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Factors that affect public engagement with eHealth services: a literature review

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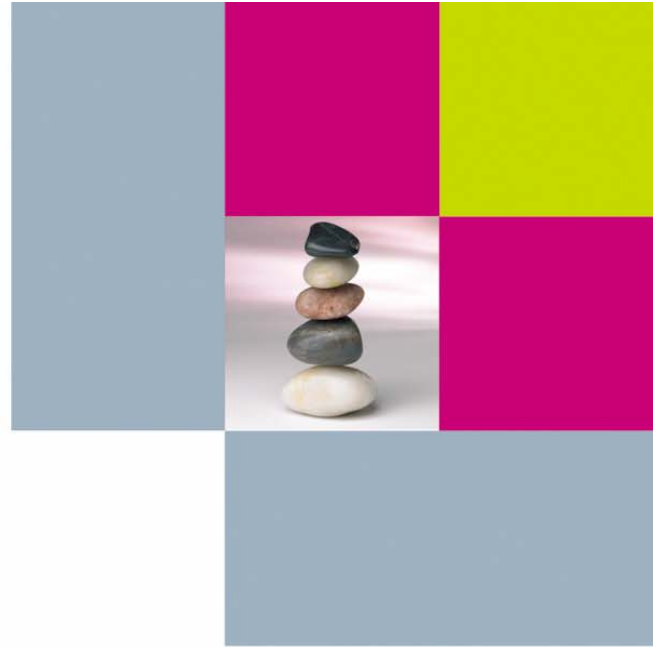
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Factors that affect public engagement with eHealth services: a literature review

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Project team

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Nick acted as principal investigator for this review and was jointly responsible for searching, filtering, appraising and synthesising.

Maria J Grant: Maria is a Research Fellow (Information) at the University of Salford. She facilitates research capacity building within Salford Centre for Nursing, Midwifery and Collaborative Research. This includes support for systematic reviews into education, and health and social care practice and policy sectors. She has an interest in evidence-based library and information practice and its role in facilitating the professional development of library and non-library professionals, and was recently appointed Editor of the Health Information and Libraries Journal. She has been involved in a large number of literature and systematic reviews, most recently including an investigation of the role of the academic in clinical practice, the impact of nursing record systems (with NH), and the impact of caring for those with chronic

obstructive pulmonary disease on carers' physical and psychological wellbeing.

Maria acted as co-investigator for this review and was jointly responsible for searching, filtering, appraising and synthesising.

Advisory team

In addition to members of the project team, the steering group for the 'Including everyone in electronic health information services' project acted as advisors to this review.

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Plain language summary

We looked for information on what helps or stops people from using computers and the Internet, going online, to help manage their health ('eHealth services'). We found four types of eHealth services: general information about health on the Internet, tailor-made health information, online support groups and going online with doctors and other health workers. People are less likely to use eHealth services with increasing age, if they are not white, if they are less affluent and if they have done less well at school. It is perhaps not surprising that people who are not interested in eHealth services, or in their own health, are also less likely to use eHealth services. People are more likely to use eHealth services if they know how to use computers and the Internet, if they have used eHealth services before, if the eHealth services fit into their day-to-day lives and if the eHealth services let them meet other people like themselves.

Executive summary

Project aims

The aims of this study were:

1. To examine literature relating to the use of eHealth services
2. To identify and explore factors (barriers and facilitators) that may influence engagement with those services by the public

Methods

Initial text word searches were undertaken on MEDLINE (via OVID) to find exemplar articles from which to harvest MeSH headings (to act as search terms). These headings fell into three categories: computer application, evaluation and health service. The search strategy was refined to ensure retrieval of all exemplar articles. It was translated 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 purposefully not restricted by date.

After the exclusion of duplicates, 2622 abstracts were independently reviewed by both members of the project team. Items were selected for further analysis if they met ALL of the review inclusion criteria, which were:

- 1) Named or identifiable examples of eHealth services
- 2) Used by the public
- 3) Barriers or facilitating factors influencing use
- 4) Readily and freely available online
- 5) Published in English

Seventy articles were obtained for closer examination. Fifty of these were identified as meeting the review inclusion criteria and were subjected to detailed analysis.

Using a data extraction tool developed, piloted and refined by the project team, the content of all included studies was summarised. Emergent themes were identified through a face-to-face meeting of project team members.

Results

Four types of eHealth service/resource were identified in the literature: health information on the Internet; bespoke online health information; online support, mailing lists and online communities; and telehealth services.

One hundred barriers and facilitators/motivators emerged from the literature. These were further categorised into 29 higher level categories and distilled into 5 overarching themes: characteristics of users; technological issues; characteristics of eHealth services; social aspects of use; and eHealth services in use.

Summary of findings

This review draws together literature on public engagement with eHealth services. It identifies new evidence while supporting what may already be known anecdotally.

The findings suggest that both increasing age and low socio-economic status might be negatively associated with perceptions and use of eHealth services. Non-white ethnicity, a lack of motivation, interest or engagement with health and eHealth services, a lack of perceived usefulness or relevance and a lack of knowledge or skills around computers

or Internet use all appear to be barriers to uptake of these services. However, exposure to eHealth services appears to improve both the perceptions of non-users and frequency of use. Engagement with eHealth services is affected by how they are implemented, by their ease of use and by their fit (or lack of fit) with everyday life.

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. Those with computer and Internet access (particularly at home) are more likely to engage with eHealth services. Service content is an important factor in terms of quantity, relevance, comprehensibility, reliability and impartiality, navigability, flexibility and tailoring of content.

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.

Health status and information needs can act either as motivators or inhibitors of engagement with eHealth services. Trust also appears to influence users' perceptions of eHealth services, although this doesn't necessarily affect patterns of use. For example, there are mixed opinions towards 'scientific' sources and researchers. Interestingly, with few exceptions, security and privacy concerns do not feature highly in this review.

The findings of this review are supported to a large extent by other earlier literature reviews.

