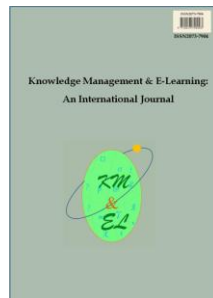

Knowledge Management & E-Learning



ISSN 2073-7904

The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems

Ole Norgaard

University of Copenhagen, Denmark

Dorthe Furstrand

University of Copenhagen, Denmark

Danish Cancer Society, Copenhagen, Denmark

Louise Klokke

Bispebjerg & Frederiksberg Hospital, Denmark

Astrid Karnoe

University of Copenhagen, Denmark

Roy Batterham

Deakin University, Melbourne, Australia

Lars Kayser

University of Copenhagen, Denmark

Richard H. Osborne

Deakin University, Melbourne, Australia

Recommended citation:

Norgaard, O., Furstrand, D., Klokke, L., Karnoe, A., Batterham, R., Kayser, L., & Osborne, R. H. (2015). The e-health literacy framework: A conceptual framework for characterizing e-health users and their interaction with e-health systems. *Knowledge Management & E-Learning*, 7(4), 522–540.

**The e-health literacy framework: A conceptual framework
for characterizing e-health users and their interaction with
e-health systems**

Ole Norgaard

Department of Public Health
University of Copenhagen, Denmark
E-mail: ole@norgaard.dk

Dorthe Furstrand

Department of Public Health
University of Copenhagen, Denmark
Danish Cancer Society, Copenhagen, Denmark
E-mail: dortheff@cancer.dk

Louise Klokke

The Parker Institute, Department of Rheumatology
Bispebjerg & Frederiksberg Hospital, Denmark
E-mail: louise.klokke.madsen@regionh.dk

Astrid Karnoe

Department of Public Health
University of Copenhagen, Denmark
E-mail: askn@sund.ku.dk

Roy Batterham

Faculty of Health
Deakin University, Melbourne, Australia
E-mail: roy.batterham@deakin.edu.au

Lars Kayser*

Department of Public Health
University of Copenhagen, Denmark
E-mail: lk@sund.ku.dk

Richard H. Osborne

Faculty of Health
Deakin University, Melbourne, Australia
E-mail: richard.osborne@deakin.edu.au

*Corresponding author

Abstract: In current e-health research and development there is a need for a broader understanding of the capabilities and resources required for individuals to use and benefit from e-health services, i.e. their e-health literacy. The aim of this study was to develop a new conceptualisation of e-health literacy with consideration of the experiences of a wide range of stakeholders and in alignment with current technologies. Concept mapping was used to generate a comprehensive and grounded model of e-health literacy. Concept mapping workshop participants included patients, health professionals and medical informatics experts. Eight workshops, carried out in Denmark and United Kingdom, generated 450 statements, separated into 128 clusters. Through an inductive structured analysis, seven domains were identified: 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. These empirically derived domains form an e-health literacy framework (eHLF) and provide new insights into the user's ability to understand, access and use e-health technologies. The eHLF offers a framework for evaluating an individual's or a population's capacity to understand, use and benefit from technology to promote and maintain their health. Such a framework also provides a potential checklist for the development and improvement of e-health services.

Keywords: e-Health; Literacy; Framework; Interaction; Technology

Biographical notes: Ole Norgaard holds a Master of Science degree in public health from University of Copenhagen. During his previous enrolment in a PhD fellowship funded by the Danish Council for Strategic Research he investigated the information behaviour of people living with chronic health conditions. The focus of his research has primarily been on health literacy and how people can use digital media to manage their health. He now works on e-mental health projects at the Danish Veteran Centre.

Dorthe Furstrand is an MD and holds a Master of Science degree in health informatics from University of Copenhagen. She is currently enrolled as a PhD fellow at the Danish Cancer society, working with development of e-health services from a user's perspective.

Louise Klokke is a physiotherapist by background, now a PhD fellow at University of Copenhagen, employed at the Parker Institute, Bispebjerg and Frederiksberg Hospitals, Copenhagen. Louise takes a special interest in scientific methodology and patient involvement in research.

Astrid Karnoe has a Master of Science degree in health informatics from University of Copenhagen. She takes special interest in the design of digital health services, e-health literacy and how to measure e-health literacy. She currently works at University of Copenhagen in a research assistant position funded by The Health Foundation in Denmark.

Roy Batterham holds a B.App.Sci (physiotherapy) and a M.Ed (program evaluation). He has worked for 20 years as a public health academic and program evaluator in academic, private and government sectors. Roy has developed many innovative methods and applications for Concept Mapping in conducting more than 500 groups in multiple countries and languages. He currently works on health literacy interventions in Thailand and South East Asia.

Lars Kayser is a board certified specialist in internal medicine, associate professor in health informatics and currently director of Health Informatics study at University of Copenhagen. He has a particular interest in health literacy, e-health literacy and innovative redesign of healthcare provision.

Richard H. Osborne is professor and the Chair of Public Health at Deakin University, Australia. He holds a prestigious Australian National Health and Medical Research Council (NHMRC) Senior Research Fellowship focusing on Global Health Literacy Development and Equity. He initiated and led the development of several questionnaires and tools used globally, including the Health Literacy Questionnaire (HLQ) and the Ophelia (OPTimising HEalth Literacy and Access) approach. The main focus of his research is the development and implementation of processes to support healthcare organisations and governments to strengthen health systems and reduce health inequalities.

1. Introduction

Today, problems and challenges are often met with digital or technological solutions. The health domain is not an exception to this phenomenon, with the e-health industry rapidly expanding in many directions. The World Health Organization (WHO) defines e-health as “the use of information and communication technology (ICT) for health” (World Health Organization, 2015). e-Health is considered a way to improve quality, capacity, efficiency and access to healthcare services and information (Hernandez, 2009), and thus holds the potential to promote health (Camerini & Schulz, 2012) and improve health equity (Dodson, Good, & Osborne, 2015; Neter & Brainin, 2012).

