Factors that influence public engagement with eHealth

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Abstract

Public engagement with eHealth is generally viewed as beneficial. However, despite the potential benefits, public engagement with eHealth services remains variable. This article explores reasons for this variability through a review of published literature. A focused search, conducted in January 2009, of three bibliographic databases, MEDLINE, CINAHL and EMBASE, returned 2622 unique abstracts. Fifty articles met the inclusion criteria for the review. Four main types of eHealth service were identified: health information on the Internet; custom-made online health information; online support; and telehealth. Public engagement with these services appears to depend on a number of factors: characteristics of users; technological issues; characteristics of eHealth services; social aspects of use; and eHealth services in use. Recommendations for policy makers, developers, users and health professionals, include: targeting efforts towards those underserved by eHealth; improving access; tailoring services to meet the needs of a broader range of users; exploiting opportunities for social computing; and clarifying of the role of health professionals in endorsement, promotion and facilitation.

Introduction

Unsurprisingly, definitions of eHealth tend to include aspects of both health and technology; health is generally viewed in terms of process rather than outcome, and technology is seen as a means to supplement, rather than replace human activity. One of the more commonly-cited definitions presents eHealth as 'an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology'[1]. eHealth is usually presented in a positive light [2] and public engagement with eHealth services is generally seen as beneficial. For example:

- The Internet provides access to a wealth of current health information [3, 4].

- Recent advances in social computing provide new opportunities for support [5, 6].

- Telecare applications have the potential to help meet the demand for care resulting from the combination of an ageing population and a depleted workforce [7].

Despite these potential benefits, and despite the continued growth in eHealth services, public engagement remains variable [3]. This review of published literature seeks to explore the reasons for this variability.

Background

This literature review forms part of a larger project '*Including everyone in electronic health information services*'. The larger project, commissioned by the National Health Service (NHS) in England seeks to find out what help people need to access and use eHealth services.

The aim of this review is to identify and explore factors (barriers and facilitators) that may influence engagement by the public with those services.

Selection of articles

Literature considered in this project includes national and international journal articles, academic or professional (non-academic), and accessible via three commonly-used bibliographic databases: MEDLINE, CINAHL and EMBASE. The search strategy was developed in stages. An initial text search of MEDLINE (via OVID) was carried out using relevant terms in order to find exemplar articles from which to harvest indexing terms i.e. Medical Subject Headings. The terms used in this initial search were: 'healthspace' (2 articles returned), 'nhs choices' (1 article), 'choose and book' (19 articles) 'ehealth services' (12 articles) and 'e-health services' (24 articles). HealthSpace, NHS Choices and Choose and Book are the names of specific eHealth services provided by the NHS in England. The harvested keywords from this initial search were allocated into one of three categories:

  a. Computer applications *e.g.* Information Systems, Internet, Telemedicine

  b. Health services *e.g.* Information Service, Referral and Consultation, Self Care

  c. Evaluations *e.g.* Attitude to Computers, Focus Groups, Patient Satisfaction

A test MEDLINE search was conducted, with keywords within each category combined by OR and the categories combined by AND. The aim was to access a broad range of evaluation literature around the use of computer applications in health care. The categories and keywords were fine-tuned to ensure that at least all exemplar articles were returned in the final MEDLINE search. Finally, the strategy was reworked for use with CINAHL (via EBSCOhost) and EMBASE (via the National Library for Health, now NHS Evidence).

All searches were carried out in January 2009 and were not limited by date. The bibliographic details for each item from the initial search were reviewed independently by members of the project team (NRH, MJG). Articles were retrieved for further analysis according to the following criteria:

- The full text of the article is readily and freely available online *i.e.* open access or available via the host institution's e-library of online journals

- The article is published in English

- The article includes a named or identifiable example of an eHealth service

- The eHealth service is intended for use by members of the public i.e. in a non-professional capacity

- The article describes barriers or facilitating factors that may influence the use of eHealth services

- Both reviewers agree that the article should be included (disagreements over which items to include being resolved through negotiation at a face-to-face meeting).

The following types of articles were excluded:

- Book reviews, commentaries, conference reports, papers or abstracts, editorials and viewpoints

Relevant literature reviews were included but these were reserved for cross-validation of the findings of this review. Agreed included articles were obtained, allocated arbitrarily to the two team members and subjected to further analysis. A tailor-made data extraction tool was used to analyse articles into the following categories: bibliographic details: eHealth service (including purpose): study design including participants (types of users, numbers of participants, comparison groups), methods of data collection and analysis and timescale;

findings; barriers; facilitators/motivators; and reviewer and review date. Emergent themes that were common across different articles were identified through a further face-to-face meeting.

Findings and discussion

The initial search returned 440 items via CINAHL, 1226 via EMBASE and 1153 via MEDLINE. After the removal of duplicates, 2622 items were reviewed by both members of the project team. The reviewers agreed that 70 articles should be obtained for closer examination of which 50 were identified as meeting the inclusion criteria – these were subjected to further analysis. Six additional literature reviews were obtained for post-analysis cross-validation of findings.

The first set of themes to emerge from the analysis concerned the type of eHealth service (or resource) featured in the articles. There were four main types of eHealth service: health information on the Internet (featured in 27 articles); custom-made online health information *e.g.* CDs, kiosks, portals (7 articles); online support *e.g.* coaching, mailing lists and online communities (12 articles); and telehealth including remote consultation, monitoring and reporting (4 articles).