Recommendations arising from the review

- 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.
- 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 fits with day-to-day life.
- The current interest in social networking should be capitalised upon to enable users of eHealth services to reap the benefits of online community engagement.
- Finally, the role of health workers in the delivery of eHealth services, including endorsement and facilitation, should be clarified.

Background

This literature review forms part of a larger project 'Including everyone in electronic health information services'. The larger project, a response to an invitation to tender issued by NHS Connecting for Health, seeks to find out what help people need to get health information using computers (eHealth services).

The aim of this aspect of the project was to examine literature relating to the use of eHealth services, and to identify and explore factors (barriers and facilitators) that may influence engagement by the public with those services, focusing if possible on use by older people, people from lower socio-economic groups and people with learning difficulties.

Ethics and Governance

The larger study, including the literature review, received ethical approval from the University of Salford and from Wrightington, Wigan and Leigh NHS Local Research Ethics Committee.

Method

Sources and searches

The breadth of the search (and to a lesser extent the depth of analysis) was shaped by resources and timescale. The literature sources considered in this project included national and international academic and professional (non-academic) journal articles available via three bibliographic databases, MEDLINE, CINAHL and EMBASE.

Other potential bibliographic sources, including sources of grey literature e.g. Health Management Information Consortium (HMIC), Web of

Knowledge, INSPEC were not consulted due to resource and time constraints. Citation tracking was not carried out on included articles for similar reasons.

The search strategy was developed in stages:

- 1) An initial text search of MEDLINE (via OVID) to find exemplar articles from which to harvest indexing terms – 'healthspace' (2 articles returned), 'nhs choices' (1 article), 'choose and book' (19 articles) 'ehealth services' (12 articles), 'e-health services' (24 articles)
- 2) Allocation of relevant keywords (Medical Subject Headings *i.e.* MeSH) into three categories (combined with AND):
 - a. Computer application e.g. Internet, Telemedicine, Information Systems
 - b. Evaluation e.g. Patient Satisfaction, Attitude to Computers, Focus Groups
 - c. Health service e.g. Self Care, Referral and Consultation, Information Service
- 3) Refinement of categorised keywords to ensure retrieval at least of all exemplar articles
- 4) Reworking of strategy for use with CINAHL (via EBSCOhost) and EMBASE (via the National Library for Health, now NHS Evidence).

The intention was to retrieve items that included an application, a service and

an evaluation. Searches were purposefully not restricted by date. All searches were carried out in January 2009 (see [Appendix A](#) for search strategies).

Criteria for inclusion and exclusion

Each item from the initial search was reviewed independently by the two members of the project team. Items were selected for further analysis according to the following criteria:

- Named or identifiable examples of eHealth services
- Used by the public
- Barriers or facilitating factors influencing the use eHealth services
- Readily and freely available online *i.e.* open access or available via the University of Salford e-library of online journals
- Published in English

Items were excluded if they were:

- Commentary, book review, conference report, conference paper, conference abstract, editorial, opinion-based

Relevant review articles were reserved for cross-validation of the final results of this review.

Disagreements over which items to include were resolved through face-to-face negotiation.

Agreed included items were obtained, allocated arbitrarily to the two team members and subjected to further review.

Thematic analysis

A data extraction tool was developed, piloted (on 3 included articles) and refined by the members of the project team (see [Appendix B](#) for extraction tool).

The tool allowed the team to analyse articles into the following categories:

- Bibliographic details
- eHealth service (including purpose)
- Study design
 - Participants (types of users, numbers of participants, comparison groups)
 - Methods of data collection and analysis
 - Timescale
- Findings
- Barriers
- Facilitators/Motivators
- Reviewer and review date

Emergent themes that were common across different studies were identified through a face-to-face meeting.

Results

Bibliographic searches

Four hundred and forty abstracts were returned via CINAHL, 1226 via EMBASE and 1153 via MEDLINE. After the removal of duplicates, 2622 abstracts were reviewed in terms of inclusion criteria by both members of the project team.

Seventy articles were obtained for closer examination. Fifty of these were identified as meeting the review inclusion criteria and were subjected to detailed analysis.

Six additional literature reviews were obtained for post-analysis comparison.

Emergent themes

The first set of themes to emerge from the analysis concerned the type of eHealth service/resource featured in the articles. Four themes emerged:

1. Health information on the Internet (27 articles featured this theme)
2. Bespoke online health information e.g. CDs, kiosks, portals (7 articles)
3. Online support e.g. coaching, mailing lists and online communities (12 articles)
4. Telehealth including remote consultation, monitoring and reporting (4 articles)

The second set of themes to emerge concerned barriers and facilitators/motivators. One hundred unique themes emerged.

These were further synthesised into 29 higher-level categories (see [Appendix C](#) for categorisation), which in turn

were distilled into 5 overarching themes (see [Appendix D](#) for categorisation):

1. Characteristics of users e.g. literacy levels
2. Technological issues e.g. security and privacy
3. Characteristics of eHealth services e.g. content issues
4. Social aspects of use e.g. shared experience
5. eHealth services in use e.g. fit with everyday life

These overarching themes are used in this report to structure the remainder of the analysis.

Characteristics of users

Age

Age appears to affect the uptake of, and satisfaction with, eHealth services. In a questionnaire survey of 235 gynaecology patients in New Zealand, Brenner [1] found that older 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 the older users to use the Internet. In a later study of 560 French breast cancer patients in 11 centres, Mancini *et al.*, [2] 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

Ethnicity 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 [3]. 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 [4]. 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 [5]. Although not statistically significant, Fogel *et al.* noted that non-whites were less likely to use the Internet. This theme recurs throughout the literature.

Socio-economic status

Economic status also appears to affect uptake of eHealth services. In a subset of a wider UK study, Blackburn and Read analysed data for 788 respondents, identified as carers of disabled children [6]. The carers, all of whom were listed on either one of three local authority databases or carers' organisations in Devon, West Sussex and Surrey, responded to a cross-sectional postal questionnaire survey regarding Internet use. 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. 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 [7]. 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.* [4] 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 unskilled 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.* [5], 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 [8, 9] 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

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 [3].