Engagement in one’s own healthcare, having access to health services and handling health information in an appropriate way is a complex task for many people, where the complexity is further increased with the addition of e-healthcare options. The challenges incorporated in finding, understanding, using and appraising health information and health services have been labelled as health literacy (Nutbeam, 1998). Health literacy has been found to be strongly correlated with socioeconomic factors such as educational level (Beauchamp et al., 2015; HLS-EU Consortium, 2012). Health literacy, often measured using tests of health-related reading ability and numeracy, has also been associated with a wide range of behavioural and health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Inspired by the concept of health literacy and the potential for it to be a health mediator, Norman and Skinner have proposed the term e-health literacy as a way to capture this emerging field (Norman & Skinner, 2006).

The many diverse aspects of e-health, from being a tool for providers to deliver better care, to a way for individuals to be informed about their own health (Oh, Rizo, Enkin, & Jadad, 2005), require that the knowledge, skills and resources needed for people to use e-health tools are well understood. This understanding should inform the

development, selection, implementation and use of tools to ensure people receive beneficial outcomes (Kayser, Kushniruk, Osborne, Norgaard, & Turner, 2015). To generate such benefits, an e-health service, ideally, should enable users to strengthen the skills, knowledge and resources they need to engage with the service at hand (Gilstad, 2014).

Norman and Skinner (2006) proposed the “Lily Model” for e-health literacy including six types of literacies: traditional (reading ability and numeracy), information, media, health, computer and science literacy depicted as petals of a lily. An expansion of this model with a cognitive element, generated through the lens of Bloom’s taxonomy was then proposed by Chan and Kaufmann (2011). More recently, Norman (2011) raised the idea that the change in context and opportunities with Web 2.0 merits a rethinking of the e-health literacy model. A further expansion to the model was suggested by Gilstad (2014) which included elements such as communicative expertise, the bodily experience, cultural, social and institutional context and propositional and procedural literacy. Further work by Koopman, Petroski, Canfield, Stuppy, and Mehr (2014) included a larger set of skills, motivation and concerns, together termed “readiness for health information technology”, in the PRE-HIT instrument. This model was developed through focus groups with patients and identified a series of themes hypothesised to have relevance in predicting use of health information technology from a patient’s point of view. The model also considered factors affecting willingness to engage in e-health, such as privacy and security concerns, computer anxiety, desire for self-management, need for information, convenience and perceived superiority of information from health professionals.

To date, the research in this field has lacked systematic inclusion of users and e-health professionals in the development of the e-health literacy concept. In this study, we applied systematic inductive methods, seeking to identify the full range of elements relevant to individuals attempting to use e-health technologies. The specific aim of the research was to develop a model of e-health literacy which includes the views and experiences of a wide range of stakeholders.

2. Methods

In order to develop a model of e-health literacy that is likely to resonate with IT users and non-users, patients, healthcare providers, IT experts and managers, we conducted a series of concept mapping workshops with this diverse range of stakeholders to capture a wide range of perspectives. Concept mapping exists in many versions; we used a computer assisted process originally developed by Trochim (Kane & Trochim, 2007; Trochim, 1989a; 1989b). This process has been used broadly for consulting with a wide range of stakeholders to develop conceptual models for questionnaire development and is described in detail elsewhere (Busija, Buchbinder, & Osborne, 2013; Klokke et al., 2015; Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013; Osborne, Elsworth, & Whitfield, 2007).

Eight workshops were completed between June and August 2012, four with patients and four with professionals (see Table 1). All patients had a chronic health condition and were recruited from a rheumatology clinic, a general practitioner and an umbrella organisation for patients’ associations. The group of professionals included health professionals, health informatics professionals, researchers in public health, and computer scientists recruited through the authors’ networks. To maximise cultural and system diversity two workshops were conducted in London, United Kingdom, with

professionals, including representatives from patient's associations. The remaining workshops were conducted in the Capital Region of Denmark.

Table 1

Workshop and participant characteristics: Overview of the eight workshops describing the characteristics of the workshops, participants and the outcomes.

Workshop	Number of participants	Age of participants, mean (range)	Country of the workshop	Type of participants	Number of statements	Number of dendrogram-derived clusters
1	9	n/a	Denmark	Professionals	46	16
2	12	n/a	Denmark	Professionals	62	17
3	7	n/a	United Kingdom	Professionals	65	17
4	10	n/a	United Kingdom	Professionals	61	18
5	3*	69 (68-71)	Denmark	Patients	47	15
6	6	57 (50-71)	Denmark	Patients	57	16
7	5	53 (42-64)	Denmark	Patients	59	15
8	6	59 (37-73)	Denmark	Patients	53	14
e-survey	23	n/a	International	Stakeholders	67	17

* Two researchers, in addition to the patients, did the sorting task, so that five people in total sorted the cards during this workshop.

The first step in concept mapping uses a nominal group technique which is a brainstorming process structured to maximise the breadth of ideas generated and to achieve equality of input from participants. In this step, participants responded to a seeding statement: "Thinking about citizens' experiences in trying to look after their health (or the health of their family), what does a person need to be able to do in order to use digital health services?" To support participants to understand the context, the term "health care" was defined as: "All places where you find treatment, rehabilitation, disease prevention or health promotion, and at all levels, private, municipal, regional or state." Given the diversity of participants, a short sensitising discussion was held about what the term "digital health services" meant. The discussion was seeded with "Think about digital health services as all kinds of services in which digital technologies are used. It is not restricted to traditional computer use". This discussion ensured that all participants had a broad understanding of the potential range of elements of this field.

A standardised method for conducting a concept mapping workshop was followed. This included printing the statements generated by participants onto cards, which were then sorted by participants in any way that made sense to them. These sorts were entered into a computer program during the workshop and combined using multidimensional scaling to produce a two-dimensional scatterplot (the "concept map") in which statements that were sorted together by many participants sit close together and statements that were rarely or never sorted together are far apart. Hierarchical cluster analysis was then undertaken to draw boundaries around groups of closely located items. Next, the map was presented to the participants who were allowed to refine the map by re-assigning items to different clusters and naming each cluster based on discussion among the group of participants. As a final task, the participants were asked to rate the importance of each statement on a five-point scale. The software used was The Concept System (version 1.0 by Trochim, 1987). This software applies non-metric multidimensional scaling using

Kruskal's algorithm (Kruskal, 1964) and cluster analysis applying Ward's method (Ward Jr., 1963).