The second set of themes to emerge concerned barriers and facilitators. One hundred agreed unique themes emerged. These were distilled into 5 overarching themes: characteristics of users *e.g.* literacy levels; technological issues *e.g.* security and privacy; characteristics of eHealth services *e.g.* content issues; social aspects of use *e.g.* shared experience; and eHealth services in use *e.g.* fit with everyday life. The remainder of the article is structured according to these 5 overarching themes.

Characteristics of users

Age appears to affect the uptake of, and satisfaction with, eHealth services. In a questionnaire survey of 235 gynaecology patients in New Zealand, Brenner [8] found that people between 50 and 60 years of age found a web-based gynaecology results reporting service less user-friendly than those in their twenties. The author suggests that this may not be due to ease of use, but to the ability of older users to use the Internet. In a later study of 560 French breast cancer patients in 11 centres, Mancini *et al.*, [9] noted that, once multivariate adjustments had been made, increasing age was a contributing factor in decreased levels of Internet use for health related information.

Ethnicity also appears to affect access to, and uptake of, eHealth services. During a 7-week period in June/July 2003, Dickerson *et al.* interviewed 315 patients attending three urban primary care clinics affiliated with the School of Medicine, University of Buffalo about their access to the Internet [10]. They found that respondents classified as white reported higher online access. In relation to direct Internet use, qualitative interviews were undertaken with 800 recently diagnosed cancer patients and 200 carers in 3 Birmingham teaching hospitals in the United Kingdom [11]. James *et al.* noted direct Internet use by Asian patients and their carers was low; 2% and 9% respectively. Comparative data for non-Asian patients and carers was not given. Between October and December 2000, 188 women with early stage breast cancer at Columbian Presbyterian Medical Center, New York, USA responded to a mailed self-report questionnaire survey [12]. Although not statistically significant, Fogel *et al.* noted that non-whites were less likely to use the Internet. This theme recurs throughout the literature.

Economic status also appears to affect uptake of eHealth services. In a subset of a wider UK study, Blackburn and Read analysed data from postal questionnaires on Internet use for 788 carers of disabled children [13]. Non-Internet users were less likely to be in paid employment, more likely to be living in rented accommodation and less likely to have access

to a PC at home. Similar findings were identified in questionnaire survey of 718 people from three disparate communities in Australia [14].. The aim of the survey was to explore attitudes to, and use of, the Internet as a source of information across high and low socio-economic groups Dart reported that those from lower socio-economic groups had lower levels of home Internet access, lower levels of accessing health information over the Internet (even amongst those who had home Internet access), and they ranked the Internet lower as a source of health information (independent of access). In their study of direct Internet use James *et al.* [11] noted that patients whose cancers are typically associated with lower socio-economic classes (bladder head and neck cancer) reported lower use of web-based information; those from semi- or un-skilled backgrounds reported lower Internet use generally. Those from professional or managerial backgrounds were more likely to have used the Internet. Although contributing factors were not explored in the study on Internet use by Fogel *et al.* [12], respondents with higher levels of income were more likely in this study to be Internet users. This finding is supported by a questionnaire survey of 139 patients attending a multidisciplinary thoracic oncology clinic in a Midwestern University Hospital in the USA [15, 16] which found that larger annual incomes, along with higher levels of education, were associated with increased levels of Internet use. Both factors were positively associated with having a computer and Internet access at home.

Educational attainment appears to influence access to, and uptake of, eHealth services. In Dickerson *et al.*'s study on Internet access, whether patients had attended or not attended college was, along with ethnicity, a significant predictor of online health information seeking behaviour [10]. Similar findings were reported by Fogel *et al.* [12] and by Peterson and Fretz [16] who also found that achieving a higher level of education and having a larger annual income were associated with higher computer use at home (100% vs. 34%) and higher Internet access at home (100% vs. 28%). Flynn *et al.* [17] undertook a longitudinal study of

high school graduates in Wisconsin, USA, to determine the characteristics of patients seeking health information online and the timing of those searches in relation to visiting a doctor. This phone and mail self report study of Internet-based health information seeking by 6279 high school graduates aged 63-66 in Wisconsin, USA, found that, for those with Internet access, years of education was positively associated with searching for health information online, irrespective of timing of a visit to the doctor. Mancini *et al.* [9] and James *et al.* [11] also reported that level of higher education correlated with greater use of information via the Internet.

In common with educational attainment, literacy levels are also a factor that affects use of eHealth services. Birru *et al.* [18] undertook a mixed method study of 8 low literacy adults (3rd to 8th US grade) who were participating in a reading assistance programme in Pittsburgh, USA. This exploration of the use of the Internet for health purposes involved self-directed searches for designated health topics. Subjects participated in a computer skills workshop 3 weeks prior to the study. In the study itself, data was captured through think-aloud protocol, keystroke capture and questionnaire. Birru *et al.* reported that a low literacy level in adults appears to inhibit health information seeking efforts, with most web sites requiring at least a high school level of reading proficiency. In evaluating 10 years of published research relating to CHESS, the Comprehensive Health Enhancement Support System, University of Wisconsin, USA, Gustafson *et al.* [19] noted that bespoke health information sources, such as CHESS, also require a greater level of literacy for optimal access. In 2005, Gray *et al.* conducted 26 focus groups with a total of 157 adolescent students (aged 11-19) in diverse geographical and socio-economic settings in the UK and USA to explore health literacy challenges when using the Internet for online health information [20]. They noted that participants' health literacy was deficient in relation to: a) functional skills *e.g.* question construction; b) critical skills *e.g.* discerning relevant information; and c)

interactive skills *e.g.* applying acquired information to own personal circumstances. In a later qualitative study of patient attitudes to a range of eHealth services, Greenhalgh *et al.* noted that respondents with higher literacy levels were likely to have a greater awareness of eHealth services [21].

