

eHealth Literacy Research – Quo vadis?

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Abstract

The concept of eHealth literacy evolved from the social and information sciences, and describes competencies necessary to use electronic health services. As it is a rather new topic, and as there is no current overview of the state of the art in research, it is not possible to identify research gaps. Therefore, the objective of this viewpoint article is to increase knowledge on the current state of the art of research in eHealth literacy, and to identify gaps in scientific research which should be focused on by the research community in the future. The article provides a current viewpoint of the concept of eHealth literacy and related research. Gaps can be found in terms of a missing ‘gold standard’ regarding both the definition and the measurement of eHealth literacy. Furthermore, there is a need for identifying the implications on eHealth developers, which evolve from the measurement of eHealth literacy in eHealth users. Moreover, a stronger inclusion of health professionals, both in the evolving concept and in the measurement of eHealth literacy, is needed in the future.

1

2 **eHealth literacy – the background**

3 eHealth literacy is a rather broad topic that can be viewed from a number of different
4 perspectives by diverse research disciplines. These disciplines reach from social scientists
5 who are interested in human and social factors associated with eHealth literacy, to health
6 professionals who are facing an increasing patient empowerment, to programmers and
7 information scientists, who want to know how the eHealth literacy of consumers can be
8 mirrored when designing eHealth services.

9 According to the definition of Eysenbach, eHealth (alternative spelling: e-health),
10 encompasses health services and health information, which are provided via the Internet, and
11 related technologies. Moreover, this definition includes a special way of thinking: “the term
12 characterizes not only a technical development, but also a state-of-mind, a way of thinking, an
13 attitude, and a commitment for networked, global thinking, to improve health care locally,
14 regionally, and worldwide by using information and communication technology” (1).

15 Over time, the concept of eHealth has had many definitions and a review conducted in 2005
16 found 51 unique definitions for eHealth (2).

17 The consumer is commonly the focus of eHealth strategies and services – the layperson who
18 has no medical background should be enabled to manage his or her own health (3). eHealth
19 strategies and services enable patients to be active participants in the process of medical
20 decision-making by providing information. This may lead to a better understanding of their
21 health and wellbeing (1, 4, 5). An analysis of eHealth strategies in Nordic countries,
22 conducted by the Nordic eHealth Research Network, showed that the strategies in 2010-2013
23 were explicit regarding the citizen’s perspective, whereas the strategies in 2014-2016 were
24 implicit in this respect (6).

25 There is a wide range of consumer-focused eHealth services. Telemedicine, first used in the
26 1920s, is the oldest form of eHealth (7). More recently, the mobile health sector (mHealth or
27 m-Health) has been offering a huge amount of services for diverse user groups and with
28 diverse objectives (8, 9). There are internet-based services such as patient forums, health
29 information pages, electronic patient records or self-tracking systems that can be used along
30 with fitness wristbands or smart watches. In this dynamic environment the eHealth consumer

1 needs to be self-reliant and able to actively participate in his or her health management. When
2 we examine the literature for the so-called digital divide, it is clear that this gap is widening in
3 western civilizations. This is not only due to a lack of access (first level digital divide) but
4 also due to a lack of use (second level digital divide) (10-12). Individuals might therefore be
5 excluded from the potential advantages of eHealth services. There is a gap in the population
6 as to whether people are able to make use of eHealth services or not (13, 14).

7 In this context, eHealth literacy has become a central issue of research in international health
8 informatics. While some people are eHealth literate and access eHealth services to enhance
9 their health and communication with healthcare services, others are eHealth illiterates and are
10 not knowledgeable about eHealth. The term eHealth literacy was first defined by Norman and
11 Skinner in 2006 as the “ability to seek, find, understand, and appraise health information from
12 electronic sources and apply the knowledge gained to addressing or solving a health
13 problem”(15). eHealth literacy is by definition a meta literacy that comprises six different
14 subtypes of literacies:

- 15 • Traditional literacy & numeracy: the ability to understand text and numbers
- 16 • Health literacy: the ability to process and understand health information
- 17 • Computer literacy: the ability to use computer hardware and software
- 18 • Science literacy: the ability to understand scientific texts, facts and correlations
- 19 • Media literacy: the ability to process media content and assess its quality
- 20 • Information literacy: the ability to process information, to know how knowledge is
21 organized and how to use the gained information