Dendrograms were used to identify commonalities across concept maps. These explore the hierarchical structure of the data from broad concepts to increasingly refined sub-concepts down to the individual statements provided by workshop participants. Hierarchical cluster analysis was applied to produce a dendrogram for each workshop showing all cluster solutions from two to 20 clusters. With these diagrams the division of clusters were explored, looking at the specific item content each time a cluster is split into two smaller clusters. As the aim of this study was a detailed and complete understanding of the key elements of e-health literacy, clusters were increasingly split until the maximum number of clusters that made conceptual sense to the researchers was reached. These clusters, 128 in total, were labelled according to the content of their statements (see Table 2). Finally, an analysis of the concept labels generated in the workshops and the analysis of the dendrograms were consolidated into one overarching model of the key hypothesized domains of e-health literacy.

As a validation, a concept mapping was subsequently applied through an e-survey of health professionals across the networks of the research group, by e-mail and posted on social media (selected LinkedIn groups). This type of e-survey, previously described by Klokke et al. (2015), involved a two-step approach; (1) statement gathering and (2) statement sorting. In the first step, participants were asked to provide up to 20 brief, narrative statements responding to the same seeding statement as used in the face-to-face workshops (outlined above). Further, participants were asked to provide demographic data including their country of residence, profession, academic qualifications, and current work role. Statements were collated, and duplicates and very similar statements removed. In the second step, the statement pool was sent back to the professionals for sorting and rating, and then analysed as described above.

All data obtained during workshops was anonymised and neither biological samples nor medical equipment was used. Consequently, specific ethical approval was not acquired under the regulations of the Danish National Data Protection Agency or the Danish National Committee on Health Research Ethics in force during the data collection period.

3. Results

The multidimensional scaling of the data collected during each workshop and the resulting two-dimensional map with collectively labelled clusters informed the subsequent analysis. An example of the output, a concept map from the first workshop with professionals, is shown in Fig. 1.

From the experience of the eight workshops and the content analysis resulting in 128 cluster labels, seven main themes were hypothesised initially through an inductive analysis by the first author (ON) followed by extensive discussions with RHO, RB, LOK and LK. The cogency of the content and labels for the themes was then further discussed and refined (ON, RHO, LK, DF, AK). The conceptual independence of each domain was carefully considered such that each could be suitable for later development into a scale within a multidimensional e-health literacy questionnaire.

The labels of the smallest meaningful clusters, resulting from the dendrogram analyses, and the domains they were attributed to, are reported in Table 2, to illustrate the

ideas promoted by patients and professionals respectively. The content and distinctions of each domain are derived from the statements belonging to these clusters.

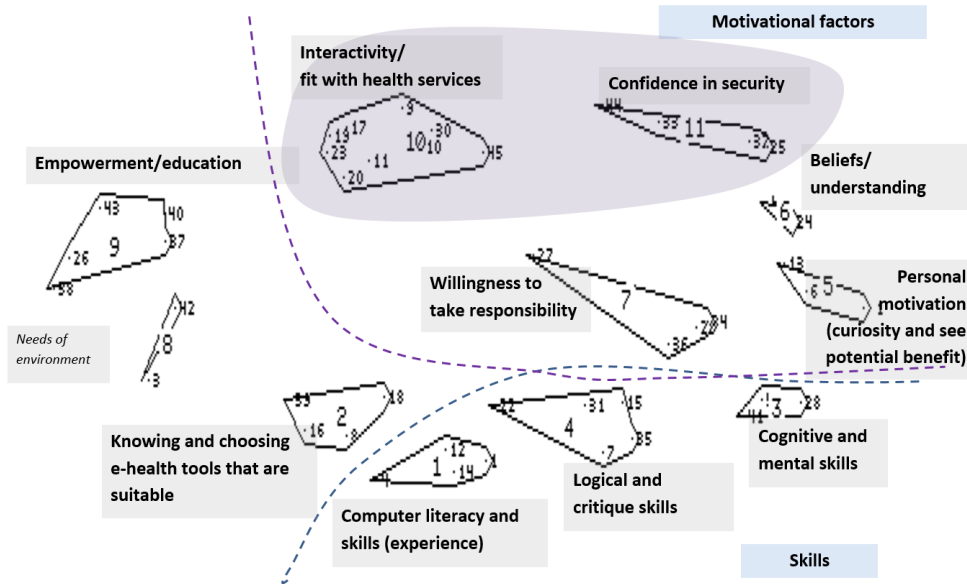


Fig. 1. Example of a concept map from the first workshop held with professionals. Each number represents a statement and each shape represents a cluster as calculated by the software. The label of each cluster is proposed by workshop participants through consensus.

Table 2

e-Health literacy domains and associated smallest meaningful cluster labels: Cluster labels with similar content were merged to create greater overview of data, thus reducing the number of cluster labels from 128 to 88.

1. Ability to process information		
Patients:	Professionals:	
<ul style="list-style-type: none"> • Have the mental resources to cope with vast information • Ability to read, write and learn 	<ul style="list-style-type: none"> • Cognitive abilities • Functional literacy 	<ul style="list-style-type: none"> • Ability to share information with others • Basic/computer literacy • Understand the language used
2. Engagement in own health		
Patients:	Professionals:	
<ul style="list-style-type: none"> • Feeling confident that you can manage your own health • Coping with your condition 	<ul style="list-style-type: none"> • Taking responsibility of own life • Being able to navigate between services • Understanding of own condition 	<ul style="list-style-type: none"> • Wanting to take responsibility of one's own health • Wish to prioritize health

3. Ability to actively engage with digital services

Patients:

- Readiness to start using the systems
- Critical thinking
- Logical thinking
- Be introduced to IT
- Ability to learn how to use IT
- Know one's limitations and be open
- IT may lower one's attention
- Feel confident in systems and data
- Ability to use existing systems
- Basic computer skills
- Feel confident in using IT
- Know how to access the systems
- Know how to read and write using IT
- Ability to appraise information
- Ability to learn the context-specific skills (IT)
- Cognitive abilities and training