Level of motivation and degree of engagement are significant indicators of uptake of eHealth resources. This includes interest in one's own health, openness to experience or a belief that information can make a difference to health. In-depth interviews were undertaken with 13 female patients, aged 55-74, attending a GP surgery in Musselburgh, Scotland over two consecutive days, regarding the provision of touch screen health information kiosks within the surgery [22]. Williams *et al.* noted that participants lacked curiosity to use the kiosk, could not see what the kiosk might have to offer, and had assumed it was for professional use only. A lack of interest was also noted in Peterson and Fretz's study of Internet use [16]. Structured interviews to examine Internet use by 200 cancer patients in the USA revealed that perceptions of information accuracy acted as barriers to use [23]. Helft *et al.* found that although 44% of non-users would access cancer information via the Internet if they had access, 49% were not interested in using the Internet as an information source, possibly as a consequence of not knowing that cancer information was available via this route. A belief that information would enable people to deal better with their health was a motivating factor reported by participants of Rogers and Mead's study of 17 people who had accessed a free Internet clinic [24]. In semi-structured interviews with a subset of 5 participants, it was noted that this group used the Internet to augment services and to fill the knowledge gap. Openness to using eHealth resources was also highlighted as a facilitating factor in Flynn *et al.*'s study of Internet health information seeking [17]. Finally, Greenhalgh *et al.* [21] noted that level of engagement and level of health literacy were associated with a positive response to eHealth services, while a lack of interest in one's own health was likely to reduce use.

While prior use and a familiarity with the Internet appear to be significant factors affecting uptake of eHealth services, poor computer skills, not being able to find specific resources or not knowing that relevant resources are available also inhibit use. During 2000, 27 focus groups were undertaken with 210 young people in Ontario, Canada regarding the quality of their experiences in searching for health information via the Internet [25]. Skinner *et al.* reported on the difficulties encountered by participants in finding information on health-related topics, compared with music, pornography or sports, and the frustration felt about knowing that information exists but not knowing how to access it. A lack of computer and searching skills is a recurrent theme in the literature. Bowen *et al.* [26] reported that in their telephone survey of 431 women aged 18-74, in King County, Washington State, USA, for respondents who were unfamiliar in using the Internet; this obviously inhibited use. The lack of Internet searching skills was also noted as an inhibiting factor in Blackburn and Read's study [13], and in the study by Helft *et al.* [23]. Ibrahim and Boulos [27] undertook a questionnaire survey of 150 Saudi cancer patients to examine Internet utilization, barriers to access and information need and found levels of awareness of the availability of online health-related resources to be minimal. Accessing the Internet in general or an eHealth service in particular appears to foster a willingness to increase subsequent use. In an observational study, supplemented by a questionnaire survey, 25 non-urgent patient attending General Practice surgeries were given the opportunity to access a secure one-to-one triage advice service online. Eminovic *et al.* [28] noted that once patients had used the service they were more positive about future use. Dart *et al.* [14] noted that frequent Internet users were more likely to access health information, and to consider it more important.

In a telephone survey of 500 Americans seeking to compare health information use between those who were sicker and those who were healthier, Houston and Allison [29] found an association between lower health status and a shorter history of Internet usage. However,

those with fair or poor health status were more likely to participate in online chat rooms.

Lower levels of mental health, along with higher perceptions of general health, were

positively correlated with levels of Internet use in Bowen *et al.* [26]. Contrary to

expectations, Greenhalgh *et al.* [21] found that those defined as having a potentially

stigmatising condition *e.g.* epilepsy, believed that the potential benefit of having an

accessible health record in the event of a seizure outweighed the risk of a third party

obtaining unauthorised access to their health record..

Differing information needs and expectations were apparent in an investigation in Denmark

of an asthma telehealth service. The online survey, undertaken by Anhoj and Nielsen in 2004,

sought to describe and evaluate use by patients and health care providers of LinkMedica [30].

LinkMedica is an online service providing an asthma diary with an algorithm for self-

management, an approved knowledge resource with summaries of evidence and detailed

articles, an un-moderated forum and the opportunity to direct questions to experts. Eighty

five individuals (including 8 health care providers) completed the online survey, and 15 were

selected for in-depth semi-structured interviews. There appeared to be two distinct user

groups, each with specific requirements and expectations of the service. The first group had

what is described as an 'outside-in perspective' in that a problem arose in the outside world

which they would expect to find answers to from LinkMedica. They expected concise

information and advice relevant to their particular and current circumstance. They did not

wish to use the diary to monitor their disease and avoided scientific articles and expert

opinion. The second group had what is described as an 'inside-out' perspective. This group

were more often males who found the news, discussion forums and expert sections a

distraction, preferring to have fast access to the diary function without technical obstacles.

