Using the Internet to influence public knowledge and attitudes about health

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Abstract. The increasing availability of evidence-based medical information on the Internet has great potential to empower patients and health professionals and equip them for better decision-making, improving health outcomes. However, previous research has only evaluated the quality and accessibility of online information rather than the impact this information is having on the user. With these new technologies, are we actually empowering patients and professionals, improving their knowledge and changing their attitudes in a way that will impact on their behaviour? This paper presents the results of a pilot study investigating whether information within a medical digital library changes user knowledge and attitudes. The study had positive results with significant changes recorded. We conclude that digital libraries have the potential to change knowledge and attitudes of a range of users, but we need to evaluate this impact to inform digital library design in order to maximise the impact on users.

1 Introduction

Recent years have seen an explosion in the amount of information available to patients. There has been a shift from the patient as a recipient of health care to a consumer of health care, taking an active role in management of their health. The balance of power is shifting, but it requires skill on the clinician's part to adapt to patient preferences. They have to know when to hand over decision-making, when to share it and when to take a paternalistic approach [1]. Patients may now present to their clinician armed with reams of information and as a result, preconceived ideas about their health. Technology has facilitated this shift, with the Internet providing access for patients to information previously unavailable to them. As well as considering usability issues of ehealth technologies it is important to consider the impact of the information they provide to patients on their knowledge and attitudes. Are patients applying the information in an appropriate manner that will assist them and their clinician in managing their health? Or is the information retrieved by patients inaccurate, or simply misunderstood?

Medical digital libraries can have an important role in empowering health professionals and patients, providing timely access to quality-controlled information. To quote the title of a paper by Brice and Gray "Knowledge is the enemy of disease" [2]. However, it is important to target information appropriately to users so that the infor-

mation accessed by them has the maximum impact on their knowledge, attitudes, and subsequent behaviour. As already suggested, health professionals have to adapt to patient preferences providing them with an appropriate depth of information. Patient empowerment should not be about providing patients with the information that will lead them to agree with their clinician, rather enabling them to make an informed decision with their health professional.

Lancaster identifies a current gap in the level of information held in NHS Direct Online, (online health information for the UK public found at: http://www.nhsdirect.nhs.uk) and that held in the National electronic Library for Health (NeLH) http://www.nelh.nhs.uk. The UK National Health Service provides both of these resources, the former aimed at patients and the public and the latter at health professionals. Lancaster suggests that the gap between these is too great and that they should provide access to a range of levels of information, indicating the level of difficulty for each resource within them and allow users to select information according to their current needs and preferences [3].

This paper shows that health information websites and digital libraries can have an impact on user knowledge and attitude and in future, become key vehicles for delivering information to empower patients, in order to allow them actively participate in the decision making process. Specifically it:

- Presents results demonstrating changes in the knowledge and attitudes of users to antimicrobial prescribing following use of a health information website/digital library
- Investigates the application of this research to evaluating the impact of digital libraries on user behaviour.

The rest of the paper is organised as follows. Section 2 discusses previous and current research around consumer health information seeking behaviour, the role of digital libraries as health information providers. Section 3 describes the health information website used in the research and provides a background to the area of antimicrobial resistance. Section 4 presents the results of the research so far and Section 5 discusses these results in the context of developing a methodology for evaluating the impact of medical digital libraries on user knowledge, attitudes and behaviour. Section 6 provides a conclusion and summarises the next steps of the research.

2. Background to the research

Consumers' use of the Internet for health information

The Internet has long been a source of health and medical information for consumers and use is growing. Pew Internet and American Life reported in November 2000 that 52 million Americans were using the internet to find health information whilst in May 2002 this had risen to 72 million [4]. Many studies have investigated consumer use of the Internet for health and medical information. Reasons for going online to find this information vary [4-8]:

- For themselves or someone they know
- For a second opinion or more information than they got from their doctor
- To see if they need to visit the doctor
- To find information to take with them to a consultation

But are they actually taking this information to their doctor? And are patients empowered by this information to take a more active role in decision-making with their doctor? The Health on the Net Foundation (HON) surveyed almost 3000 internet users using websites approved by HON. They found that 63% of users discuss information found on the internet with their doctor [8]. The Pew Internet Survey indicated that only a third of those surveyed would check Internet information with their doctor [4]. The difference here may be partly cultural as the HON survey was web-based whilst the Pew Internet survey was telephone based and only undertaken in the US.