- Ability to progress in acquiring skills
- Sense of control over own health and the systems

Professionals:

- Basic skills in using IT
- Critical assessment skills
- Health literacy
- Feeling comfortable with what information is used
- Know when and how to get help
- Information exchange and feedback from health care professionals and systems
- Be able to make sense of data and understand what it is used for
- Being able to use the IT systems
- Knowledge about your different options
- Being critical when using the information one gets from the system

- Know how to use the systems in general
- Know how to use systems related to health
- Understand and appraise information
- Ability to utilize information and system
- Know how to critically interact
- Have confidence in oneself
- Know other people's (hidden) agenda
- Understand confidentiality
- Ability to access the systems
- Accept non-human interface during interaction with health care
- Confidence in using IT
- Incorporate use of IT into one's life
- Deeper understanding of how systems work

4. Feel safe and in control

Patients:

- Trust that your information is secure
- Security
- Feel that data are secure
- Ownership of personal data
- Data security
- Know where your data is

- Secure and stable systems
- Easy access to correct information
- Access to help and support so you can act safely when using IT

Professionals:

- Feeling safe/secure
- Feel that data is secure

- Know that data is secure
 - Data ownership
 - Feeling of ownership of data and systems
 - Trustworthy information
 - Trust that the systems are safe
-

 5. Motivated to engage with digital services

Patients: <ul style="list-style-type: none"> • Empowerment of patients • Have interest and cognitive ability • Ability to adjust own behaviour • Feeling unsure about new things • Forced to use IT • Be motivated to learn 	<ul style="list-style-type: none"> • Feeling of distance (mentally) created by IT • Having the energy to use new technology Professionals: <ul style="list-style-type: none"> • Motivation • Having the courage and be curious 	<ul style="list-style-type: none"> • Feel that use of IT is beneficial • Benefits are made clear • Need to be "pulled" • Use of IT makes good sense • Motivated to use IT • Ability to self-manage via IT
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

 6. Access to digital services that work

Patients: <ul style="list-style-type: none"> • Accessibility (to equipment, to systems) • Access to relevant information • Ability to interact with the systems • Access to help • Systems should be able to work together • Using IT may be high on resource consumption • Physical access to IT 	<ul style="list-style-type: none"> • Easy access to systems and support • Access to systems that work efficiently (and work together) • Correct use of registered information • IT systems should work to be beneficial • Access to equipment (computers etc.) • Having access to well-functioning services 	<ul style="list-style-type: none"> • Trust that using IT is as good as the personal (old) way Professionals: <ul style="list-style-type: none"> • Easy access to receiving and adding relevant information • Physical access (x2) • Access to systems • Easy access to information
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

 7. Digital services that suit individual needs

Patients: <ul style="list-style-type: none"> • Adaptable systems • Accessible systems • Access to help (x2) • Access to support • Communication that fits the individual • Experience that IT helps you in managing your health • Access to help and support that suit one's needs 	<ul style="list-style-type: none"> • Personal contact with health professionals Professionals: <ul style="list-style-type: none"> • Access to service that suits your needs • Relatives • Having power over the IT systems (and the opposite way) • Digital services that suit individual needs 	<ul style="list-style-type: none"> • Physical abilities (x2) • Systems that can be adjusted to individual needs • Access to training in system use • Access to information that suit individual needs • Access to the help and support that one needs • Empowerment of carers
----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

1) *Ability to process information*

The processing of information has several steps, from recognizing the need for and finding information, through reading and understanding, to the process of appraising and applying information to one's own situation. Each of these steps was present in statements assigned to this domain. A core element of this domain is the "Ability to use the written word" (professional) as well as basic numeracy, along with the notion of logical thinking. Some participants suggested deeper cognitive skills, including having "Cognitive ability to understand basic information" (professional), and the ability to understand medical language: "Able to read medical information" (professional). Other participants suggested issues related to accessing, clarifying and evaluating information: "Knowledge of how to access" (professional); "Ability to discuss and share information with others" (professional); and "You have to be smart, so you can filter the information ..." (patient). The domain also includes statements with focus on memory, attention and having the strength to get involved in the information. This domain was well represented in all workshops and was discussed as a fundamental skill, necessary for all.

2) *Engagement in own health*

This domain included the basic knowledge about one's own health conditions, how to approach the healthcare system, as well as the approach to health in terms of will and responsibility. All of these imply that the person has an interest in learning about and managing their health. A basic level of engagement is seen in statements such as "Basic knowledge about your condition (symptoms or needs)" (professional), statements that indicate some familiarity with health systems: "Be able to navigate in an authorised organised healthcare system" (professional); and statements indicating an ongoing focus on health: "You should be able to take responsibility for your own disease" (patient); and "Health has to be a priority in their lives compared with other issues" (professional). There was also the ethical consideration, that there "Needs to be respect for people's personal choice to engage or not" (professional).

3) *Ability to actively engage with digital services*

This was a broad domain containing 153 statements. It contains not only the basic knowledge and skills connected to the use of digital services, but also an important element on how to process information and data in the framing of the digital media, thus including the abilities needed to use these technologies in a healthcare setting. According to statements, "You need competencies to use and understand information technology" (professional), and experience from use of information technology in other contexts was seen as a strength. Basic skills included "Understanding how to use search engines" (professional), "Being able to navigate the Internet" (professional), and logic skills appear across workshops. Higher skills were also noted: "Develop confidence to use the technology" (professional) and have the "Ability to absorb new concepts" (professional). The idea that "One should know the pitfalls on the Internet" (patient) is in line with the reappearing notion that "You should have a healthy scepticism" (patient). Other skills surrounding the use of digital services are responsibility: "Patience (to deal with problems)" (professional) and to "Accept the technology into their home/lifestyle" (professional).