Fogel *et al.* [5] reported that of the 42% who reported using the Internet for breast health-related medical information, those with a college education were three times more likely to use the Internet. Similar findings were reported by Peterson and Fretz [9] 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.* [10] 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.* [2] noted a significant increase in health-related Internet use if participants had achieved a higher educational level (adjusted odds ratio 2.1) or if they were currently, or had previously been, employed in a health-related occupation (adjusted odds ratio 2.6).

Finally, confirming the findings of previous studies, James *et al.* [4] reported that higher education levels correlated with greater use of information via the Internet.

Literacy levels

In common with educational attainment, literacy levels are also a factor that affects use of eHealth services. Birru *et al.* [11] 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 (in which participants are encouraged to think aloud as they carry out specified tasks), keystroke capture (which records the keys struck on a keyboard) and questionnaire. Birru *et al.* reported that 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.* [12] noted that bespoke health information sources, such as CHESS, also require a greater level of literacy for optimal access.

As might be anticipated, higher levels of literacy are generally positively related to the uptake of eHealth services. 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 [13]. They noted that participants' health literacy was deficient in relation to: a) functional skills e.g. question construction and correctly spelling medical terms; b) critical skills e.g. knowing which web sites to trust and discerning relevant information; and c) interactive skills e.g. application of acquired information to their personal circumstances.

In a later qualitative study of patient attitudes to a centrally-stored medical record (NHS Summary Care Record) and internet-based personal health organiser (HealthSpace), by Greenhalgh *et al.* noted that respondents with higher literacy levels

were likely to have a greater awareness of eHealth services ($\frac{1}{2}$ with high literacy levels compared with $\frac{1}{4}$ with medium or low literacy levels)[14]. This study involved 103 semi structured interviews with participants recruited from GP surgeries, walk in centres, out of hour services and A&E departments, and seven focus groups involving representatives from voluntary sector organisations.

Motivation

Levels of motivation and degree of engagement were 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 [15]. This study used Sense-Making's 'time-line interview' technique, where users are asked to describe what they have experienced in a small segment of time, to gather data. In this study 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 [9]. They reported that patients who were unlikely to use the Internet in everyday life were much less likely to use the Internet access point within the clinic (16% unlikely [not used] vs. 65% very likely [had used]).

Structured interviews to examine Internet use by 200 cancer patients in the USA revealed that perceptions of

information accuracy acted as barriers to use. Helft *et al.* [16] 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 [17]. 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 [10].

Finally, Greenhalgh *et al.* [14] noted that level of engagement and level of health literacy were associated with a positive response to eHealth services such as NHS Summary Care Records and HealthSpace, while a lack of interest in one's own health was likely to reduce use.

Skills and Knowledge

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 [18]. The goal was to provide an in-depth

evaluation of young people's perspectives on using a) the Internet to access health information and b) other eHealth resources. 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 was a recurrent theme in the literature. Bowen *et al.* [19] reported that in their telephone survey of 431 women aged 18-74, in King County, Washington State, USA, respondents 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 [6] postal questionnaire survey, and in the study by Helft *et al.* [16]. Ibrahim and Boulos [20] 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 GP surgeries were given the opportunity to access a secure one-to-one triage advice service online. Eminovic *et al.* [21] noted that once patients had used the service they were more positive about future use.

In the more recent study of attitudes and use of the Internet as a source of

information by Dart *et al.* [7], it was noted that frequent Internet users were more likely to access health information over the Internet and to consider it more important.

Health status

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 [22] 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. And lower levels of mental health, along with higher perceptions of general health, were positively correlated with levels of Internet use in Bowen *et al.* [19].

Contrary to expectations, Greenhalgh *et al.* [14] 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. A 'virtual sealed envelope' securing sensitive information, for example for mental health service users, drug rehabilitation service users or those who had terminated a pregnancy, was viewed positively by some participants.

Information needs

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 [23]. 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. 85 individuals (including 8 health care providers) completed the online survey, and 15 were selected for in-depth semi-structured interviews. What became apparent was that two distinct user groups existed, each with specific requirements and expectations of the service. The first group identified by the researchers 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 perspective of the second group is described as 'inside-out'. 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

Trust was a factor associated with the use of many of the eHealth services identified for 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 [24] 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 [2] 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 [25] study of patients with long term conditions into the use of English language web sites. More than 79% of respondents visited scientific-based 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.* [26] 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 [27] 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 the Internet and 65% expressed concern about the reliability of sources, although these issues were not explored in detail.

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.* [14].

And finally, Chung and Kim [28] 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

Technological issues were a key factor in the uptake of eHealth services. Unsurprisingly, Internet use was strongly linked to access.

Access to resources

In 1999, Pennbridge *et al.* [29] 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.* [16] 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 [6]. This finding is supported by Ibrahim and Boulos [20] who showed through multivariate analysis that the only distinguishing feature between Internet users and non-users was PC ownership.

Similarly, Dart [7] indicated that using the Internet at home was a factor in the frequency of Internet in general and health information in particular. Although in Andreassen *et al.*'s [30] telephone interview study of citizens in 7 European countries it was noted that 71% of respondents were Internet users and had used the Internet for health purposes.

Technological issues

Boukhors *et al.* [31] 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 [23] noted that connection speed and logging on times were an obstacle to uptake of an asthma telehealth service. As these issues are not commonplace, it would be reasonable to assume in line with the authors that these technological barriers were transient *i.e.* associated with the use of analogue modems.

Operational issues

Eminovic *et al.* [21] noted that the average duration of contact for a one-to-one online triage advice service was 30 minutes - two times the duration of typical calls to NHS Direct telephone helpline for a similar cohort of patients. Patients responded positively to using the online 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 [32]. 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 information posted to the list between 1st January and 23rd July 2005 [33] 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.