22 eHealth literacy can occur on different levels. The lower level requires operational and
23 navigational skills, while the higher level requires the ability to choose and critically evaluate
24 available information. Each of these levels contributes to the ability to find and assess the
25 quality of health information online. Therefore, a deficiency in any may result in inadequate
26 health literacy and prevent individuals from accessing eHealth resources of high quality (12).
27 A high level of eHealth literacy is argued to be directly connected with the intention to use
28 eHealth services (16). eHealth literacy, as with other literacies, is not a static set of skills but
29 can change over time (15). If the level of eHealth literacy can be identified, services and
30 information can be tailored specifically to the needs of the target group. Therefore, if eHealth
31 services are bespoke to the consumer, they may benefit from the potential advantages (17,
32 18). In line with the eHealth literacy concept, Norman and Skinner provided the eHealth

1 literacy scale (eHEALS) to measure the individual's literacy level (19). Currently there are
2 papers that mention problems with the existing concept of eHealth literacy or with
3 measurement methods (20-24). In 2011, Cameron Norman provided a guest editorial for the
4 Journal of Medical Internet Research concerning eHealth literacy. In this editorial he
5 mentioned the problem that the original eHealth literacy concept had been developed for the
6 first generation of eHealth services and thus does not include social media. He reasoned that
7 skills and tasks, including, for example, the confidence in expressing oneself clearly in social
8 interactions online, should be part of a measurement instrument of eHealth literacy (23). Since
9 this editorial paper from 2011 there, indeed, has been a lot of work on the topic of eHealth
10 literacy but it remains unclear where the research community in this area is standing at the
11 moment and if the problems with the measurement of such a dynamic concept have been
12 solved.

13 Therefore, this viewpoint paper aims to provide an overview – it does not intend to give a
14 systematic review of the literature but aims to address the following two questions:

- 15 - Question 1: What is the current state of the art of eHealth literacy research?
- 16 - Question 2: Which research gaps should the scientific community focus on more in the
17 future?

18 **Question 1: What is the state of the art of eHealth literacy research?**

19 The number of the articles using the concept “eHealth literacy” has risen over the years.

20 Having a closer look at the current literature, several findings are revealed, that are presented
21 below.

22 **Finding No. 1: There is a lot of research that deals with eHealth literacy but 23 uses other terms.**

24 Although eHealth literacy is the term most widely used by authors when they are referring to
25 literacies linked to the use of electronic health services, there are numerous articles that used
26 other terms but probably mean the same thing. This, of course, was expected because the
27 concept of eHealth literacy (or e-health literacy) has been launched quite recently and has
28 been mainly used in the fields of research where the concept of health literacy has a strong
29 background, such as in health sciences. In the fields of research where information literacy,
30 health information literacy, and digital or media literacy are the focus, the concepts relating to
31 them are more popular when speaking about the issues related to eHealth literacy.

1 Other terms used include “Internet health literacy” (25), “e literacy” (26), or “digital health
2 literacy” (27). Other researchers do not state the term “eHealth literacy” but describe
3 combinations of different literacies, such as online health literacy, digital literacy, health
4 literacy (28) or talk just about health literacy or health information literacy, even when they
5 indicate competencies relevant for searching for health information on the Internet (29-32).
6 Furthermore, it must be remembered that there is a lot of research done on the research areas
7 of information seeking and information behavior that do not necessarily use the concept of
8 literacy in the context of seeking, understanding and using online health information.

9 **Finding No. 2: There are several models to describe eHealth literacy.**

10 As Norgaard et al. describe in their work, first came the well-known Lily Model by Norman
11 and Skinner (22). This model describes eHealth literacy as a meta literacy consisting of six
12 other competencies (15).

13 This is the most commonly cited model of eHealth literacy. Nevertheless, over the years this
14 model has been critically commented on. As mentioned above, Cameron Norman, one of the
15 pioneers of the eHealth literacy concept, argued that the Lily Model does not describe
16 contexts of use and does not fully fit with interactive Web 2.0 contents where other
17 competencies might be necessary as well (23). Therefore, he points out that researchers, such
18 as Xie (33) and van der Vaart and colleagues (24) have continued to develop the concept
19 further.

20 In 2013 Griebel et al. (34) placed the eHealth literacy model by Norman and Skinner in a
21 wider context by linking it with the Unified Theory of Acceptance and Use of Technology
22 (35).

23 Gilstad took another approach to widen the eHealth literacy concept in 2014 by combining it
24 with contextual factors, such as cultural context, institutional context or the type of eHealth
25 technology (36).

26 In the same year (2014), Koopman, Petroski, Cansfield, Stuppy and Mehr developed the PRE-
27 HIT instrument which was based on a widened understanding of eHealth literacy: they
28 included further variables, including, for example, computer anxiety, computer expertise, or
29 health information, and validated them in focus groups of patients with chronic diseases.