Trust was a factor associated with the use of several of the eHealth services identified in this

review. In a 4-week online virtual focus group of 13 members of an online community

('Zappers') for recipients of an implantable cardioverter defibrillator (ICD), and follow-up email interviews with 8 participants in the USA, Dickerson [31] discovered that the Internet was considered by many as 'a goldmine of ICD knowledge' and is greatly valued as an open and trustworthy source of ICD information and the latest news and research. However not all studies were so positive in their findings. In Mancini *et al.*'s study on health information via the Internet [9] the views expressed about web sites were divided: 11.1% both positive and negative views expressed, 23.8% positive views expressed; 31.7% negative views expressed; 33.3% no opinion. Those respondents who expressed negative opinions about health information web sites indicated a preference to be directed to specific web sites, reporting that the difficulties they experienced in understanding detailed medical web sites was stressful. In contrast, 121 English-speaking Canadians completed an 18 item online questionnaire in Khechine *et al.*'s [32] study of patients with long term conditions into the use of English language web sites. More than 79% of respondents visited science-oriented web sites, including government websites, and the sites of chronic illness associations and foundations, for trustworthy information on treatment options, application or follow-up. However, this trust in research and researchers is not universal. In Norway, Glenton *et al.* [33] undertook 4 focus groups of back pain sufferers or their carers and family members to evaluate attitudes to the use of research-based information. All users had easy access to the Internet and were sent a hyperlink to the BackInfo web site, a resource developed using the results of Cochrane systematic reviews on low back pain. Respondents expressed a suspicion towards research evidence on the basis that it was part of the health establishment and therefore are more likely to be biased towards orthodoxy. There was also dissatisfaction that research situations were not transferable to real life with an enthusiastic preference for personal stories of back pain sufferers. Concerns over the reliability of web sites were also expressed in Khoo *et al.*'s [34] interview survey of parents' search patterns for children's

health information. Respondents were parents attending a tertiary paediatric emergency department in Melbourne, Australia. 55% of the 360 respondents expressed concern about health information on the Internet and 65% expressed concern about the reliability of sources. Negative past and present experiences of healthcare and government surveillance were perceived as barriers to the uptake of the NHS Summary Care Record in Greenhalgh *et al.* [21]. And finally, Chung and Kim [35] reported that blogs are perceived as credible sources of information on prevention and care in their self-administered questionnaire survey of 113 members of a cancer-related blog frequented by patients and carers.

Technological aspects

In 1999, Pennbridge *et al.* [36] undertook a random digit dialling computer-assisted telephone questionnaire survey of 1007 adults in California to investigate how Californians use and rate health information sources, and noted that respondents with Internet access were significantly more likely to have sought health information (56%). Also in 2005 Helft *et al.* [23] noted that only 10% of their sample used the Internet and a further 21% obtained information via a proxy. However 44% of respondents reported a willingness to use the Internet for health information if they had Internet access. In the same year, Blackburn and Read noted that a key reason cited for not using the Internet was not having a PC at home [13]. This finding is supported by Ibrahim and Boulos [27] who showed through multivariate analysis that the only distinguishing feature between Internet users and non-users was PC ownership. Similarly, Dart [14] indicated that using the Internet at home was a factor in the frequency of access to the Internet in general and health information in particular. In contrast to Helft *et al.* [23], Andreassen *et al.* [37] noted in their telephone interview study of citizens in 7 European countries that 71% of respondents were Internet users and had used the Internet for health purposes.

Boukhors *et al.* [38] conducted a randomised cross over trial involving the use of computer-assisted insulin dose management by 10 type 1 diabetes patients. The aims of the trial included an assessment via pre and post treatment questionnaires of the impact of the computer programme on knowledge, behaviour and quality of life. Although there appeared to be no improvement in terms of quality of life or behaviour, participants' knowledge of their disease improved and they appreciated the software and wanted to continue using it.

Anhoj and Nielsen [30] noted that connection speed and logging on times were an obstacle to uptake of an asthma telehealth service (although these were probably associated with the use of analogue modems).

Eminovic *et al.* [28] noted that although the average duration of contact for a one-to-one online triage advice service was 30 minutes, patients responded positively to using the service. In 2005 Bruwer and Stein emailed a questionnaire survey to subscribers of two Internet support groups for people suffering from hair-pulling (trichotillomania) (n=1010) to investigate the support groups' perceived effectiveness [39]. The study was conducted in South Africa and the findings were based on an analysis of 81 questionnaires. Although respondents felt supported, they indicated three issues that impacted on their use and satisfaction with the group: the abrupt ending of discussion threads; the large number of messages to be read and/or responded to; and, deviation away from the topic in question. It should be pointed out that neither of the support groups in question was moderated, which may have contributed to the frustration of members. In a study of another un-moderated Internet breast cancer list, Esquivel *et al.* assessed the accuracy of information posted to the list between 1st January and 23rd July 2005 [40] and identified 10 postings (out of a total 4600 postings, (0.22%) that were either misleading or false. However, 7 of these were identified and corrected by other participants, typically within an average of 4 hours 33 minutes.