4) *Feel safe and in control*

Consistently through all workshops, with both patients and professionals, the issue of safety was mentioned. The statements ranged from feeling safe and trusting the systems,

to the sense of security and control over data. “Feeling that your information is safe and secure” (professional) appeared to be imperative to participants. Many statements focused on the notion of trust: “Trust in the source of information” (professional) and “You have to trust that the information you give is not misused” (patient). This reflects the sensitive nature of health data and demonstrated that safety and security was a high priority to participants. Further, it leads to the need of being in control and promotion of user rights: “You should own your own data” (professional) and “You should know what your data are used for” (patient), with transparency being a key value. The need for personal contact was also raised for participants to feel safe: “Human contact is still required” (patient). Commercial interests were raised but not frequently emphasised: “Need to feel that the technology is not driven by commerce (being tracked – big brother is watching you)” (professional).

5) *Motivated to engage with digital services*

Statements concerning the incentives for using e-health formed this domain, with a focus on benefits aligned with use, but also including attitudes such as curiosity, courage, enjoyment and feeling of closeness and comfort as motivational factors for use. The label arose from statements such as “Citizen is motivated to use IT” (professional). The value of the system to the user, the “Purpose or need to use the technology” (professional) was a core feature, as was “Some people might need an incentive (a sense that they will get something from it, e.g. might save money, link with others)” (professional). Some statements included specific motivations such as “You should have courage” (professional), “You should not be afraid to click around on the [web] pages” (patient), “You should be curious” (professional) and “You should believe in yourself” (patient).

In this domain statements also touched on other aspects of the attitude towards digital health, such as “Your age is of significance” (patient), that “Social isolation can be a reason to use it” (professional) or a situation where it can be “Imposed upon you (you will have to accept IT in the health system)” (patient), so you feel forced to use it, resulting in “You can feel alienated” (patient).

6) *Access to digital services that work*

In this domain, the statements related to access to hardware and software. Statements included “Access to devices (electronic and medical)” (professional), “You should have access to solutions” (professional) and that “The system should be easily accessible (user friendly)” (patient). A recurring point was that “You should be able to afford to buy and use the technology” (patient). The need for flexibility was also evident, i.e. the need to be “Able to have 24/7 access” (professional) and that “The systems should communicate with each other (integration)” (patient). A broad understanding of access emerged, including “Access to help/manuals” (patient). Not only the user needs access, there was also an aspiration for “Health information kept in one place where you and relevant health care professionals have access” (professional). The statement “There are fewer errors when the patient helps to register drugs and test results” (patient) suggested why this was important to participants and supports that “The solutions should work” (professional).

7) *Digital services that suit individual needs*

This domain focused on the system matching the needs of the individual user. It includes the user interface: “The user interface must match the user (the user must help to develop)” (patient) and “There should be understandable feedback from the health system” (patient). Also it should be “Available in my language” (professional) and “You should be able to understand the messages you get (not medical language)” (patient).

Essentially, “The system should be able to be fitted to the citizen (an adaptive system)” (professional) and “The system should support the citizen’s development (from novice to experienced user)” (professional). Data should be adapted to fit the receiver, so that it provides “Access to having results (e.g. a blood test) interpreted” (patient). An important aspect of this domain was the systems adapting to disabilities, such as “Options for blind/visually impaired” (patient) and the option of including personal networks when needed, in the form of “Empowering relatives when citizens are not able” (professional). Finally, the system should be receptive to the user’s rights, such as “Having the right not to know” (professional) and “Acknowledgement that there will be people who will not use the technology” (professional).

Confirmatory e-consultation process

The e-consultation resulted in 67 unique statements, which were broadly consistent with the seven domains, and all domains were represented in the data. The health aspect in the second domain, “Engagement in own health”, was represented by statements such as “Understand health concepts (bodily functions etc.)”. The fourth domain: “Feel safe and in control”, was illustrated by the statement “Trust the source of information”. The fifth domain on being motivated to engage with digital services was included in statements such as “Have an incentive for using the digital health service.” Thus the e-consultation confirms the results as presented above.

The e-health literacy framework (eHLF)

The seven domains were clearly related to each other and connect the individual and the individual’s experience with the system acting as an e-health literacy framework. Fig. 2 represents the seven domains on a pair of axes: from domains largely dependent on the individual to domains largely dependent on the system, on the horizontal axis; and from domains that relate to externalized, observable actions to domains representing more internalised concepts and feelings on the vertical axis. The first two domains concerning ability to process information (domain 1) and engagement in own health (domain 2) were largely dependent on the competences of the individual and thus placed on the individual’s side in the model. Access to working systems (domain 6) and a system’s ability to suit individual needs (domain 7) depend mainly on the characteristics of the e-health systems, so these two domains were placed on the system side of the model. The user skills and knowledge have little influence on whether there is hardware accessible or an Internet connection when needed, or whether the system adapts to individual needs, such as visual impairment, if the system is not providing this option. However, individual capabilities and resources do influence perception of access to a system and to what extent the system adapts to individual needs. Therefore, knowing about the user’s perception of the technology contributes to an inclusive understanding of e-health literacy.

The interaction between the individual and the system is where unique aspects of the concept of e-health literacy start to unfold. How a person might engage with information in the context of a system (domain 3) is dominated by more than just technical skills. Experiencing safety and control (domain 4), benefit and comfort, and having the right attitude in approaching technology (domain 5) become just as relevant as knowing the inner workings of the systems and having the skills to navigate it.

Moreover, the model includes the relative level of internalization of each ability. Within each circle the more external skills, such as reading or having access to a working system, were placed in the upper regions, whereas the more internalized concepts such as motivation, engagement and individualisation were placed in the lower regions.