30 In 2015 Monkman and Kushniruk published the Consumer Health Information System
31 Adoption Model (37). They argued that the consumers’ eHealth literacy level and the

1 demands, which a system has for eHealth literacy are moderating the adoption and the
2 successful use of a consumer-oriented eHealth system. eHealth literacy was placed into
3 context with usability and usefulness of eHealth services and described as a moderating
4 variable between the usefulness and usability of a system and the adoption, value and
5 successful use of it.

6 Also in 2015, Norgaard, Furstrand, Klokke, Karnoe, Batterham, Kayser, and Osborne
7 provided the “framework for characterizing e-health users and their interaction with e-health
8 systems” (22). They performed workshops with patients and medical professionals, identified
9 eHealth literacy domains and divided them in an eHealth literacy framework (eHLF). The
10 eHLF includes not only individual factors (e.g. the ability to process information) necessary to
11 use eHealth systems but also system relevant factors (e.g. digital services that suit individual
12 needs) and user-system interaction aspects (e.g. the motivation to engage with digital
13 services). Therefore, the eHLF provides a broad picture of viewpoints that need to be taken
14 into account when creating eHealth tools that fit with the intended users’ eHealth literacy.

15 To conclude, in the described models, eHealth literacy has been looked at under the following
16 perspectives:

- 17 - What sub-competencies are included in the idea of eHealth literacy?
- 18 - What context or user-specific factors might influence the users’ eHealth literacy?
- 19 - What role does the eHealth system play when regarding the individuals’ eHealth
20 literacy?
- 21 - What role does eHealth literacy play when it comes to the adoption and use of eHealth
22 services?

23 **Finding No. 3: The eHealth Literacy Scale (eHEALS) was mostly used but**
24 **there are also other measurement approaches.**

25 Mostly the eHealth Literacy Scale (eHEALS) by Norman and Skinner was used (19) to
26 measure the eHealth literacy of diverse study groups. The scale has been translated from
27 English into at least six languages:

- 28 - Italian (38, 39)
- 29 - Chinese (40)
- 30 - Japanese (41)
- 31 - Spanish (42)
- 32 - German (43)

1 - Dutch (24)

2 Exploring the literature over the years it is clear that there have been numerous critical voices
3 regarding the eHEALS. In general, Hargittai stated that measurements based on self-
4 assessment show problems of validity (44).

5 More specifically, in his 2011 article, Norman explains that the Lily Model and the
6 subsequent eHealth literacy scale were developed before the rise of social media and Web 2.0
7 (23). So the concept and the scale do not consider the use of digital interaction via social
8 media (e.g. Facebook) or specific Internet forums where people share their medical
9 experience with others and exchange best-practice examples. To use such interactive media,
10 Norman states that other competencies are needed and that maybe a social media interactive
11 subscale should be included into eHEALS. This extension of eHEALS should be possible as
12 eHealth literacy is an integrative model of diverse skills and it subsequently can evolve over
13 time.

14 Additional to Norman's thoughts, Van der Vaart et al. found only a weak correlation between
15 eHealth literacy measured by eHEALS and the Internet use of a person and mentioned that
16 this correlation was high when eHEALS was developed (17). They, similar to Norman,
17 concluded that this change evolved from the fact that electronic media has changed over time:
18 Social media and mobile web are common today and are viewed as a dynamic, multifaceted
19 form of media – there is more interaction and not only static health information on the
20 Internet. The skillset that eHEALS should measure has not changed over time, however, the
21 context in which the skills are needed has become more dynamic regarding social media and
22 mobile health.

23 Besides all critical voices, some literature describes eHEALS as a valid and reliable tool to
24 measure patients' eHealth literacy (45). Nevertheless, there are several articles that mention
25 other measurement approaches (e.g. (17, 20, 22, 24, 46-57).

26 - The research group around Furstrand, Kayser, Norgaard et al developed the so-called
27 eHealth Literacy Assessment Toolkit (eHLA) (50). It is based on a framework by
28 Noorgard et al (22) which took both the user and the system perspectives into account.

29 - Koopman et al developed the PRE-HIT instrument to measure the patient's readiness
30 to engage in health information technology (55).

31 - Sekcin et al examined a new 19-item eHealth literacy measurement (e-HLS) and
32 found that it consisted of three factors: communication, trust, and action (56).