Information seeking habits may vary between patient groups. For example, in contrast to the image of the information hungry consumer portrayed by these surveys, a study of cancer patients in the UK suggested that these patients would actively avoid seeking more information than provided by their doctor for fear of losing hope of recovery [9]. In addition they had faith in their doctor that he/she had told them all they needed to know and were concerned about using what they perceived to be limited information resources when others may be more in need. This latter concern is addressed by the ubiquitous nature of the Internet providing unlimited access to one information resource. However, this study, although small and not with a statistically representative sample, highlights the importance of not assuming that patients want all the information that ever existed on a particular topic. Henwood et al also found that some patients do not want to seek out information and are happy to trust their doctor, leaving decisions to them and avoiding the responsibility of managing their own health [10]. Given these conflicting behaviours it is becoming increasingly important for clinicians to adapt to patient preferences.

An important question to be asked of health information on the world wide web (WWW) is "What is the point of it?". The ultimate aim of providing any non-biased, authoritative health information aimed at consumers has to be to improve health outcomes, reducing the burden on the current health system. The NHS would not be investing millions of pounds into provision of digital information via a variety of platforms if it did not see some long-term benefit to the healthcare system from the education of consumers [11]. At Stanford University, Bob Fogg is pioneering an area of research he has called "captology" (the role of computers as persuasive technologies). He discusses the methods used by businesses and government to persuade consumers to change their attitudes or behaviour in specific ways [12]. Online health information providers have similar aims. They are attempting to provide the public with specific information in order to influence public knowledge, attitudes and subsequent behaviour. It is clear from the research discussed above that consumers are using the Internet to retrieve health information. But what is the impact of online health information on consumers and how can we evaluate it? Are we actually empowering people by providing this information? We know people are looking for information, but we also need to know how and where they are looking. The next section discusses current research into consumer online information seeking behaviour.

Consumer health information seeking behaviour

The Pew Internet and American Life survey reports extensively on consumers search techniques on the internet [4]. Eighty six percent of consumers didn't ask anyone advice about which sites to use and of those that did most asked family or friends rather than health professionals or librarians. Most just go to general search engine sites rather than medical information portals. The typical American consumer will visit an average of 2-5 sites per visit and spend 30 minutes doing so. In their last search most were concerned with retrieving information quickly rather than recognising a trusted name or sponsor. A study in the British Medical Journal, using web logs to record the searching activity, supported the idea that consumers use search engines first in their search for medical information online [7]. This is in contrast to the HON survey which found that 70% of users will go to medical professional sites with the second most popular sites being not-for-profit organisations [8]. This difference reflects the variation between the groups surveyed suggesting that for HON users the need to ensure the authority of the information is greater than the need for a prompt answer. These findings suggest that appropriate meta tagging and submission to quality portals and promotion in the virtual world is more important to increase awareness of resources than promotion via health professionals in the "real" world.

It is the concern that most consumers are relying on their own judgments of quality when retrieving resources e.g. from search engines, that has prompted the development of portals like HON (http://www.hon.ch) and Organising Medical Networked Information (OMNI) (http://www.omni.ac.uk) where users have access to a database of medical Internet resources, safe in the knowledge that these resources have been given a seal of approval (each site has a checklist to assess the quality of resources) by the portal indicating the quality and currency of the resource. A more recent development in the UK is the National electronic Library for Health. Although aimed mainly at professionals this site is a gateway to quality appraised, evidence-based information to equip professionals and patients with knowledge on which to base healthcare decisions. (See http://www.nelh.nhs.uk/new_users.asp).

But what do consumers consider marks of quality? We have already discussed that sometimes speed or retrieval may be more important to consumers than authority [4]. Four key attributes cited by consumers as important are; the source, accuracy, authority and trustworthiness of the information [4, 7, 8]. Consumers are reassured when information is duplicated across different sites, they avoid sites that are too commercial, may leave if they cannot see a source or date, and if they don't understand the information they will look somewhere else but are less likely to ask their doctor [4, 5, 8].