Respondents (specifically those *with* Internet access) in the study of attitudes to information sources by Pennbridge *et al.* raised concerns about security and privacy issues [36]. Participants expressed unease about the further integration of the Internet with their care and apprehension about medical records being made available via the Internet.

Characteristics of eHealth services

In a UK-based exploration via questionnaire (n=195) of Internet use for information concerning Barrett's oesophagus [41], 53.8% of respondents (average age 58.7 years) said that, given access, they would use the Internet. 40.5% of respondents (average age 69.4 years) reported that they would not use the Internet. Several people who had used the Internet reported that all the sites were American and were 'produced in a way that made them difficult for the average man on the street to understand'. The authors remarked that the information on these sites was often 'unvalidated'. Sim *et al.* [42] also found issues with content in their study of health information seeking via the Internet. 94% of respondents reported that they found the Internet useful. However of these, 18% found the information 'too technical', 18% reported that the information was 'too distressing' and while 15% felt there was too little information, 13% felt there was too much. 6% of respondents did not find the Internet useful.. 31% of respondents in the study by Mancini *et al.* [9] had negative views of web sites (in the context of cancer information). Among Internet users, negative comments indicated that detailed medical information is difficult to understand, and that a recommended web site would be preferable to having to search (particularly as many medical web sites are written in English). In the study by Birru *et al.* of Internet use for health purposes [18], although subjects were judged to have answered only 8 out of 24 questions 'correctly' via the Internet, self-reported data was generally more positive, indicating that the subjects were overestimating their own ability. Several subjects had difficulty searching and navigating web

sites and had problems understanding health-related web sites due to a mismatch in literacy levels. In contrast to this, in a randomised controlled trial in the USA involving an Internet-based health coaching resource [43] only one participant (out of 121 patients with chronic pain, depression or impaired mobility) reported difficulty understanding or using the educational materials. A study in the USA by Bernhardt and Felter [44] of 20 young mothers in 4 focus groups explored the use of the Internet for paediatric health information. Most participants had used the Internet to access health information both during pregnancy and after childbirth. The study reported that, although participants did use commercial websites, they expressed disdain for product websites. Organisational websites were seen as useful but sometimes 'too scientific' (note that the average reading age of participants was higher than average). Many participants were concerned about the reliability of websites and had their own strategies for determining credibility *e.g.* trusting websites from education (.edu or .ac) over those from the commercial sector (.com). In terms of online support, participants preferred online health information to come from health professionals but parenting information to come from parents. Again in the USA, Diefenbach and Butz [45] evaluated an interactive educational system for survivors of prostate cancer. The study involved a preliminary survey of 675 patients (response rate unknown), 3 patient focus groups (n=18) and 2 spouse focus groups (n=15). Overall, participants were very interested in the software and appeared to prefer it to print material. They appreciated the use of metaphors, the tailoring of information according to individual needs, and the flexibility to access information in any order.

Clearly, content does not always act as a barrier to engagement with eHealth services. For example, Khechine *et al.*[32], found that the most commonly-reported reason for seeking information was at the treatment identification phase of an illness (94.2%), closely followed by the treatment application or follow-up phase (86%). Interestingly, the most visited web

sites were those that provided scientific information (*e.g.* governmental web sites, or web sites of associations or foundations).

In 2003, Skinner *et al.* [25] reported that in terms of the popularity of the Internet as a source of information, anonymity was a common theme *i.e.* anonymity acts as a facilitator for managing sensitive content. Participants with dental phobias (n=143) in an online survey of an international online support group to provide support to those with dental anxiety [46] appeared to benefit from a feeling of not being alone and appreciated a safe and non-judgemental, empathic, understanding environment. Participants reported that online communication conferred a degree of autonomy and control that would not be possible in face-to-face interactions. As well as having access to practical information from others, group members also reported a degree of empowerment in relation to their condition. These findings are supported by Bruwer and Stein [39] and Dickerson [31]. A further study by Hoybye *et al.* exploring attitudes towards a mailing list (SCAN-BC-LIST) involved participant observation and semi-structured face-to-face and on-line interviews with 15 women with breast cancer who had undergone breast surgery and had received or were receiving chemotherapy in Scandinavia [47]. The findings were similar to those of Buchanan and Coulson [46] although participants reported that it was absence of face-to-face contact on the Internet rather than anonymity that made it easier to start discussions on difficult and painful subjects; the intimacy and trust formed online created the basis for discussion when women met face-to-face. Anonymity may actually act as a barrier to engagement with some eHealth services. In a comparison between a telephone helpline and a personalised online cancer information service, Hardyman *et al.* [48] found that, while participants valued the use of a range of media, the impersonal nature of online services may affect people's willingness to seek information on sensitive topics. The UK-based study involved an analysis of anonymised summaries for 994 telephone enquiries and 3096 web enquiries. Users of the

web tended to focus on facts to fulfil basic information needs *e.g.* types of cancer and were less likely to request information on sensitive issues, while telephone users wanted to discuss less tangible issues *e.g.* living with cancer. Williams *et al.* [22], found value also in direct person-to-person communication in their study of touch screen health information kiosks. For the people involved, the first and major source of information was the doctor; other sources were consulted when recommended or provided. There was a lack of curiosity and an assumption that the kiosk was not intended for patients or would not meet their needs.