- 1 - Ivanitskaya et al used an interactive 56-item online assessment – the Health Research
2 Readiness Self-Assessment (Health-RRSA) for measuring readiness to receive health
3 information. They describe the Health-RRSA as a combination of an electronic survey
4 and an electronic test (52, 53).
- 5 - Ashurst et al criticized eHEALS as a self-assessment tool and used other self-
6 efficiency items. (20).
- 7 - Britt et al used the eHEALS in combination with items from Ajzen’s planned behavior
8 theory (46).
- 9 - Chan et al proposed the combination of the eHealth literacy model and Bloom’s
10 Taxonomy – a classification of intellectual behavior in learning that includes six
11 cognitive process dimensions which differ in regard to their complexity (47, 48).
- 12 - Van der Vaart et al. performed observation studies on how users solved eHealth-
13 related tasks (17, 24). As well as Ashurst et al. they criticized the self-assessment
14 character of eHEALS (20).
- 15 - Chew presented a new eHealth literacy scale based on six components of eHEALS
16 (49).
- 17 - Hanik and Stellefson investigated the perceived and actual eHealth literacy of students
18 using the Research Readiness Self-Assessment (RRSA-h) instrument (51).
- 19 - Stellefson, together with Hanik, Chaney and Tennant, used a Q-technique factor
20 analysis to identify students’ perspectives of personal eHealth search practices and
21 linked it with the participants’ eHealth literacy (57).
- 22 - Jones developed the “Patient eHealth Readiness Scale” (PERQ), which includes
23 competency-related items as well as contextual factors such as Internet use, support by
24 other persons and demographics such as age or gender (54).
- 25 - Most recently Van der Vaart and Drossaert published a new Digital Health Literacy
26 Instrument – the DHLI which takes Health 1.0 as well as interactive Health 2.0 aspects
27 into account (58). This self-assessment tool should be tested in the future among
28 diverse population groups.

29 Overall, it appears that researchers who developed new measurements did not take previous
30 work by other researchers into account. Therefore, currently it appears that the research
31 community in eHealth literacy is providing numerous “stand-alone tools” that are not used or
32 reworked by others.

1 **Finding No. 4: There are several definitions of eHealth literacy.**

2 Norman and Skinner, pioneering in the field of eHealth literacy, provided the definition of
3 eHealth Literacy that is widely used: eHealth literacy is “the ability to seek, find, understand,
4 and appraise health information from electronic sources and apply the knowledge gained to
5 addressing or solving a health problem” (15).

6 In 2015 Bautista performed a literature review on eHealth literacy definitions and, besides the
7 one by Norman and Skinner cited above, found three definitions (59):

- 8 - Chan and Kaufman: “A set of skills and knowledge that are essential for productive
9 interactions with technology-based health tools” (47).
- 10 - Koss: “The ability of consumers (directly or with assistance) to use computers and
11 other communication technologies to find, read and understand health information to
12 make personal decisions” (59). It has to be noted that, for us, it was not possible to
13 find the definition Bautista cited in his article on the Internet or elsewhere - the source
14 might have been removed.
- 15 - Gilstad: “The ability to identify and define a health problem, to communicate, seek,
16 understand, appraise and apply eHealth information and welfare technologies in the
17 cultural, social and situational frame and to use the knowledge critically in order to
18 solve the health problem” (36).

19 Furthermore, Bautista found seven definitions of “health literacy” and three of “digital
20 literacy” and subsequently condensed all found definitions in a new one. According to him,
21 eHealth literacy can be defined as follows:

22 “eHealth literacy involves the interplay of individual and social factors in the use of
23 digital technologies to search, acquire, comprehend, appraise, communicate and apply
24 health information in all contexts of healthcare with the goal of maintaining or
25 improving the quality of life throughout the lifespan” (59).

26 This definition might be supplemented by the following definition by Klecun, Lichtner, and
27 Cornford:

28 “[eHealth literacy is] a dynamic and context-specific ensemble of the skills, attitudes
29 and understandings necessary and appropriate for working with digital tools and
30 systems (including computers, smart phones and other devices) in order to perform

1 health care related tasks both individually and as part of a team, and to participate in
2 processes of (technology-led) change within institutional settings” (26).

3 Furthermore, the eHealth literacy concept by Kayser et al (21) possibly adds further aspects to
4 a definition of eHealth literacy. The researchers defined seven eHealth literacy domains
5 including:

- 6 - Knowledge about one’s own health
- 7 - Ability to interact with information
- 8 - Ability to engage with technology
- 9 - Access to technologies that work
- 10 - Access to technologies that suit individual needs
- 11 - Feel that using technologies is beneficial
- 12 - Feel in control and secure when using technologies

13 Moreover, the ability to search, acquire, comprehend, appraise, communicate and apply health
14 information should not be the only part of a definition of eHealth literacy. The creation of
15 health information is an additional aspect relating to the recent “Framework for Information
16 Literacy for Higher Education by the Association of College & Research Libraries“ (60) that
17 highlights the role of the individuals’ ability to create information as a key element for
18 information literacy.