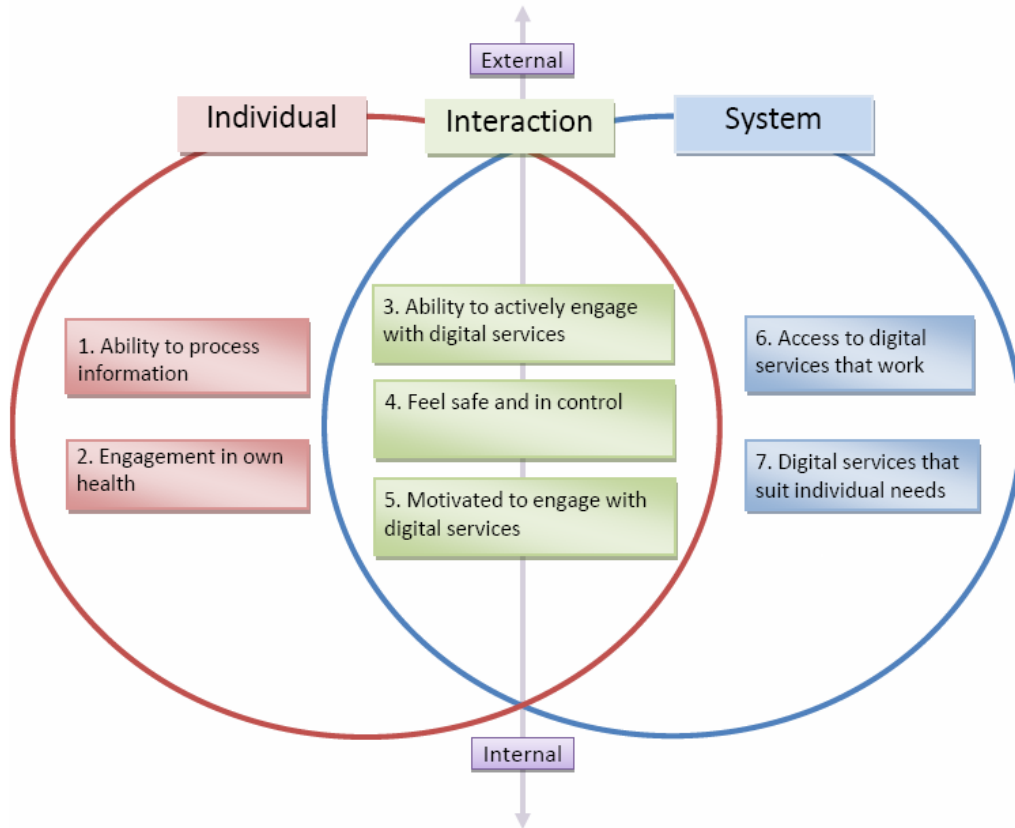


Fig. 2. The e-health literacy framework (eHLF). The figure shows the interaction between individual and system as illustrated by the domains.

4. Discussion

This study presents the development of a model of e-health literacy based on the experiences of a wide range of stakeholders, by applying a systematic, inductive approach. This has resulted in a seven-domain framework, the e-health literacy framework (eHLF), which provides a new way to understand the interaction and relation between individuals and the system.

The strength of the eHLF is that it includes not only the known domains of health, information and basic digital skills, but also includes new elements with relevance to the dynamics that occur when the system meets the individual, as exemplified by the domains 3. Ability to actively engage with digital services, 4. Feel safe and in control, and 5. Motivated to engage with digital services, placed in the interaction between these two (see Fig. 2). Together with the domains 6. Access to digital services that work and 7. Digital services that suit individual needs, bound to the system, this illustrates how the eHLF supports an understanding of e-health literacy that is not only about the individual's abilities and resources but also strongly context dependent and related to the complexity of systems.

The eHLF is a new contribution to the debate on how electronic, digital or technology health literacy can be understood. Since Norman and Skinner proposed their model almost a decade ago, only one other study has contributed to the evolution of the understanding of e-health literacy with a new model (Koopman et al., 2014; Norman & Skinner, 2006). Table 3 compares the Norman and Skinner and Koopman models to the seven domains of the eHLF, according to the similarities and differences of the elements in the models. Some elements have been mapped to more than one of the domains in eHLF, while others exceed the scope of the eHLF.

Table 3

Similarities and differences between eHLF and two other e-health literacy models by Norman and Skinner and Koopman respectively

eHLF (domains)	Norman & Skinner (literacies)	Koopman et al. (themes)
<i>Domain 1</i> <i>Ability to process information</i>	Information literacy Traditional literacy Media literacy	Poor computer and search abilities Need for information
<i>Domain 2</i> <i>Engagement in own health</i>	Health literacy Science literacy	Desire to be a more active participant in own care Anxiety about what information might be found on the Internet
<i>Domain 3</i> <i>Ability to actively engage with digital services</i>	Computer literacy Science literacy Media literacy	Poor computer and search abilities Convenience
<i>Domain 4</i> <i>Feel safe and in control</i>		Privacy and security concerns
<i>Domain 5</i> <i>Motivated to engage with digital services</i>		Preference for the health care team as a source of information Anxiety about what information might be found on the Internet Desire to be a more active participant in own care Convenience
<i>Domain 6</i> <i>Access to digital services that work</i>		Asynchrony
<i>Domain 7</i> <i>Digital services that suit individual needs</i>		Looking for information for or about others
<i>Not covered by the seven eHLF domains</i>		Preference for the health care team as a source of information Looking for information for or about others

All literacies included in Norman and Skinner's Lily Model are contained in the first three domains of eHLF that describe basic skills to process information, understand health and use technology, although both eHLF domains concerning engagement are broader. The content of the remaining four domains of eHLF are not included in Norman and Skinner's model.

The nine themes suggested by Koopman et al. are all represented in the eHLF domains. Compared to the domains of eHLF, the themes from Koopman et al. tend to be more specific. E.g. the theme "Asynchrony", attentive to the digital influence on increasing asynchrony in the access to healthcare professionals, but not regarding the access to hardware, software, training and economic means, that are also included in the eHLF domain.

Two of the Koopman themes mapped into domains 5 and 7 were only partially covered in eHLF while most other themes are partially but not fully contained by the eHLF. For example, the theme "Looking for information for and about others" is about an individual's need for information (domain 7), but it also contains a specific need for looking up information on conditions not affecting one self.

Interestingly, the elements incompletely covered by the eHLF are already well defined in broader understandings of health literacy. Our model is limited to the users interacting with technology and digital services in a health context while the current understanding of the concept of health literacy has multidimensional characteristics (HLS-EU Consortium, 2012; Osborne et al., 2013), and includes aspects of social support networks and engagement with health professionals.