Security and privacy

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 [29]. 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

The characteristics of eHealth services themselves, particularly concerning content and physical separateness (or virtual contact), play a major role in engagement with those services.

Content issues

In a UK-based exploration via questionnaire (n=195) of Internet use for information concerning Barrett's oesophagus [34], 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.* [35] 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. Of these 50% found little or no information, 38% felt there was too much information and 13% thought that the information was too technical.

Ibrahim and Boulos [20] found that the most frequently reported barriers to accessing health-related Internet resources were an inability to use

computers (57%) and an inability to read and or write in English (55%). Even though their study was conducted among Saudi cancer patients, an inability to read and/or write in Arabic was reported as a barrier by 31% of respondents.

31% of respondents in the study by Mancini *et al.* [2] 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 [11], 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 [36] 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 [37] 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 [38] 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 software employed the notion of a virtual health centre with a consulting room, a library and a support group room), the tailoring of information according to individual needs, and the flexibility to access information in any order.

Access to information

Clearly, content does not always act as a barrier to engagement with eHealth services. For example, Khechine *et al.*[25], 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).

Physical distance

In 2003, Skinner *et al.* [18] reported that in terms of the popularity of the Internet as a source of information, anonymity was a common theme (e.g. the ability to frame a question and receive support without being identified or judged) *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 [39] appeared to benefit from a feeling of not being alone and appreciated a safe and non-judgemental, empathic, understanding environment. There were three emergent themes: 'Searching for help', 'Sharing fears' and 'I feel empowered'. 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.

Similarly, Bruwer and Stein found that the users of mailing list support groups felt supported, decreased their sense of isolation and valued the ability to obtain information and tips about the condition and treatments via the lists [32].

Dickerson [24] also found contact with other people in a similar position and sharing experiences first-hand to be important.

Five related themes emerged (from an analysis of the discussion forum postings and emails):

- Getting past fear with knowledge and support
- Gaining context through a window into the future (though the first hand a personal experience of others)
- Internet as a mountain of information: A goldmine of ICD knowledge (required filtering and evaluating)
- Internet as social interaction (cyber friendship and humour)
- Becoming informed consumers

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 [40]. In common with the findings of Buchanan and Coulson [39] this resource also appeared to break down the sense of isolation, facilitate the sharing of experiences as a means of finding ways of living with cancer (including for those with a recent diagnosis), empower users and foster a sense of control. 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.* [41] 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 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.* [15], 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 – patients wanted little more than the minimum information of instructions needed to deal with their condition – and an assumption that the kiosk was not intended for patients or would not meet their needs.

Social aspects of use

In the majority of cases online discussion and support groups are viewed positively in that they appear to provide a forum for social contact, fostering a sense of belonging and shared experience.

Belonging

In Dickerson's study of an online community [24], 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. Respondents in the Bruwer *et al.* study also indicated a sense of feeling supported by discussion list members [32].

Members of the HeartNET online support group investigated in Boniface and Green's [42] mixed method study indicated that they gained a sense of reassurance and empathy from the online community. Boniface 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 [39] 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.

Shared experience

The sharing of experiences was instrumental in members initiating postings in the qualitative analysis by Frost and Massagli of a sample of 123 (2%) of messages posted to PatientsLikeMe online community for amyotrophic lateral sclerosis [43].

It was noted by Glenton *et al.* [26] 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.

Social contact

In Dickerson [24] 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.* [40] 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 experience and advice 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.

Reassurance

Respondents in Boniface and Green's [42] study of the HeartNET online support group found the provision of information and mutual support 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.* [44] undertook semi-structured interviews with 28 RCT participants into their perceptions of JTC. Participants reported that they found the presence of the GP reassuring during JTCs with specialists, felt they had the undivided attention of the specialist, and could ask the questions they wanted to ask. They particularly liked the debriefing after the consultation though 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.* [45] undertook a comprehensive study involving a 1 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 found 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).

Shared Responsibility

A sense of shared responsibility and community was evidence in the study by Esquivel *et al.* [33] in the self-policing of a breast cancer mailing list. This ethos was also evident in HeartNET [42] in that the support group demonstrated a shared responsibility in dealing collectively with difficult questions posed by members.

Interpersonal issues

Not all aspects of online support groups are positive. Bruwer *et al.* [32] 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 [42] investigation of HeartNET mentioned a reticence in sharing her experiences because she did not want to dwell on her illness, nor cultivated a 'victim-like or competitive environment' of sharing.

eHealth services in use

Certain facilitators and barriers to eHealth engagement concern the practical implementation of services: empowerment, fit with everyday life, people as enablers, usability and usefulness, user response and threat to the patient/doctor relationship.

Fit with everyday life

In Blackburn and Read's study [6], 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 available time available at school or in community centres was reported as an issue also by Skinner *et al.* [18], and cost was cited as an issue in Helft *et al.* [16].

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.* [46] 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. 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 [23] found a lack of fit due to timing and technical and psychological factors.

Usability and usefulness

In their exploration of health-related Internet access and use by women in USA, Bowen [19] 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.

In exploring the use in the UK of the Internet in managing health and illness and engaging with health services, Rogers and Mead [17] revealed for some participants a lack of perceived 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 in the use of the Internet to complement the use of health services. 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 [47]. 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.

Ease of use was also cited by participants in the study by Ibrahim and Boulos [20] with participants being influenced in their choice of web site by ease of use (62%) and 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).

While participants in the study by Anhoj and Nielsen [23] 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, they also found it simple and easy to use. They were more inclined to favour its role in informing rather than advising.

Participants in the study by Glenton *et al.* [26] 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.* [15]. Participants in the Glenton *et al.* [26] 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 website 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.

People as enablers

While participants in the study by Skinner *et al.* [18] 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 rather than in sponsoring exploration.

van der Meer *et al.* [45] 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. They appreciated receiving messages when their condition deteriorated and valued advice on how and when to change medication. 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.* [48] 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.