19 Thus, supplementing Bautista’s meta-definition with the one by Klecun et al. and enriching it
20 with the aspects by Kayser et al., that eHealth literacy also needs to be viewed from a
21 system’s point of view (technologies that work and suit individual needs), and by the
22 Framework for Information Literacy, we might come to a new definition of eHealth literacy.
23 The following definition is proposed. The basis is the definition by Bautista; words in italics
24 are added and include aspects from the definition of Klecun et al., from the extended eHealth
25 literacy view by Kayser et al. and from the Framework for Information Literacy:

26 “eHealth literacy *includes a dynamic and context-specific set of individual and social*
27 *factors as well as technology constraints (such as the fit of a system to a user)* in the
28 use of digital technologies to search, acquire, comprehend, appraise, communicate,
29 apply *and create* health information in all contexts of healthcare with the goal of
30 maintaining or improving the quality of life throughout the lifespan.”

1 **Finding No. 5: Most articles on eHealth literacy are patient-/citizen-/user-**
2 **oriented and do not put eHealth literacy in a broader context.**

3 A large part of articles on eHealth literacy describes the measurement of eHealth literacy and
4 most of the articles are strongly consumer-/citizen-/patient-oriented. This means that they
5 measure the literacy of certain groups, to draw conclusions such as working on appropriate
6 education programs for individuals to enhance their eHealth literacy (61), or to better
7 understand factors that lead to the misunderstanding of electronic health information (62).
8 Mostly, the eHealth literacy of students (e.g. (31, 46, 51-53, 61, 63-67)), and patients (e.g.
9 (16, 17, 25, 29, 30, 68-75)) have been measured in studies focusing on eHealth literacy. The
10 eHealth literacy of elderly persons has also been investigated (e.g. (69, 76-80)) just like the
11 literacy of adult population groups in general (e.g. (78, 81-85)). The eHealth literacy of
12 parents of ill children was measured in some articles (e.g. (62, 86-88)), and the eHealth
13 literacy level of children has been examined as well (e.g. (28)). Some articles focus on the
14 eHealth competencies of patients regarding genetic testing (e.g. (71, 89)), or they focus on
15 the eHealth literacy of war veterans (e.g. (90)).

16 There might be a lack of theoretical frameworks in studies which regard the measurement of
17 eHealth literacy. Most of them use measurement instruments (mostly the eHealth literacy
18 scale) and draw conclusions. Nevertheless, there is only a weak foundation on theoretical
19 aspects such as the fact that eHealth literacy consists of several sub-literacies as found by
20 Norman and Skinner (15). The finding is supported by the work of Mackert et al. which states
21 that more than 90% of all published studies on eHealth literacy or health literacy are not based
22 on theories (91).

23 Furthermore, the conclusions drawn are often rather vague and do not provide specific
24 recommendations e.g. for eHealth developers on how to process the finding that, for example,
25 the majority of people analyzed have a low or medium eHealth literacy.

26 Nevertheless, there are a few articles with a more context-oriented focus on eHealth literacy,
27 such as the paper by Chen and Lee that describes the finding that eHealth literacy has a direct
28 effect on eHealth behavior (64). Another example of more context-oriented work is the paper
29 by Diviani et al. – the authors had a closer look at the relationship between health literacy and
30 the evaluation of online health information (81). Furthermore, Suri et al. found that eHealth
31 literacy was associated with the use of the Internet for obtaining information on a healthy
32 lifestyle (31). Another general approach to see eHealth literacy in a broader context is

1 represented by the paper by Xesfingi and Vozikis, who used a large sample of citizens to
2 explore factors that contribute to their eHealth literacy (92). Klecun, Lichtner and Cornford
3 also explored eHealth literacy in a multi-dimensional way and even provided suggestions for
4 third persons (in this case policy makers and managers) on how to factor the eHealth literacy
5 of citizens in their decisions (26). Monkman and Kushniruk also provided suggestions for
6 third parties by enhancing the online guide on health literacy of the U.S. Department of
7 Health and Human Services (93) by mobile health applications (94). Park, Cormier and
8 Glenna have recently published a study that aimed to link the self-assessed eHealth literacy of
9 citizens to implications on healthcare professionals as to best communicate with their patients
10 (85).

