors in the use of digital technologies to search, acquire, comprehend, appraise, communicate and apply health information in all contexts of healthcare with the goal of maintaining or improving the quality of life throughout the lifespan." (Bautista 2015).

Griebel et al.'s (2018) viewpoint paper is an interesting contribution to any discussion of eHL. It calls for updated definitions of eHL, for standardised measurements tools, for justification of new research by critical appraisal of state of the art, for an approach to eHL that is relevant throughout lifespan, for considering eHL in relation to technology design, constraints or acceptance, and providing guidelines for developers (Griebel et al. 2018).

Two recent contributions to the body of knowledge on eHL can be added to illustrate the increasing interest in eHL and online health information (OHI). The title of Diviani et al.'s (2019) study of how adults (aged 18-65) relate to OHI is telling: "Where else should I look for it?" OHI is always available for individual or group-based searches and discussions. Magsamen-Conrad et al. (2019) are finding support with the same argument – technological and health literacy is a collective practice with tech-savvy doers, watchers, teachers, and learners. This collective practice enables people to access, analyse, and share OHI. As has been shown above, health literacy is an essential social determinant of health and should not be reduced to an individual risk factor. Interestingly, Papen (2009) suggested more than a decade ago that literacy can be understood as a social

practice, as is the Internet. This illustrates a point made by Griebel et al (2018) in their conclusion, that existing knowledge often was ignored.

Following on from the introduction and discussion of e-health literacy above, the section on methodology is presented below. Results follow and are divided in three strands; i) older adults' navigation through the Internet, ii) individual needs regarding OHI, and iii) eHealth literacy as social practice. The discussion unpacks drivers and barriers for seniors' ICT and OHI usage. The concluding section makes explicit proposals on how ICT and OHI can be assets for healthy ageing.

## 2. Methodology and participants

This study sits in a qualitative sociological tradition (Silverman 2015). Data was produced through open-ended interviews with 17 participants aged 65-90 years. Eligible participants were home-dwelling adults above 65 years, able to read, hear, and communicate in Norwegian without specialized equipment or interpreter, recruited through senior communities and snowball sampling. The study included Caucasian middle-class Norwegian citizens from 2 rural and 2 urban municipalities in Southern Norway. They were: 9 men and 8 women, 4 from each group had received primary or high school education, while 5 men and 4 women had received graduate education. The paper focuses on healthy seniors' online behaviour and does not differentiate between the categories of early and late elderhood (Aronson 2019, Inker, Gendron, and Brooks 2019)

Participants received printed and e-mailed information, gave written consent to participate and receive text messages, e-mails, or phone-calls before interviews. They used ICT (information and communication technology) 1-3 hours a day, on up to 7 gadgets (e.g. phone, watch, tablet, laptop computers, stationary PC, smart TV, gaming console) used for different purposes.

The interview venue was optional (private homes, offices, activity centres). The interview guide included prompts for OHI (athlete's foot and a swollen finger) to lessen the risks of ethical violations of privacy/personal searches. Some interviewees suggested practical demonstrations; others were solicited to demonstrate their online behaviour on their iPad or computer. The authors conducted the interviews in 2017. The interviews lasted 45-90 minutes, and were summarized immediately, and professionally transcribed.

This paper focuses on the key features of eHL relevant to healthy ageing as presented above: a) individual and socioeconomic factors, b) the different technologies, c) actions taken, d) healthcare context, e) quality of life, and e) lifespan. These features served as an analytical lens for exploring seniors' use of technologies. Therefore, we regrouped and examined a) actions for navigating on the Internet, b) thoughts about using OHI, and c) reflections on eHL as social practices. A key challenge for researchers and designers of health technology or online health information, is to understand barriers and drivers for using these resources. The discussion section relates these challenges to definitions of health, and to everyday life as social interaction and participation.

## 3. Results

As summarised above, eHL encompasses actions as accessing, appraising, and applying OHI, using health technologies and digitized services, and implicit and explicit demands on skills, competencies, and sociomateriality (e.g. access to ICT). This section shows how seniors negotiate these demands.