Empowerment

In the study by Sim *et al.* of health information seeking via the Internet [35], 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 [49]. The authors identified 3 forms of empowerment that were related specifically to Internet use: a professional form of empowerment where individuals preferred the point of view offered by mainstream medicine over self-exploration; a consumerist form of empowerment where individuals take a more participatory and consumer-focused approach; and

a community form of empowerment where participation in online communities can contribute to personal empowerment.

Fogel *et al.* [50] 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 in the USA. 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 [28] 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, taking control and presenting their conditions online.

Motivation

Most participants in the study by Greenhalgh *et al.* [14] 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, a fear of government surveillance and the degree of trust towards the primary care team and the wider health service. Interestingly, people with stigmatising illnesses were more positive than those claiming to speak for vulnerable groups such as victims of domestic violence.

Summary and recommendations arising from the review

This review considered public engagement with four types of eHealth service:

1. Health information on the Internet
2. Bespoke online health information
3. Online support
4. Telehealth.

In an early review of health information on the Internet, Cline and Haynes [51] 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 'Bespoke online health information'), participating in support groups (*i.e.* 'Online support') and consulting with health professionals (*i.e.* 'Telehealth').

From the current review, barriers and facilitators to engagement appear to fall into one of five categories:

1. Characteristics of users
2. Technological issues
3. Characteristics of eHealth services
4. Social aspects of use
5. eHealth services in use.

Characteristics of users. The findings suggest that both increasing age and low socio-economic status might be negatively associated with perceptions and use of eHealth services. Non-white ethnicity also appears to be a potential barrier. A

understanding of their child's online cancer support groups found that African Americans were indeed under-represented (although the authors note that there is no evidence to suggest that online support groups improve health and social outcomes). The situation concerning engagement with online support groups becomes even more complicated when considering both ethnicity and gender [53]. There appear to be higher levels of eHealth service use among people describing themselves as white and among people with higher socio-economic status. Higher levels of educational attainment and literacy appear to be associated with increased awareness and use of eHealth services. Lack of motivation, interest and engagement, both in eHealth services and in health in general, appear to be barriers to the use of those services. A lack of knowledge and skills around computer or Internet use appears to be a barrier to the uptake of eHealth services, as confirmed by Cline and Haynes [51]. However, exposure to these services appears to improve both the perceptions of non-users and frequency of use. Both health status and information needs play a less predictable role in engagement with eHealth services. For example, poor health status provides an impetus for individuals to seek information. However, poor health status may also inhibit an individual's ability and motivation to seek this type of support. Trust also appears to influence users' perceptions of eHealth services, although it doesn't necessarily affect patterns of use. For example, opinion towards 'scientific' sources and researchers appears to be mixed. Trust was identified as a significant issue also in the literature review by Fogel *et al.* [52]

Technological issues. Unsurprisingly, lack of access and poor access to computers and/or the Internet are significant barriers to engagement with eHealth services. Simply put, those with better access (particularly at home) are more likely to engage with services. Cline and Haynes [51] also recognised that access is inequitable. However, having good access does not guarantee use. Perceptions of users are also dependant on operational aspects of the service along with how it handles data security and privacy, as supported by a recent literature review by Botsis and Hartvigsen of telecare for older people [54]. Interestingly, security and privacy concerns did not feature highly in many of the articles included in the current review. Design features were an important consideration also in the Cline and Haynes review [51].

Characteristics of eHealth services. As might be expected, and as supported by Cline and Haynes [51] the content of eHealth services is an important contributing factor to engagement. Important characteristics include: quantity, relevance (including cultural relevance), comprehensibility (both technical and linguistic), reliability and impartiality, navigability, flexibility and tailoring of content. Cultural relevance was also identified as important by Fogel in a literature review on ethnicity and literacy levels and Internet use for cancer information [55].

Social aspects of use. A decreased sense of isolation is seen by many as an important benefit of eHealth services, along with autonomy and an increased sense of control. Anonymity is also valued, although the impersonal nature of online communication might in some circumstances act as a barrier. Cline and Haynes [51] also

acknowledged both a 'shifting balance of informational power' and the potential benefits of anonymity.

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 [56] 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 still be a place for direct face-to-face communication. To support this, Botsis and Hartvigsen [54] 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 by 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 [56]. Active engagement appears to reap the most benefit.

eHealth services in use. Issues affecting engagement with eHealth services arise from their implementation and use. An obvious barrier concerns ease of use. An equally obvious barrier is lack of fit with everyday life in terms of time, cost and technical or psychological factors e.g. unfamiliarity with the resource. A lack of perceived usefulness or relevance is a significant barrier to engagement with eHealth services. 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 supportive.

In light of the findings of this review, there are a number of recommendations:

- There should be targeted efforts to engage those who are underserved by eHealth services due to age, ethnicity, educational attainment and socioeconomic status
- Attempts should be made to maximise exposure to eHealth services across all sections of society, in order to increase familiarity and improve perceptions of usefulness and relevance, thereby maximising potential use
- Maximising exposure to eHealth services includes improved access to computers and the Internet
- There should be a continued focus on the appropriate design and delivery of eHealth services in terms of ease of use and fit with everyday life *i.e.* time and cost
- Efforts should be made to ensure that the content of eHealth services meets the needs of the target audience for those services (perhaps through a balance between quality criteria for content and information skills training for users). Content should be understandable, relevant and trustworthy to a wide variety of potential users

- eHealth services should capitalise on the continued public interest in social computing and allow users of those services to reap the benefits of online community engagement
- The role of health workers in the delivery of eHealth services, including endorsement and facilitation, should be clarified.