11 **Finding No. 6: There are interventions to improve the eHealth literacy of**
12 **potential users.**

13 Besides the papers on the measurement of eHealth literacy and the papers which consider
14 eHealth literacy in a more context-oriented or theoretical way, there is a huge amount of
15 articles describing eHealth literacy interventions. These intervention include programs,
16 schedules etc. which have been developed to improve the eHealth literacy of numerous
17 individuals. The researcher group of Watkins and Xie has performed various interventions to
18 improve the eHealth literacy of elderly people (33, 95-97). They have also performed a
19 systematic literature review which found that most intervention studies lacked the
20 measurement of health outcomes (98). According to them, currently there is a need for
21 theory-based and well-planned interventions (98).

22 Besides Watkins, Xie and other researchers of this group, Manafo and Wong, dealt with the
23 promotion of eHealth literacy in individuals. They also focused on elderly persons (99, 100).
24 We can conclude that there might be a gap in the research on the promotion of eHealth
25 literacy in other groups at the moment.

26 Similar to articles in which eHealth literacy was measured, a theoretical background is often
27 missing - also in the field of eHealth literacy interventions (98). Furthermore, there still is the
28 question of how to link measured levels of eHealth literacy to the development of eHealth
29 services. How do we as consumers or information providers benefit from the information on
30 the differences of individual eHealth levels?

1 **Question 2: Which are the research gaps on which the scientific**
2 **community should focus more in the future?**

3 **Gap No. 1: Literature on eHealth literacy is mostly focused on the**
4 **measurement of literacy and does not often take theoretical backgrounds**
5 **or implications for third parties into account.**

6 It has been shown that patients who want to manage their health status actively can have
7 better health outcomes than patients who act more passively (101-103). That is one reason
8 why the US American Office of the National Coordinator for Health Information Technology
9 (ONC) developed the so-called Blue Pledge program to support providers of eHealth services
10 in enabling patients to easily access their individual health data (104). Furthermore, there are
11 practice recommendations for physicians on how to help the patient understand direct
12 communication (105). There are also recommendations for designers of eHealth services on
13 how to build easy-to-use websites (93). Nevertheless, both approaches do not take different
14 eHealth literacy levels into account.

15 Moreover, as described above, there are numerous approaches to measure eHealth literacy. A
16 big gap can be found in the conclusions of the articles. Several authors measured the level of
17 eHealth literacy of individuals and they even identified barriers of using eHealth services.
18 Nevertheless, it remains unclear what to do with these findings.

19 If an eHealth service developer wants to create a tool that is suitable for people with
20 low/medium/high eHealth literacy – what are the next steps? The tailoring of health
21 communication, in other words, health information services and their content, should be taken
22 into account in the design of eHealth services (see e.g. (106)). Tailoring can be based, for
23 instance, on the health literacy level of the user. The user's health literacy level and his/her
24 preferences, e.g. for a specific presenting style, can be measured by a short questionnaire and
25 /or usability tests (for example eye-tracking) when the user accesses a website for the first
26 time. Then the content is represented accordingly. Individuals who consider their health
27 literacy level to be poorer most probably prefer texts presented in summarized and
28 popularized form, without difficult scientific concepts. They may also benefit by a
29 visualization of information (107).

30 Ideas like these are linked only weakly to eHealth literacy articles. One example that, indeed,
31 represents practical guidelines for eHealth developers and considers the user's skill set is the
32 work of the research group of Norgaard, Kayser et al. They provided practical guidance for
33 eHealth designers on how to take eHealth literacy into account by proposing an iterative

1 framework to assess the needs of the users. Developers should therefore design personas of
2 the intended users and follow the seven eHealth literacy domains (knowledge about one's
3 own health; ability to interact with information; ability to engage with technology; access to
4 technologies that work; access to technologies that suit individual needs; feel that using
5 technologies is beneficial; feel in control and secure when using technologies) (21).

6 One can look at this gap from a different point of view as well: The measured eHealth literacy
7 of the user has implications on the design of eHealth services and there is no possibility for
8 existing eHealth services to be assessed according to the level of eHealth literacy their use
9 would require.

10 As we found during our research, self-assessment is still the state-of-the-art to measure
11 eHealth literacy in terms of its practicability – therefore it would be helpful if a bridge
12 between these measurements and the design of eHealth services could be built.