Social aspects of use

In Dickerson's study of an online community [31], as with Bruwer *et al.* [39], respondents valued being part of a group of individuals who were in a similar position to themselves and could comprehend and identify with their experience. Members of the HeartNET online support group investigated in Bonniface and Green's [49] mixed method study indicated that they gained a sense of reassurance and empathy from the online community. Bonniface and Green used a combination of formal semi-structured in-depth interviews and an analysis of discussion board data and other information exchanges. Respondents to Buchanan and Coulson's [46] questionnaire survey indicated that access to and sharing of personal stories in a safe and non-judgemental environment were key motivators for continued membership of the support group.

The sharing of experiences was instrumental in members initiating postings in the qualitative analysis by Frost and Massagli of a sample of 123 (2%) messages posted to PatientsLikeMe online community for amyotrophic lateral sclerosis [50]. It was noted by Glenton *et al.* [33] in their study on the use of research-based information that participants were sceptical and mistrustful of researchers and research evidence, believing them to be biased for or against particular types of medicine and different from 'real life'. However, participants indicated

that when research findings were integrated with case histories the findings could be personalised and were subsequently viewed as more meaningful.

In Dickerson [31] respondents reported the value of social interaction as facilitated by the 'Zappers' online community. The accessibility of the group compared with face-to-face meetings, and the opportunity to relate to, confide in and encourage others were particularly appreciated. Hoybye *et al.* [47] reported a similarly positive reaction to online support groups in their study. Participants valued the mailing list for its role in breaking down social isolation. Newly diagnosed women used the list to seek the advice and experience of women who had already lived through surgery and various treatments, while women who had lived with breast cancer for some time 'gratefully took the opportunity of telling their stories'. Members reported that the lack of a physical presence (not to be equated with anonymity) made it easier to start discussions on difficult and painful subjects.

Respondents in Bonniface and Green's [49] study found the HeartNET online support group to be emotionally supportive and providing a sense of reassurance. In a purposive sample of participants in a randomised controlled trial (RCT) of joint teleconsultation (JTC), Harrison *et al.* [51] undertook semi-structured interviews with 28 RCT participants into their perceptions of JTC. Participants reported that they found the presence of a generalist clinician reassuring during JTCs with specialists, felt they had the undivided attention of the specialist, and thought they could ask the questions they wanted to ask. They particularly liked the debriefing after the consultation, although they indicated that they would prefer a face-to-face consultation if a physical examination was required. In March-April 2005, van der Meer *et al.* [52] undertook a comprehensive study involving a one month observational study of Internet based lung function and symptom monitoring of 97 adolescents from 19 GPs in the Netherlands. This was followed up with 35 of the adolescents taking part in one of eight focus groups. van der Meer *et al.* noted that those with poor asthma control gained

reassurance from messages when function or symptoms deteriorated and from advice on how and when to change medication. This population found the site useful in formulating care plans and were able and ready to use the self-management plan for a long period (defined as at least a year).

A sense of shared responsibility and community was evident in the study by Esquivel *et al.* [40] into the self-policing of a breast cancer mailing list. This ethos was also evident in HeartNET [49] in that the support group demonstrated a shared responsibility in dealing collectively with difficult questions posed by members.

Not all aspects of online support groups are positive. Bruwer *et al.* [39] indicated that personal interactions and alternative view points of other members or the owners of mailing lists were potential barriers to ongoing participation. Also, one participant in Bonniface and Green's [49] investigation of HeartNET mentioned a reticence in sharing her experiences because she did not want to dwell on her illness, nor cultivate a 'victim-like or competitive environment' of sharing.

eHealth services in use

In Blackburn and Read's study [13], circumstantial barriers to Internet use included lack of time due to caring (57%) or other circumstances (61%), and costs associated with telephony (22%) and equipment (15%). Lack of time available was reported as an issue also by Skinner *et al.* [25], and cost was cited as an issue in Helft *et al.* [23]. However, while time may be an issue, in a study of 138 questionnaires completed by attendees at a rheumatology clinic in Scotland, Gordon *et al.* [53] found that 31% of people felt that using the Internet to find information about their condition was easier than asking a doctor or a nurse (and while the study was conducted some years ago, it is interesting that none of the participants recalled ever having been advised by a doctor or nurse to search the Internet for information on their

diagnosis). In contrast, in their evaluation of an asthma telehealth service, Anhoj and Nielsen

[30] found a lack of fit due to timing and technical and psychological factors.

In their exploration of health-related Internet access and use by women in the USA, Bowen

[26] reported that of the 21% of participants without Internet access 1:3 cited cost as a

barrier. However, perceived lack of usefulness of the Internet as an information source and

unfamiliarity with using the technology appear to be equally important reasons. Email was

reported as the most frequently used resource and the most desired by those without access.