Appendix A – Search strategies

MEDLINE (via OVID)

1. Information Systems/
2. Internet/
3. Medical Informatics Applications/
4. Medical Records Systems, Computerized/
5. Telemedicine/
6. 1 or 2 or 3 or 4 or 5
7. Attitude to Computers/
8. Public Opinion/
9. Computer Literacy/
10. Longitudinal Studies/
11. Patient Satisfaction/
12. Program Evaluation/
13. Questionnaires/
14. Interviews as Topic/
15. Focus Groups/
16. 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15
17. Access to Information/
18. "Appointments and Schedules"/
19. Choice Behavior/
20. Consumer Health Information/
21. Health Education/
22. Information Services/

23. "Referral and Consultation"/

24. Self Care/

25. "Delivery of Health Care"/

26. Patient Education as Topic/

27. 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26

28. 6 and 16 and 27

Key: / = MeSH Heading

CINAHL (via EBSCOhost)

- S1 (MH "Information Systems")
- S2 (MH "Internet")
- S3 (MH "Medical Informatics")
- S4 (MH "Patient Record Systems")
- S5 (MH "Telemedicine")
- S6 S5 or S4 or S3 or S2 or S1
- S7 (MH "Attitude to Computers")
- S8 (MH "Public Opinion")
- S9 (MH "Computer Literacy")
- S10 (MH "Prospective Studies")
- S11 (MH "Questionnaires")
- S12 (MH "Interviews+")
- S13 (MH "Focus Groups")
- S14 S13 or S12 or S11 or S10 or S9 or S8 or S7
- S15 (MH "Access to Information")
- S16 (MH "Appointment and Scheduling Information Systems")
- S17 (MH "Consumer Health Information")
- S18 (MH "Health Education")
- S19 (MH "Information Services")
- S20 (MH "Referral and Consultation")
- S21 (MH "Self Care")
- S22 (MH "Health Care Delivery")
- S23 (MH "Patient Education")
- S24 S23 or S22 or S21 or S20 or S19 or S18 or S17 or S16 or S15
- S25 S24 and S14 and S6

Key: MH = MeSH Heading

+ = Explode MeSH heading to include all sub-headings

EMBASE (via the National Library for Health – now NHS Evidence)

1. INFORMATION SYSTEM/
2. INTERNET/
3. MEDICAL INFORMATICS/
4. ELECTRONIC MEDICAL RECORD/
5. DECISION MAKING/
6. TELEMEDICINE/
7. 1 OR 2 OR 3 OR 4 OR 5 OR 6
8. PATIENT SATISFACTION/
9. ATTITUDE TO COMPUTERS/
10. PUBLIC OPINION/
11. HUMAN COMPUTER INTERACTION/
12. LONGITUDINAL STUDY/
13. QUESTIONNAIRE/
14. exp INTERVIEW/
15. 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14
16. ACCESS TO INFORMATION/
17. CONSUMER HEALTH INFORMATION/
18. HEALTH EDUCATION/
19. INFORMATION SERVICE/
20. PATIENT REFERRAL/
21. SELF CARE/
22. HEALTH CARE DELIVERY/
23. PATIENT EDUCATION/
24. 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23
25. 7 AND 15 AND 24

Key: / = MeSH Heading

exp = Explode MeSH heading to include all sub-headings

Appendix B – Data Extraction Tool

Bibliographic details:	
What was the eHealth service?	---
<ul style="list-style-type: none"> • Named/Identifiable: 	
<ul style="list-style-type: none"> • Purpose: 	
Study design	---
<ul style="list-style-type: none"> • Who was involved/used the eHealth service? • (<i>Older people; learning disabilities; social groups D&E; COPD; Diabetes</i>) 	
<ul style="list-style-type: none"> • Number of participants and comparison groups 	
<ul style="list-style-type: none"> • Data collection/Analysis methods: 	
<ul style="list-style-type: none"> • Over what timescale? 	
<ul style="list-style-type: none"> • Findings: 	
What were the eHealth service outcomes?	---
<ul style="list-style-type: none"> • Barriers: 	
<ul style="list-style-type: none"> • Facilitators/Motivators: 	
Other comments:	
Reviewer:	
Review date:	

Appendix C – Lower level and intermediate content themes

Access to information

Access to information

Information about treatments and follow up

Access to resource

Internet access

Lack of Internet access

Lack of access to computers

Owning a PC

Age

Older people found the web site less user friendly

Old age

Belonging

Sense of reassurance from an empathic community

Shared experience

Finding support

A safe and non-judgemental environment

Content issues

Difficulty using materials

Use of a range of media

Tailoring of information according to information need

Flexibility and accessing information

Internet sites are culture specific

Language specific web sites

Internet sites difficult for lay people to understand

Content - appropriate for audience

Educational attainment

Low educational attainment

High educational attainment

Empowerment

Empowerment

For empowerment, reassurance, support, understanding

Ethnicity

Ethnicity - Asian

Ethnicity – white

Fit with everyday life

Lack of fit with everyday lives

Not time consuming

Did not interfere with activities of daily living

Lack of time

Cost

Convenience

Health status

Nature of illness

Poor mental health

High perceptions of health

Low health status

Information needs

Different needs

Interpersonal issues

Negative online competition for attention

Disagreements

Literacy levels

Low literacy levels

High health literacy

Miscellaneous

- Use of metaphors
- Threat to the patient/doctor relationship
- Involvement in development
- Being a carer

Motivation

- Lack of interest in own health
- Lack of curiosity/interest in resource
- Degree of engagement
- Lack of interest
- Openness to experience
- Belief that information will make a difference to health

Operational issues

- Lack of moderation
- Timing of session
- Large numbers of messages
- Loss of discussion thread
- Deviation of topic

People as enablers

- One-to-one teaching
- People as enablers

Physical distance

- Absence of physical contact made it easier to begin discussions
- Anonymity
- Perceived additional benefits of face-to-face consultations
- Impersonal