As the only e-health literacy model for almost a decade, Norman and Skinner's Lily Model became the foundation for another two expansions of the original model (Chan & Kaufman, 2011; Gilstad, 2014): Chan and Kaufman applied Bloom's taxonomy to each of the six literacies adding a cognitive dimension to the existing model (Chan & Kaufman, 2011). The eHLF does not contain this taxonomic construct, most likely due to its origin from a concept mapping-based development process. However, this could be incorporated into the development of instruments to measure e-health literacy based on eHLF.

In 2014, Gilstad suggested an extension of Norman and Skinner's Lily Model (Gilstad, 2014). Through an interdisciplinary review of technology studies, human and social sciences and health studies she applied elements of communicative expertise, the bodily experience, cultural, social and institutional context and propositional and procedural literacy. These additions are not covered by eHLF but the context, relationship and personal values may be covered in the understanding of health literacy or should be included in a third dimension placed outside the interaction between the individual and the system.

The concept mapping process that we undertook included a broader range of stakeholders than was reported for the other models. The other models focus on individual skills and none include the system domains that are represented in our model. The two domains attributed to the system: 6. Access to digital services that work and 7. Digital services that suit individual needs, include important features of what is needed for the user to use and benefit from a digital service. The grounded approach with inclusion of a wide range of stakeholders across settings is a strength of the eHLF development that has generated new and highly relevant aspects of e-health literacy that have the potential to advance this field.

The eHLF is a comprehensive framework, as it can be applied on both the micro, meso and macro level. At the micro level, key factors for successful implementation of e-health services include involving the user and understanding the users' competences. A lack of focus on these two may result in less effective systems or risk of project failure (Cresswell & Sheikh, 2009; Greenhalgh, Hinder, Stramer, Bratan, & Russell, 2010; Lluch, 2011). There is a need for a framework guiding developers to better understand and meet the needs of consumers.

At the meso level, the seven domains contain a broad range of features relevant to planning, design and development of e-health services (Kayser et al., 2015). Inclusion of users in the process of creating e-health tools is becoming an accepted practice (Kayser et al., 2015; Roehrer, Bjørnes, Cummings, & Nøhr, 2014). However, there is a need for a framework to ensure that all elements are systematically considered.

The concept mapping process has successfully been used as a technique for validity-driven questionnaire development (Osborne et al., 2013; Osborne, Elsworth, & Whitfield, 2007). The authors are currently using the model presented here to guide the development of new instruments for measuring e-health literacy. The possibilities for such a tool are many, including assessment of requirements of potential users and evaluation. It could also be used to analyse the characteristics and strengths and weaknesses of different digital services, and to identify socioeconomic factors associated with limited e-health literacy.

The eHLF does not, however, need to be operationalized as a questionnaire to prove useful in research. Working with qualitative methodologies, for example a project looking into how a specific digital health service was received, can use the framework as interview or observation guide, to ensure relevant elements are included.

On a macro level, decision makers often use specific, quantifiable markers to guide the commissioning of new digital services or strategies. This framework has the potential to provide policy makers with a structured approach to include the user perspective in their decision making.

In the near future, cooperating with digital services will become a central skill for all health professionals. In their education and training, a deep understanding of the factors involved in e-health literacy will become increasingly important and the eHLF has the potential to become a framework for studying this field.

In this study, e-health literacy was approached with as broad a perspective as possible, including allowing completely new ideas to be able to emerge through the concept mapping process. Breadth was encouraged through the diversity of the participant panels, the open brainstorming environment at the workshops and the inductive approach to the analysis.

Most of the 450 statements gathered throughout the workshops, fitted well within the seven domains. Some statements were central to the theme of the domain whereas others were more peripheral. Other aspects are generic such that they relate to multiple domains. For example, the need for training, which is a part of not only 3. Ability to actively engage with digital services, but also a part of 4. Feel safe and in control, as well as 7. Digital services that suit individual needs.

Diversity in cultural perspectives and health systems was facilitated by conducting consultations in two countries – Denmark and United Kingdom. Both countries are within western European culture. While we expect the eHLF to be robust in

these and similar setting, the framework may require refinements in other contexts, such as cultures from outside the European continent or in developing countries.

The background of the participants was wide ranging. The recruitment was through convenience sampling, mainly via our own networks (professionals and e-survey participants) and patients were recruited from clinics but also through patient associations. Importantly, the structure of the concept mapping workshops ensured that all participants felt safe to contribute their own view, with careful attention to not let the facilitators' perspectives influence participants. A wider demographic spread among the participants may have generated a wider set of responses. While the concept mapping provides some reassurance that the eHLF domains are comprehensive, further work in this area is warranted, particularly with individuals from non-European backgrounds.

The process of constructing a concept like e-health literacy will always involve multiple analytic and decision-making stages. The systematic approach provided by the concept mapping method and software contributed structure to the data, that supported the inductive work of identifying themes among the statements. Being qualitative work, the prior understanding of the researchers will influence the analysis. Thus the authors' background in public health as well as medicine, education, and medical informatics, will have an impact on the results. The validity and rigor of the qualitative process was strengthened by repeated immersion in the content of the statements in multiple sessions with different groups of authors as well as the confirmatory process of the e-survey. In this work, the method facilitated the emergence of domains not previously recognized from the literature that were clearly relevant to participants in the workshops.

5. Conclusion

This paper presents a new e-health literacy framework (eHLF) which provides a comprehensive scaffold for investigation of an individual's ability to use and benefit from e-health technologies at the micro, meso and macro level. The seven domains provide novel insight into e-health literacy from the perspective of the system and the individual as well as the interaction between the two. The eHLF provides a starting point to assist researchers, practitioners, funders and policymakers to explore e-health literacy from a development, research, policy or user point of view in order to obtain a better match between the demands of e-health systems and the knowledge, skills, resources and motivation of users.