Rogers and Mead [24] also revealed for some participants a perceived lack of usefulness and

relevance of information for managing their health and health care. The study concluded that

access to health information via the Internet would not guarantee equity. For participants

adept at using computers and with high expectations about good outcomes for information

utilisation, Internet information enabled them to negotiate better and optimise their contact

with services; it empowered them by representing a form of authority. However, for those

with less confidence, services were viewed as predetermined and they felt unable through

Internet information to alter negotiations or health matters. For this group, information was

anxiety-promoting and a source of interference with established ways of coping. Usability

was seen as a key facilitator in a study conducted in the USA exploring the use of the Internet

for health information by 12 adolescent students [54]. Participants were observed, using a

think-aloud protocol, as they searched for answers to 6 health-related questions. 69% of

searches were successful, and these were based on search engine results (77%, with 83% of

links followed appearing in the top 9 results), search engine recommended links (10%), links

from other pages (7%) and direct access (5%). Participants avoided sponsored links and most

went only one page 'deep' at most sites. They used trial-and-error to formulate searches,

scanned pages randomly rather than systematically, and did not appear to consider the

sources of content. The authors recommended that information should be easy-to-find

(including if searches were misspelled), well organised, concise and understandable and expressed the need for education around searching. Participants in the study by Ibrahim and Boulos [27] were influenced in their choice of web site also by ease of use (62%) and by currency of content (58%). Only 1:3 participants were cited as being influenced by sponsorship or by the qualifications of the authors of the materials (it is not stated whether this influence was positive or negative). Participants in the study by Anhoj and Nielsen [30] felt there to be a lack of fit between the resource and their everyday lives - hence their unwillingness to use the resource for more than short periods. However, they also found it simple and easy to use and were more inclined to favour its role in informing rather than advising. Participants in the study by Glenton *et al.* [33] to evaluate research-based information questioned: a) the credibility of research; and b) its applicability to them as individuals. Clarity of purpose was also found lacking in the touch-screen health information kiosk study by Williams *et al.* [22]. Participants in the Glenton *et al.* [33] study suspected a bias towards orthodoxy (and they expressed frustration over the effectiveness of treatments presented) and a mistrust of the health care 'establishment'. Some participants found the resource difficult to understand but recognised the need to familiarise themselves with medical terms. They recognised that treatment decisions are often made in times of pain or despair – and solutions are often sought from people rather than from research. Thus there was enthusiasm towards personal stories of fellow sufferers in contrast to the mixed response to research-based information.

While participants in the study by Skinner *et al.* [25] of health information seeking via the Internet valued anonymity, they also identified health and education professionals and parents both as gatekeepers and solution enablers. Professionals were seen as having a role in fostering their ability to use the Internet effectively and safely and in recommending quality web sites. Parents were seen as having a vested interest more in terms of keeping them safe

than in terms of sponsoring exploration. van der Meer *et al.* [52] found that for people with poor asthma control, Internet-based monitoring and control was feasible, was not time consuming, did not interfere with daily life and was well-received. Unlike those with good asthma control, people with poor asthma control were able to incorporate Internet-based asthma self-management for a long period of time. In a Canadian study exploring the value of Internet training sessions, Edgar *et al.* [55] found value in one-to-one training in searching for and appraising cancer-related information. The study involved 40 cancer patients and family members whose views on a training session delivered by a health librarian were sought via pre- and post- questionnaires and by follow-up phone interview. The teaching sessions were reported as being well received and patients felt empowered and in a better position to ask questions. At 2 months, the vast majority felt better able to deal with cancer as a result of the intervention (94%) and better able to evaluate cancer information (84%). 68% had used the Internet again for cancer information.

In the study by Sim *et al.* of health information seeking via the Internet [42], while there were issues over content, 84% of parents found the Internet useful in developing further an understanding of their child's condition. They also found in the information obtained, reassurance (37%) and support (29%) along with possible diagnoses (15%). Feelings of competence and control were expressed in a survey of 2275 participants in a study exploring the use of a Canadian web site dedicated to illness prevention and health promotion [56]. Fogel *et al.* [57] found the Internet to be useful in terms of social support and in reducing a sense of loneliness. The USA-based study involved interviews (with completion of multiple assessment tools) with 188 women with breast cancer. The authors found that Internet use for breast health issues was associated with greater social support and less loneliness than both Internet use for other purposes and non-use, with only a minimal weekly time commitment. However, the authors pointed out that those with more social support and less loneliness

might be more likely to seek out information via the Internet. Chung and Kim [35] found four perceived outcomes of blog use (based on actual gratifications received rather than merely sought): management of emotions, information sharing, problem solving and prevention and care (in decreasing order of importance). The results indicate that active blogging appears to make for a more useful blogging experience by allowing users to express their frustrations, take control and present their conditions online.

Most participants in the study by Greenhalgh *et al.* [21] on attitudes to the NHS Summary Care Record and HealthSpace were unaware of the resources and there appeared to be a general lack of interest by participants in their own health. Participants indicated a lack of perceived usefulness in the resources; most were not interested in recording or accessing data from the NHS Summary Care Record via HealthSpace but saw some potential in terms of self-management of chronic illness. There was also confusion about what the NHS Summary Care Record would contain and who would have access. In weighing up benefits and drawbacks to having an NHS Summary Care Record, key factors included the nature of any illness, levels of engagement and health literacy. Perceptions were coloured by past and present experience of health care, fear of government surveillance and degree of trust towards the primary care team and the wider health service. Interestingly, people with stigmatising illnesses were more positive that those claiming to speak for vulnerable groups such as victims of domestic violence.