13 **Gap No. 2: A gold standard of measurements of eHealth literacy is missing.**

14 As mentioned above, several researchers have created new measurement approaches.
15 However, most of the approaches are not based on well-founded theories as they use
16 measurement items that do not cover all aspects of eHealth literacy (but only self-efficacy, for
17 example). Nevertheless, there are some alternative measurement approaches that are well-
18 based and might be used in the future. The eHealth literacy scale (e-HLS) by Seckin et al.
19 could be an interesting approach that takes the three factor groups “communication”, “trust”,
20 and “action” into account and could be viewed as a tool which provides an up-to-date
21 understanding of eHealth literacy and its measurement (56). The new scale by Van der Vaart
22 and Drossaert might also be interesting (58).

23 To the best of our knowledge, and besides all criticism and the fact that there are other
24 measurement approaches, we found that other measurement tools besides the eHEALS have
25 either not yet been used in practice (like the 2016 approach by Seckin et al. (56)) or have not
26 been used other than in the publication in which the approaches were originally introduced
27 (such as the framework by Chan et al. (47)) .

28 The eHealth literacy community needs to evaluate the existing measurement possibilities and
29 agree on how to measure eHealth literacy in the future.

1 **Gap No. 3 There is only a weak inclusion of medical professionals in the**
2 **measurement and definition of eHealth literacy.**

3 Doctors and nurses have been focused in information-seeking studies for a long time and
4 these studies also include the search for and the use of online information (for reviews see e.g.
5 (108, 109)). On the contrary the focus of the articles in which eHealth literacy is measured is
6 mostly on laypersons. Only a few studies - such as a study on an online health platform for
7 physicians, patients and caregivers by Griebel et al. - measured the eHealth literacy of both
8 medical professionals and laypersons (110).

9 Norgaard et al. performed several workshops, which included patients as well as health
10 professionals and experts in medical informatics to try to identify relevant aspects of eHealth
11 literacy among these various individuals (22). According to these researchers “research in this
12 field [eHealth literacy] has lacked systematic inclusion of users and eHealth professionals in
13 the development of the eHealth literacy concept” (22).

14 MacLure and Stewart published articles on the digital literacy of pharmacists and pharmacy
15 staff. In one study they found that the self-reported digital literacy of pharmacy staff was at a
16 basic level (111). This finding was supported by a systematic review whose authors found that
17 in Australia, Canada and the US, pharmacy staff in general are lacking digital literacy (112).

18 The works by Griebel et al., Norgaard et al. and MacLure and Stewart are the only papers on
19 eHealth literacy aspects we have found where other stakeholders than laypersons have been
20 taken into account. In general, there is a weak point considering eHealth literacy research
21 when it comes to health professionals.

22 **Gap No. 4 Concepts of interactive and mobile eHealth services are generally**
23 **not included in eHealth literacy research.**

24 As Norman criticized in 2011, the Lily Model lacks interactive aspects that might request
25 special types of competencies (23). For example, the use of a smartphone app that enables
26 data upload into a cloud, might require a user who is able to judge if his/her data is safe. More
27 recent measurement approaches like the work done by Seckin et al. provide extended aspects
28 of eHealth competencies – nevertheless, they still focus on webpages (56). The concept of
29 mobile health literacy has recently been introduced in literature (for example (113)).

30 Gilstad provided an extended model in which context plays an important role (36) – this
31 should be taken as the starting point to broaden the understanding of eHealth literacy.

1 **Gap No. 5: eHealth literacy is not the only barrier within the use of eHealth.**

2 There are also other research areas dealing with barriers regarding the use of technology.
3 There are, for example, technology acceptance models (35, 114-116) or research models in
4 the social sciences such as the Theory of Reasoned Action (117) or the Social Cognitive
5 Theory (118).

6 Technology acceptance models have been tailored to fit with eHealth services. Model
7 extensions like the e-HTAM (119) or the work of Ahadzadeh et al., who combined the Health
8 Belief Model and TAM (120), could be linked to the concept of eHealth literacy.

9 **Conclusion: eHealth literacy research - Where are we and where to go?**

10 Although we did not intend to provide a systematic review of the literature in eHealth literacy
11 and might have missed some articles, we can draw several conclusions.