## 3.1 Navigating the Internet

The participants presented themselves from ignorant to tech-savvy, depending on the subject matter and the social situation. All participants used computers when they were gainfully employed, e.g. Word Perfect and Excel. All were confident with e-mail, and online services, e.g. on-line banking, news, booking at travel agencies, and using social media. All of them owned more than one ICT platform. Even though they were confident in the everyday use of ICT, navigating the Internet for health purposes was a new challenge for them. Later, this will beg questions about how older adults can convert their everyday ICT knowledge to online health behavior and [appreciation of OHI. Keeping up to speed with technology development is harder in retirement as these quotes illustrate:

"I was among the five first teachers at our school to graduate in computing, almost 40 years ago. It doesn't help me much today because we learned to program (woman, 80)."

"I used to be a leader and computer teacher and taught others how to punch on those old-fashioned computers. Now I'm a computer student because the development in (ICT) is fabulous. I can't keep up, you know (man, 66)."

They were smiling while talking, acknowledging the speed of technological development and their shift from being tech-savvy to lagging behind. Their basic knowledge about ICT made it easy to ask more skilful (often younger) peers, friends, or family for help. All participants expected that their younger family members were able to keep up with technological development better.

"Sometimes I'm able to find it myself, and if not, I ask my daughters or my wife to help me (man, 74)."

They considered e-Literacy to be precarious and to require nurturing e.g. through course work:

"I've been to a course, run by SeniorNet, which was very useful. I've actually been an assistant teacher there as well. SeniorNet has a help-line, and they walk you through everything (woman, 84)."

Where available, the participants showed interest in making themselves familiar with electronic health records (EHR). All knew that the Internet abounded in health information but were not confident in how to find and see the differences between diamonds and rhinestones. Few, if any, had any knowledge about how search engines rank search results, and none (save for one) had noticed that the presentation of search hits (e.g. titles, URLs, colors) could be used to evaluate trustworthiness or quality of content. All, except for one guided by an instructor from SeniorNet, took the ranking as a kind of quality assurance (the best at the top) and were annoyed when some of the links were ads.

## 3.2 From individual needs to OHI

All participants launched OHI-searches by entering one or two Norwegian concepts, using the default browser on their preferred device. Searching was motivated by their own concerns or wishes to help others, or they were purely curiosities (e.g. regarding celebrities' illnesses):

"I search for OHI to help others and to get information (man, 74)".

They also searched to get repeat or confirmatory knowledge:

"After I've seen my GP, I go home and search for OHI to assure myself that I understood the information (woman, 76)."

When a medical diagnosis could identify a complaint, this concept was usually used as a search term:

"When I searched for OHI about my daughter's diagnosis, I just wrote the diagnosis in the search field. I read whatever turns up (man, 74)."

Others did not use the diagnosis as a search term:

"When I search, I describe it, write [about] the symptoms, and then I always get an answer (woman, 88)."

Searching was motivated by finding information that imparted trustworthiness, coherence, and fidelity (Dahlstrom 2014, Li et al. 2018). They 'favorited' Norwegian hits and pages without ads. Webdesign and owner of domene (health services compared to social media) or author, i.e. from whom the content came, were also critically appraised. If the page was "nice" and readable, and the information was recognizable, they were more likely to trust it:

"I've no idea about how I choose or sort information, maybe I've seen it before, or heard of it? (man, 70)."

Only a few seniors did strategic searches and cross-checked until their queries were settled:

"I google and get an extensive list, which I scroll. You do not open all of them, but look for keywords, and then click the ones that look OK. It must be a serious and really [credible] answer to my queries. The best is when it rings a bell about some previous information so that I can judge the content (woman, 69)."

## **3.3** eHealth literacy as social practice

Online health information seeking emerged as a site and case for social participation and interaction (Papen 2009, Dennis 2003), which was appreciated, mainly as an opportunity to ponder health concerns :

"Well, sometimes I help others, my peers are my age, and we discuss how we do OHI, and share how and where we find what we need. I see one of my colleagues quite often, we talk about everything, and at our age, ailments and diseases flourish. We share our concerns and our OHI findings, and we share information (man, 66)."