Reassurance

- Presence of GP in teleconsultation
- Reassurance

Security and privacy

Security

Invasion of Privacy

Shared experience

Access to experience based knowledge e.g. personal stories

Sharing information

Use of experience based knowledge e.g. personal stories

Shared responsibility

Dealing collectively with difficult questions

Self police and self correction

Skills and knowledge

Prior exposure

Lack of skill/Not knowing how to use computers or the Internet

Difficulties finding information

Not knowing relevant information/resources available

Lack of Internet use

Familiarity with the Internet

Social contact

Breaks down social isolation

Social interaction

Socio-economic status

Low socio-economic status

High socioeconomic status

Technological issues

The Internet

Technical issues

Trust

- Perceptions of blogs as credible
- Negative prior experience
- Lack of trust in research
- Concerns over content and reliability
- Openness/trust in sources
- Scientific basis for information

Usability and usefulness

- Simplicity and ease of use
- Utility
- Lack of clarity of purpose
- Lack of perceived usefulness
- Lack of applicability
- Perceived lack of utility of Internet
- Well-organised web sites
- Ease of use
- Content - currency
- Adaptable searching e.g. allow for spelling mistakes

User response

- Informing rather than advising
- Access to advice and how and when to change medication

Appendix D – Intermediate and overarching content themes

Characteristics of users

- Age
- Being a carer
- Educational attainment
- Ethnicity
- Health status
- Information needs
- Literacy levels
- Motivation
- Skills and knowledge
- Socio-economic status
- Trust

Technological aspects

- Access to resource
- Involvement in development
- Operational issues
- Security and privacy
- Technological issues
- Use of metaphors

Characteristics of eHealth services

- Access to information
- Content issues
- Physical distance

Social aspects of use

Belonging

Interpersonal issues

Reassurance

Shared experience

Shared responsibility

Social contact

eHealth services in use

Empowerment

Fit with everyday Life

People as enablers

Threat to the patient/doctor relationship

Usability and usefulness

User response

References

Included articles

1. Brenner, B., Is the provision of laboratory results via the Internet acceptable to patients? A survey of private patients in a large, specialist gynaecology practice. *New Zealand Medical Journal*, 2003. 116(1187).
2. Mancini, J., *et al.*, Patients' characteristics and rate of Internet use to obtain cancer information. *Journal of Public Health*, 2006. 28(3): p. 235-237.
3. Dickerson, S., *et al.*, Patient Internet use for health information at three urban primary care clinics. *Journal of the American Medical Informatics Association*, 2004. 11(6): p. 499-504.
4. James, N., *et al.*, A study of information seeking by cancer patients and their carers. *Clinical Oncology*, 2007. 19(5): p. 356-62.
5. Fogel, J., *et al.*, Use of the Internet by women with breast cancer. *Journal of Medical Internet Research*, 2002. 4(2): p. E9.
6. Blackburn, C. and J. Read, Using the Internet? The experiences of parents of disabled children. *Child: Care, Health & Development*, 2005. 31(5): p. 507-515.
7. Dart, J., The internet as a source of health information in three disparate communities. *Australian Health Review*, 2008. 32(3): p. 559-569.
8. Markman, M., *et al.*, Profile of ovarian cancer patients seeking information from a web-based decision support program. *Journal of Women's Health* (15409996), 2006. 15(3): p. 312-318.
9. Peterson, M.W. and P.C. Fretz, Patient use of the Internet for information in a lung cancer clinic. *CHEST*, 2003. 123(2): p. 452-457.
10. Flynn, K.E., M.A. Smith, and J. Freese, When do older adults turn to the internet for health information? Findings from the Wisconsin Longitudinal Study. *Journal of General Internal Medicine*, 2006. 21(12): p. 1295-301.
11. Birru, M.S., *et al.*, Internet usage by low-literacy adults seeking health information: an observational analysis. *Journal of Medical Internet Research*, 2004. 6(3): p. e25.
12. Gustafson, D.H., *et al.*, CHES: 10 years of research and development in consumer health informatics for broad populations, including the underserved. *International Journal of Medical Informatics*, 2002. 65(3): p. 169-77.
13. Gray, N.J., *et al.*, The Internet: a window on adolescent health literacy. *Journal of Adolescent Health*, 2005. 37(3): p. 243.
14. Greenhalgh, T., *et al.*, Patients' attitudes to the summary care record and HealthSpace: qualitative study. *BMJ: British Medical Journal*, 2008. 336(7656): p. 1290-1295.

15. Williams, P., D. Nicholas, and P. Huntington, Non use of health information kiosks examined in an information needs context. *Health Information & Libraries Journal*, 2003. 20(2): p. 95-103.
16. Helft, P.R., *et al.*, Use of the Internet to obtain cancer information among cancer patients at an urban county hospital. *Journal of Clinical Oncology*, 2005. 23(22): p. 4954-4962.
17. Rogers, A. and N. Mead, More than technology and access: primary care patients' views on the use and non-use of health information in the Internet age. *Health & Social Care in the Community*, 2004. 12(2): p. 102-110.
18. Skinner, H., S. Biscope, and B. Poland, Quality of internet access: barrier behind internet use statistics. *Social Science & Medicine*, 2003. 57(5): p. 875-880.
19. Bowen, D., Predictors of women's Internet access and Internet health seeking. *Health Care for Women International*, 2003. 24(10): p. 940-51.
20. Ibrahim, E.M. and M.N.K. Boulos, Access to online information by adult Saudi cancer patients. *Internet Journal of Health*, 2006. 5(1): p. 11p.
21. Eminovic, N., *et al.*, First evaluation of the NHS direct online clinical enquiry service: a nurse-led web chat triage service for the public. *Journal of Medical Internet Research*, 2004. 6(2): p. e17.
22. Houston, T.K. and J.J. Allison, Users of internet health information: Differences by health status. *Journal of Medical Internet Research*, 2002. 4(2): p. 10-24.
23. Anhoj, J. and L. Nielsen, Quantitative and qualitative usage data of an internet-based asthma monitoring tool. *Journal of Medical Internet Research*, 2004. 6(3).
24. Dickerson, S.S., Technology-patient interactions: Internet use for gaining a healthy context for living with an implantable cardioverter defibrillator. *Heart & Lung*, 2005. 34(3): p. 157-168.
25. Khechine, H., D. Pascot, and P. Premont, Use of health-related information from the Internet by English-speaking patients. *Health Informatics Journal*, 2008. 14(1): p. 17-28.
26. Glenton, C., E.S. Nilsen, and B. Carlsen, Lay perceptions of evidence-based information--a qualitative evaluation of a website for back pain sufferers. *BMC Health Services Research*, 2006. 6: p. 34.
27. Khoo, K., *et al.*, Health information seeking by parents in the Internet age. *Journal of Paediatrics & Child Health*, 2008. 44(7/8): p. 419-423.
28. Chung, D.S. and S. Kim, Blogging activity among cancer patients and their companions: uses, gratifications, and predictors of outcomes. *Journal of the American Society for Information Science & Technology*, 2008. 59(2): p. 297-306.
29. Pennbridge, J., R. Moya, and L. Rodrigues, Questionnaire survey of California consumers' use and rating of sources of health care information including the Internet. *Western Journal of Medicine*, 1999. 171(5-6): p. 302-5.