12 eHealth literacy research includes a large number of articles describing studies where the
13 eHealth literacy of defined user groups has been measured. Another broad field of research
14 includes articles which deal with the promotion of eHealth literacy in (mostly elderly)
15 individuals. Both topics – the measurement of eHealth literacy and the promotion of those
16 competencies – are often lacking both a well-founded theoretical basis and approaches to put
17 eHealth literacy in a broader context. Furthermore, the researchers often did not draw
18 conclusions, especially when it came to the design of fitting eHealth solutions for the
19 individual's eHealth literacy level. The eHealth literacy scale eHEALS is based on a cognitive
20 view of learning and knowledge acquisition, and is mostly used to assess the literacy level of
21 individuals. There are critical voices regarding the underlying eHealth literacy concept of
22 Norman and Skinner and the scale itself. Numerous researchers are aware of limitations in
23 relation to both social media platforms and interactivity in eHealth services. Therefore, there
24 are approaches based on social constructivism to extend or rework the understanding of
25 eHealth literacy and to create new measurement tools. However, these approaches often seem
26 to be stand-alone and are not built upon work of other researchers. The concept of eHealth
27 literacy has been defined several times but mostly the definition by Norman and Skinner from
28 2006 has been used.

29 A new gold standard of the understanding of what defines eHealth literacy is needed, as the
30 one by Norman and Skinner is no longer up-to-date. The authors of this paper propose a new
31 definition that includes aspects like interactivity, a dynamic evolvement of literacy, changing

1 information practices of individuals and the integration of technology aspects. The new
2 definition is stated as follows:

3 “eHealth literacy includes a dynamic and context-specific set of individual and social
4 factors, as well as consideration of technological constraints in the use of digital
5 technologies to search, acquire, comprehend, appraise, communicate, apply and create
6 health information in all contexts of healthcare with the goal of maintaining or
7 improving the quality of life throughout the lifespan.”

8 A gold standard is also needed for measuring eHealth literacy – there are several approaches
9 besides eHEALS but they have not been used in practice and do not take the work of other
10 researchers into account. Methods are needed that are based on theories that also include
11 further acceptance factors and interactive Health 2.0 aspects.

12 Methods and measurements, which combine subjective self-assessments and the objective
13 measurement of the individual’s skills and abilities concerning eHealth should be developed.
14 In general, self-reports are more susceptible to retrospective recall of behavior and social
15 desirability than objective measurements. In fact, there is an on-going debate on whether
16 health (information) literacy represents a skill-based construct for health self-management or,
17 in a broader sense, whether it captures the personal activation or motivation to manage health
18 (121). The self-assessed measurements may reflect more on the self-efficacy and motivation
19 of the individual than his/her actual skills and abilities (see e.g., (122)). However, both aspects
20 are important and they also make independent contributions to health.

21 Another research gap can be found in the deficient integration of health professionals in the
22 research of eHealth literacy – both in measuring and in defining eHealth literacy aspects.
23 eHealth literacy is mostly seen from a laypersons’ perspective. There are only few approaches
24 where the potential aspects of eHealth literacy – beyond the personal factors of a layperson -
25 are taken into account. This includes technical aspects (the systems’ suitability for the user)
26 and the point of view of health professionals.

27 Last but not least the linkage between the measurement of eHealth literacy and the design of
28 appropriate eHealth solutions is very weak. There is almost no starting point for eHealth
29 designers who might want to take the individual’s eHealth literacy level into account when
30 creating electronic health solutions.

1 To conclude, the research community in eHealth literacy needs to focus on the following
2 aspects in the future:

- 3 1. To agree on an updated definition of eHealth literacy.
- 4 2. To set a gold standard for measuring eHealth literacy subjectively (and objectively).
5 To take the work of other researchers into account when creating new scales in order
6 to avoid numerous “stand-alone approaches”.
- 7 3. In case of studies that aim at measuring eHealth literacy: To provide clear information
8 on the reasons why the literacy was measured, on the theoretical basis on which the
9 research is taking place and on the handling of the results.
- 10 4. To consider the design of eHealth literacy interventions not only for elderly people but
11 for other user groups as well.
- 12 5. To consider the viewpoints of health professionals and laypersons AND other aspects
13 such as technological constraints as well as to not consider eHealth literacy as isolated
14 from related areas of research such as research on usability or technology acceptance.
- 15 6. To provide a clear guidance for the developers of eHealth services on how to process
16 the different levels of eHealth literacy of their intended users.

17 **Authors' contributions**

18 LG, HE, HG, ALP and JM work together in an international research group on eHealth
19 literacy. For this article they all provided their expertise and knowledge on eHealth literacy.
20 LG carried out the writing of the manuscript, HE, HG, ALP and JM commented intensely and
21 provided further aspects and text pieces. MS supervised the work and provided the initial idea
22 to write a viewpoint paper on eHealth literacy.

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1 **Conflicts of Interest**

- 2 We have read and understood the policy on the declaration of interests of Informatics for
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