Online health behaviour and discussions in social media, or with a physically present person, offer an opportunity to consider whether the reason for searching for OHI should be followed by a GP-visit, or settled by oneself:

"I know that OHI may contain wrong and misinformation, so if I'm really worried, I always ask those who are knowledgeable. I can ask our daughter, a nurse, to check my medication. Or I go to my GP; our relationship is very good, he would gladly discuss OHI with me. I don't trust OHI 100%, and if I believe something is really serious, I would always see my GP (man, 66)."

Participants reported that different user-interfaces (phone, tablet, laptop computer, desktop computer, health watch, or TV) demanded different skills and presented different challenges. Age takes its toll, and crooked fingers, dry skin, poor eyesight, and small icons or buttons were annoying barriers:

"I have my own PC, but don't use it too much, due to poor eyesight. My tablet is new, and much better for my eyes (woman, 66)."

Age or ability-related barriers were overcome by the changing user-interface, or by collective searches. A striking similarity between the old participants in our study compared to the youngest participants in Diviani et al's study (Diviani et al. 2019), is that OHI is often done in social settings, so search strategies and results can be discussed. The striking differences between these age-groups (comparable to grandchildren and grandparents) is the self-efficacy and confidence the young have in their own ability to find, critically analyse and apply OHI, compared to senior's suspicion of OHI content, lack of trust in themselves, and reluctance to apply whatever they find:

*"I'm very sceptical of OHI, there's too much information. And how can a lay-person sort this information in an intelligible way?* (woman, 76)."

"I don't believe this information is doing any good, one gets sicker of it, at the best one is no worse. And not any wiser (man, 70)."

All participants discussed OHI with family and peers and compared hits on "google" with social media. Many of them were laughingly telling about e-mail commercials, alternative medicine, and Facebook ads, adding a solemn comment like "We are not fooled so easily". They displayed or wished to show a cool attitude (Zimmermann and Grebe 2014) towards technology and OHI, often with a twinkle. The coolness displayed by these seniors can be compared to calmness and self-control. It takes more than an appealing design or user-interface to convince them to act upon online health information.

## 4. Discussion

A key challenge for researchers and designers of health technology or online health information, is to understand barriers and drivers for using these resources. Senior citizens receive and give help on ICT use and online behaviour, whether this is between family members, friends or communities of interest (e.g. the Senior Net or

other communities). As shown above they are rich in initiative and determined in their quests for information or in their decision to abstain from trusting OHI. If health is to be understood as collective practice, interaction with general practitioners (GPs), is a vital part of any health resource. This section shows that seniors are quite strategic in their self-presentation and interaction with their GPs (Goffman 1959, 1969). Seniors are considerate to make sure they are welcomed and treated as credible patients (Werner and Malterud 2003).

#### 4.1 Drivers and barriers for using OHI

Participants were ambivalent towards sharing their online experiences with their GP and health care personnel, as it might affect the outcome of the consultation negatively. The justification for this standpoint was related to the perceived poor quality of OHI:

"I wouldn't dream of telling my GP about my OHI-searches. I'd rather hear the GP's opinion first, and if I'm unsatisfied or disagree, then I might consult OHI and try to sort it out afterward. There is so little time to talk, and I want us to stay focused. That's it! No room for discussing the Internet's answers as well (woman, 76)."

Even though few planned to tell their GP about online searches, some expected it would be well received, while others had tried without much of a response:

"I never refer to the Internet, but I think a conversation about it is relevant, and I expect that it would be accepted (man, 74)."

"I don't think the GPs are very happy about us reading on the Internet. When I go there and tell him about what I read on the Internet, he doesn't answer too much (man, 70.)"

A well-known barrier is that one can be led astray – towards more or less depressing results and prognosis of an anticipated disease:

*"I'm born into a cancer family, and I believe that's why I'd rather see my GP and get a clear answer, rather than worrying yourself about possible cancer (woman, 69)."* 

Participants shared with us a variety of health and ICT competencies, interest, knowledge, and skills in OHI, and shared their considerations about when to offer or ask for help, and when to see or not see their GPs. All participants discussed a wide range of health issues with family, friends, or peers, and with the researchers, and were not bothered by lacking skills. This supports an understanding of health and Internet as social practices, for reflection and learning (Diviani et al. 2019, Hemsley et al. 2018, Huber et al. 2011, Magsamen-Conrad et al. 2019, Norgaard et al. 2015, Silver 2015) – at least outside the realm of the health care sector. Citizens' self-presentation, negotiations and considerations in everyday social interaction emerge as issues designers of ICT and OHI should take into account.