30. Andreassen, H.K., *et al.*, European citizens' use of E-health services: a study of seven countries. *BMC Public Health*, 2007. 7: p. 53.
31. Boukhors, Y., *et al.*, The use of information technology for the management of intensive insulin therapy in type 1 diabetes mellitus. *Diabetes & Metabolism*, 2003. 29(6): p. 619-27.
32. Bruwer, B.R. and D.J. Stein, A survey of participants in two internet support groups for people with hair-pulling. *BMC Psychiatry*, 2005. 5: p. 37.
33. Esquivel, A., F. Meric-Bernstam, and E.V. Bernstam, Accuracy and self correction of information received from an internet breast cancer list: content analysis.[see comment]. *BMJ*, 2006. 332(7547): p. 939-42.
34. Gough, M.D., *et al.*, Barrett's esophagus: patient information and the Internet. The patient's perspective. *Diseases of the Esophagus*, 2003. 16(2): p. 57-9.
35. Sim, N.Z., *et al.*, Information on the World Wide Web--how useful is it for parents? *Journal of Pediatric Surgery*, 2007. 42(2): p. 305-12.
36. Allen, M., *et al.*, Improving patient-clinician communication about chronic conditions: description of an Internet-based nurse E-coach intervention. *Nursing Research*, 2008. 57(2): p. 107-112.
37. Bernhardt, J.M. and E.M. Felter, Online pediatric information seeking among mothers of young children: results from a qualitative study using focus groups. *Journal of Medical Internet Research*, 2004. 6(1): p. e7.
38. Diefenbach, M.A. and B.P. Butz, A multimedia interactive education system for prostate cancer patients: Development and preliminary evaluation. *Journal of Medical Internet Research*, 2004. 6(1): p. 25-31.
39. Buchanan, H. and N.S. Coulson, Accessing dental anxiety online support groups: an exploratory qualitative study of motives and experiences. *Patient Education & Counseling*, 2007. 66(3): p. 263-269.
40. Hoybye, M.T., C. Johansen, and T. Tjornhoj-Thomsen, Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-Oncology*, 2005. 14(3): p. 211-220.
41. Hardyman, R., *et al.*, It's good to talk: comparison of a telephone helpline and website for cancer information. *Patient Education & Counseling*, 2005. 57(3): p. 315-20.
42. Bonniface, L. and L. Green, Finding a new kind of knowledge on the HeartNET website. *Health Information & Libraries Journal*, 2007. 24 Suppl 1: p. 67-76.
43. Frost, J.H. and M.P. Massagli, Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. *Journal of Medical Internet Research*, 2008. 10(3): p. e15.
44. Harrison, R., *et al.*, Patients' perceptions of joint teleconsultations: A qualitative evaluation. *Health Expectations*, 2006. 9(1): p. 81-90.
45. van der Meer, V., *et al.*, Internet-based self-management offers an opportunity to achieve better asthma control in adolescents. *Chest*, 2007. 132(1): p. 112-9.

46. Gordon, M.M., H.A. Capell, and R. Madhok, The use of the Internet as a resource for health information among patients attending a rheumatology clinic. *Rheumatology*, 2002. 41(12): p. 1402-5.
47. Hansen, D.L., *et al.*, Adolescents searching for health information on the Internet: an observational study. *Journal of Medical Internet Research*, 2003. 5(4): p. e25.
48. Edgar, L., A. Greenberg, and J. Remmer, Providing Internet lessons to oncology patients and family members: a shared project. *Psycho-Oncology*, 2002. 11(5): p. 439-446.
49. Lemire, M., C. Sicotte, and G. Pare, Internet use and the logics of personal empowerment in health. *Health Policy*, 2008. 88(1): p. 130-40.
50. Fogel, J., *et al.*, Internet use and social support in women with breast cancer. *Health Psychology*, 2002. 21(4): p. 398-404.
54. Botsis, T. and G. Hartvigsen, Current status and future perspectives in telecare for elderly people suffering from chronic diseases. *Journal of Telemedicine & Telecare*, 2008. 14(4): p. 195-203.
55. Fogel, J., Internet Use for Cancer Information Among Racial/Ethnic Populations and Low Literacy Groups. *Cancer Control (Cancer, Culture and Literacy Supplement)*, 2003. 10(5): p. 45-51.
56. McMullan, M., Patients using the Internet to obtain health information: how this affects the patient-health professional relationship. *Patient Education & Counseling*, 2006. 63(1-2): p. 24-8.

Supporting literature reviews

51. Cline, R.J. and K.M. Haynes, Consumer health information seeking on the Internet: the state of the art. *Health Education Research*, 2001. 16(6): p. 671-92.
52. Fogel, J., *et al.*, The Underrepresentation of African Americans in Online Cancer Support Groups. *Journal of the National Medical Association*, 2008. 100(6): p. 705-712.
53. Im, E.-O. and W. Chee, The use of Internet cancer support groups by ethnic minorities. *Journal of Transcultural Nursing*, 2008. 19(1): p. 74-82.