Conclusions and recommendations

This review draws together literature on public engagement with four main types of eHealth service: health information on the Internet, custom-made online health information, online support and telehealth. The findings of this review support and augment the findings of earlier literature reviews. For example, in an early review of health information on the

Internet, Cline and Haynes [3] characterised access to online health information in three ways: searching directly for information (corresponding in the current review to both 'health information on the Internet' and 'custom-made online health information'), participating in support groups (*i.e.* 'online support') and consulting with health professionals (*i.e.* 'telehealth'). Five key themes around barriers and facilitators to public engagement emerged from the review: characteristics of users; technological issues; characteristics of eHealth services; social aspects of use; and eHealth services in use. Increasing age and low socio-economic status appear to have a negative impact on perceptions of eHealth services and their use. Non-white ethnicity, a lack of motivation, interest or engagement with health and eHealth services, and a lack of perceived usefulness or relevance, all act as potential barriers to uptake of services. Higher levels of educational attainment and literacy appear to be associated with increased awareness and use of eHealth services, and higher levels of use exist among those describing themselves as white or from a higher socio-economic background. This supports and adds to the findings of earlier reviews. For example, Fogel *et al.* [4] found that African Americans were under-represented in online cancer support groups; this situation becomes more complex when considering both ethnicity and gender [5]. A lack of knowledge and skills around computer or Internet use appear to be barriers to the uptake of eHealth services, as found also by Cline and Haynes [3]. However, exposure to eHealth services appears to improve both the perceptions of non-users and frequency of use.

Those with computer and Internet access (particularly at home) are more likely to engage with eHealth services. Cline and Haynes [3] also recognised that access is inequitable. Having good access does not guarantee use. Perceptions of users are also dependant on operational aspects of the service, as supported by a relatively recent literature review by Botsis and Hartvigsen of telecare for older people [7]. Engagement with eHealth services is affected by how those services are implemented, by their ease of use and by their fit (or lack

of fit) with everyday life. While certain potential users of eHealth services believe that information will make little impact on the status quo, and may actually be a burden, other users find eHealth services empowering, reassuring and supporting. Cline and Haynes [3] also acknowledged a 'shifting balance of informational power'. People are often seen as important adjuncts to certain eHealth services: as gatekeepers, as enablers, as trainers and as coaches. A literature review conducted by McMullan [58] on the impact of Internet use on the patient-health professional relationship suggests three ways in which health professionals may respond to their patients as active consumers of health information: 1) re-assert their role as expert, 2) collaborate in obtaining and analysing information, 3) guide patients to reliable resources. There appears to be a place still for direct face-to-face communication; Botsis and Hartvigsen [7] found that 'patients and nurses foresee the need for real nurse home visits along with telemedicine ones'. Social computing (*e.g.* online discussion and support groups) is generally seen in a positive light and is seen as providing a safe, flexible and personal environment in which to share experiences and responsibility, foster a sense of belonging, offer empathy and support and gain reassurance. The review by McMullan made a similar observation [58]. Active engagement with social computing appears to reap the most benefit. Health status and information needs can act either as motivators or inhibitors of engagement with eHealth services; content is an important factor in terms of quantity, relevance, comprehensibility, reliability and impartiality, navigability, flexibility and tailoring. Both content and other design features were important considerations in the Cline and Haynes review [3]; cultural relevance was identified as important by Fogel in a further literature review on ethnicity, literacy levels and Internet use for cancer information [6]. Trust appears to influence users' perceptions of eHealth services (although this does not necessarily affect patterns of use). For example, opinion appears mixed concerning 'scientific' sources; attitudes towards scientific researchers are variable. . Trust was identified as a significant

issue also by Fogel *et al.* [4] Interestingly, with few exceptions, security and privacy concerns did not feature significantly in this review. There are 4 main recommendations that concern policy makers, developers, users and health professionals:

1. Efforts should be targeted towards those who are underserved by eHealth services due to age, ethnicity, educational attainment and socioeconomic status. This should include encouraging use through improved access to computers and the Internet in order to increase familiarity and improve perceptions of usefulness and relevance.

2. There should be continued focus on appropriate design and content of eHealth services. Services should aim to provide understandable, relevant and trustworthy content to a wide variety of potential users and in a way that is straightforward to use and that fits with day-to-day life.

3. The current interest in social computing should be capitalised upon to enable users of eHealth services to reap the benefits of online communities.

4. Finally, the role of health professionals in the delivery of eHealth services, including endorsement, promotion and facilitation, should be clarified.

Authors' contributions

Nicholas Hardiker and Maria Grant carried out the work described in this article with advisory support from the *Including everyone in electronic health information services* project team. Nicholas Hardiker and Maria Grant collaboratively authored this article with Nicholas Hardiker taking the lead.

Connecting for Health and received ethical approval from the University of Salford and by

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Statement on conflict of interest

There are no known conflicts of interest.

Summary table

What was already known on the topic	What this study added to our knowledge
• Public engagement with eHealth is viewed as beneficial • Public engagement with eHealth services remains variable • Age, ethnicity, socio-economic status, educational attainment and degree of motivation appear to affect public engagement with eHealth services	• Certain users of eHealth services, particularly active users, derive significant benefits from their use; other potential users believe that information will have little impact on the status quo • Access to eHealth services is essential for public engagement although this does not guarantee use • Health status and information needs can act either as motivators or inhibitors of public engagement with eHealth services • Trust appears to influence users' perceptions of eHealth services although this does not necessarily

	affect patterns of use

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