#### 5. In conclusion

The aim of this study was to explore how a group of Norwegian seniors accessed, appraised, and applied online health information (OHI) individually and collectively, and how they evaluated this information compared to face-to-face health-encounters. Our participants acknowledged their lack of trust and/or skills in critical appraisal of the validity and relevance of OHI, particularly in relation to potentially serious symptoms or concerns. As shown above, the social settings around internet searches paved the way for discussions with peers and family, which partly compensated for a lack of skills, or affirmed their lack of trust in the findings. The coolness they displayed, i.e. being calm and critical towards the content, also made them prioritise seeing their GP when there were any pressing issues or concerns (Zimmermann and Grebe 2014). Health and Internet are social practices for them (Papen 2009, Hall et al. 2015, Norgaard et al. 2015, Friemel 2016, Matthews, Nazroo, and Marshall 2018, Magsamen-Conrad et al. 2019). This study acknowledges the usefulness of e.g. Wang's suggestion for combining individual and collective access (Wang et al. 2008) to online media in order to achieve higher trustfulness in the retrieved data.

The seniors in this study used digital technologies on an everyday basis to access news media, Internet banks, emails or travel agencies. They shifted roles between guiding peers on the Internet and being supervised by peers or younger next of kin – they literally enacted health as a social practice. Interestingly, none of the definitions of eHL presented in section 1, include theoretical discussion or definitions of health. The WHO (1948) definition of health builds on a medically informed approach to the body, which is quite different from Crawford's (2006) understanding of health as a meaningful social practice and Huber'et al.s' (2011) understanding of health as an amalgam of resources (including the body). This might put new definitions of eHL at risk of being less useful and outdated because they do not capture contemporary framings of health as a bodily and social phenomenon. A a theoretical discussion of health is necessary when we inquire into health-related use of digital technologies and the Internet, to understand why and how citizens approach digital health technology at large. Neither of the definitions of eHL discuss citizens' participation in defining or measuring eHL, or their opinions on the usefulness of OHI in everyday living, quality of life, or in shared decision-making in health-encounters. Lastly, but no less, neither of the framings of eHL acknowledge the complexity of social interaction, ICT use and OHI, and healthy ageing. ]

The amount of OHI is soaring and should be used as a resource for supporting and assuring citizens of all ages to engage in digital services for co-/self-management of one's own or others' health. Shared decision-making implies knowledge management and mutual learning to reach WHO e-health goals and to reduce the burden of social inequalities in health due to low e-health literacy. E-health literacy is a social determinant for health, and healthy ageing presupposes e-health literacy – broadly defined. Knowledge management – from acquisition to use – is a social practice where the relevance of ICT, OHI or knowledge is negotiated in a situated context. Our findings do not provide new knowledge about how socio-economic status or cognitive or physical capabilities affect OHI behaviour. Further studies need to look into this.

Handling eHealth is slowly becoming an integral part of our life, and eHL influences quality of life (Bautista 2015, World Health Organization 2016, 2020). This study illustrated the differences between skills for handling ICT and strategies for interpreting and assessing trustworthiness of OHI for a group of seniors in Norway. However, further research is needed not primarily for improving user experiences, but on how end-users can be engaged as active participants in design of ICT and OHI throughout their lifespan, to enhance the value of ICT and OHI as assets for healthy ageing, quality of life and social participation.

The current advice from this study can be summed up as a cool pragmatic strategy: OHI is relevant for curiosity, for easily self-managed minor concerns, and for peer support. When really worried, however, the seniors in this study preferred to see their GP and did not trust OHI. Their strategy can be supported by including dialogues on OHI in every health encounter to promote digital inclusion in later life, particularly inclusion in digital health. Knowledge management related to health is a social practice, and the contingency of ICT or OHI must be addressed.

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