Acknowledgements

Parts of the project took place when LK and ON were funded by the Danish National Strategic Research Council. RHO was funded in part by a National Health and Medical Research Council of Australia Senior Research Fellowship. DF is a PhD fellow supported by the Tryg Foundation. Author AK was funded by The Health Foundation in Denmark for a six month project regarding e-health literacy. Mr. Jacob Østberg Hansen provided assistance in collating statements gathered through the e-survey. Thank you to all who contributed to this work by participating in the workshops or the e-consultation. Thanks to Ms Lena Sundby Jensen for assisting in editing the paper.

References

- Beauchamp, A., Buchbinder, R., Dodson, S., Batterham, R. W., Elsworth, G. R., McPhee, C., Sparkes, L., Hawkins, M., & Osborne, R. H. (2015). Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). *BMC Public Health, 15*(1): 678.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low health literacy and health outcomes: An updated systematic review. *Annals of Internal Medicine, 155*(2), 97–107.
- Busija, L., Buchbinder, R., & Osborne, R. H. (2013). A grounded patient-centered approach generated the personal and societal burden of osteoarthritis model. *Journal of Clinical Epidemiology, 66*(9), 994–1005.
- Camerini, L., & Schulz, P. J. (2012). Effects of functional interactivity on patients' knowledge, empowerment, and health outcomes: An experimental model-driven evaluation of a web-based intervention. *Journal of Medical Internet Research, 14*(4): e105.
- Chan, C. V., & Kaufman, D. R. (2011). A framework for characterizing eHealth literacy demands and barriers. *Journal of Medical Internet Research, 13*(4): e94.
- Cresswell, K., & Sheikh, A. (2009). The NHS care record service (NHS CRS): Recommendations from the literature on successful implementation and adoption. *Informatics in Primary Care, 17*(3), 153–160.
- Dodson, S., Good, S., & Osborne, R. (2015). *Health literacy toolkit for low- and middle-income countries: A series of information sheets to empower communities and strengthen health systems*. New Delhi: World Health Organization, Regional Office for South-East Asia. Retrieved from http://apps.searo.who.int/PDS_DOCS/B5148.pdf
- Gilstad, H. (2014). Toward a comprehensive model of eHealth literacy. In *Proceedings of the 2nd European Workshop on Practical Aspects of Health Informatics*. Retrieved from <http://ceur-ws.org/Vol-1251/paper7.pdf>.
- Greenhalgh, T., Hinder, S., Stramer, K., Bratan, T., & Russell, J. (2010). Adoption, non-adoption, and abandonment of a personal electronic health record: Case study of HealthSpace. *BMJ, 341*: c5814.
- Hernandez, L. M. (2009). *Health literacy, eHealth, and communication: Putting the consumer first: Workshop summary*. Washington, DC: Institute of Medicine of the National Academies, National Academies Press.
- HLS-EU Consortium. (2012). *Comparative report on health literacy in eight EU member States - The European health literacy project 2009-2012*. Vienna: Ludwig Boltzmann Institute for Health Promotion Research.
- Kane, M., & Trochim, W. M. K. (2007). *Concept mapping for planning and evaluation*. SAGE Publications, Inc.
- Kayser, L., Kushniruk, A., Osborne, R. H., Norgaard, O., & Turner, P. (2015). Enhancing the effectiveness of consumer-focused health information technology systems through eHealth literacy: A framework for understanding users' needs. *JMIR Human Factors, 2*(1): e9.
- Klokner, L., Osborne, R., Wæhrens, E. E., Norgaard, O., Bandak, E., Bliddal, H., & Henriksen, M. (2015). The concept of physical limitations in knee osteoarthritis: As viewed by patients and health professionals. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation, 24*(10), 2423–2432.
- Koopman, R. J., Petroski, G. F., Canfield, S. M., Stuppy, J. A., & Mehr, D. R. (2014). Development of the PRE-HIT instrument: Patient readiness to engage in health information technology. *BMC Family Practice, 15*(1): 18.
- Kruskal, J. B. (1964). Multidimensional scaling by optimizing goodness of fit to a

- nonmetric hypothesis. *Psychometrika*, 29(1), 1–27.
- Lluch, M. (2011). Healthcare professionals' organisational barriers to health information technologies - A literature review. *International Journal of Medical Informatics*, 80(12), 849–862.
- Neter, E., & Brainin, E. (2012). eHealth literacy: Extending the digital divide to the realm of health information. *Journal of Medical Internet Research*, 14(1): e19.
- Norman, C. (2011). eHealth literacy 2.0: Problems and opportunities with an evolving concept. *Journal of Medical Internet Research*, 13(4), e125.
- Norman, C. D., & Skinner, H. A. (2006). eHealth literacy: Essential skills for consumer health in a networked world. *Journal of Medical Internet Research*, 8(2): e9.
- Nutbeam, D. (1998). Health promotion glossary. *Health Promotion International*, 13(4), 349–364.
- Oh, H., Rizo, C., Enkin, M., & Jadad, A. (2005). What is eHealth (3): A systematic review of published definitions. *Journal of Medical Internet Research*, 7(1): e1.
- Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, 13(1): 658.
- Osborne, R. H., Elsworth, G. R., & Whitfield, K. (2007). The health education impact questionnaire (heiQ): An outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Education and Counseling*, 66(2), 192–201.
- Roehrer, E., Bjørnes, C. D., Cummings, E., & Nøhr, C. (2014). Human factors considerations when developing eHealth solutions to support patients : Comparison of Danish and Australian experiences. *International Journal of Healthcare Technology and Management*, 14(3), 157–175.
- Trochim, W. M. K. (1987). *The concept system (c)*. New York: Concept Systems Software Training.
- Trochim, W. M. K. (1989a). An introduction to concept mapping for planning and evaluation. *Evaluation and Program Planning*, 12(1), 1–16.
- Trochim, W. M. K. (1989b). Concept mapping: Soft science or hard art? *Evaluation and Program Planning*, 12(1), 87–110.
- Ward Jr., J. H. (1963). Hierarchical grouping to optimize an objective function. *Journal of the American Statistical Association*, 58(301), 236–244.
- World Health Organization. (2015). *Health topics: eHealth*. Retrieved from <http://www.who.int/topics/ehealth/en/>