Recognising the source, checking the date is often quickly and easily done by consumers. However, the key problem for a lay user assessing the quality of a resource comes with checking the accuracy. Cline et al comment that consumers may:

- Fail to recognise that key information is missing
- Fail to distinguish between bias and unbiased information
- Fail to distinguish between evidence-based and non-evidence-based claims
- Misunderstand health information intended for health professionals [6]

All this research provides a useful insight into consumer behaviour when searching for health information online. It is important to look at what factors they take into account so that health information websites and digital libraries can make their sites more appealing to consumers and maximize their impact on users. However, what consumers say and what they do are probably not the same. Few consumers refer to checking the date and source of medical information when reporting their online behaviour [4]. To gain a wider picture of consumer behaviour we need to know what they actually do when online. The next section discusses the value of web log analysis in evaluating actual user behaviour.

Recording user online behaviour

Web log analysis provides information about the path a user takes through a website [13]. We can find general patterns in use e.g. most commonly visited pages, search terms used, time spent on a page etc. We can also employ a technique known as microanalysis, analysing use of the library by a small number of individual users. This provides a clearer picture of individual user behaviour when in the library, rather than general trends [14].

But what is the benefit of this analysis? Apart from informing general site restructuring and design [13] patterns of user behaviour can be used to personalise websites, providing the user with an individual experience when the visit the site. In the health information/digital library domain personalisation of medical information has been shown to improve patient satisfaction with information [15], reduce hospital admission of asthma patients [16], and to improve physician knowledge and attitudes about Chlamydia screening [17]. However, it is not so simple that any form of personalisation or tailoring will increase the impact of a resource or intervention on the user [18]. In addition many of these personalisation techniques rely on previously obtained knowledge about the user e.g. questionnaires to find out about user demographics, current knowledge and attitudes and personal preferences.

An alternative or indeed complimentary method of personalisation uses web logs and data mining techniques. This has been pioneered in ecommerce, the personalisation of Amazon being one such example [12]. Here the user is presented with products they have recently purchased or viewed and products they may like to purchase. The identification of potential purchases is based on activity by other users who have similar online behavioural characteristics. Patterns of user online behaviour are recorded over time and may be linked with collected personal data. When a new user visits the site their initial behaviour can be matched to that of previous users, and the site can be tailored accordingly. This technique can be particularly useful for attracting new visitors to register with a site, making them feel that the site is appropriate to their needs [19].

So personalisation could be a useful tool to aid digital libraries in empowering users. But we need to measure the impact of such techniques on user knowledge and attitude to evaluate their effectiveness. The next section discusses the context of the project, outlines the public health concern that is antimicrobial resistance and describes the methods used in the initial evaluation.

3. Initial evaluation methods

Information about antimicrobial resistance for the public

In his 2002 report "Getting ahead of the curve" the Chief Medical Officer identifies antimicrobial resistance as a key priority [20]. The report suggests that educating and informing the public is an essential component of any strategy for reducing the further development and spread of antimicrobial resistance, a view that is supported by previous influential reports [21, 22]. Research has shown that doctors believe patient expectations play a major role in inappropriate use of antibiotics [23-25].

Investigations into the impact of community-wide campaigns and videotapes about antimicrobial resistance, on prescribing patterns and patient expectations, have shown that they can reduce the expectation of antimicrobial prescribing [26, 27]. However, in spite of the increasing interest in providing health information over the Internet resulting in initiatives from Government organisations e.g. NHS Direct Online (http://www.nhsdirect.nhs.uk), commercial enterprises Netdoctor e.g. (http://www.netdoctor.co.uk) and non-profit organisations e.g. Health on the Net Foundation (http://www.hon.ch), and whilst some research, as discussed above, has attempted to discover how consumers search for and assess health information on the Internet little is known about the impact of this health information on knowledge and attitudes. A recent systematic review suggested that there was a paucity of evidence showing that consumer use of the Internet for health information has any effects on health outcomes [28]. We could not find any studies which investigated if the Internet could influence attitudes to antimicrobial prescribing.

The antimicrobial resistance website

The website was developed as an interface for the public to information held in the National electronic Library Communicable Disease (NeLCD) for http://www.nelcd.co.uk. The NeLCD is a specialist library of the UK National electronic Library for Health (NeLH) and provides a freely accessible, online, evidencebased, quality-tagged Internet portal to the best available evidence on prevention, treatment and investigation of communicable disease [29]. As indicated earlier in this paper, the education of the public about antimicrobial resistance is key in tackling this problem, therefore, although the NeLCD is aimed at health professionals it was considered important to provide an access point for the public to evidence-based information in this particular area of medicine.

The aim of the site is to "to inform the public of current evidence-based guidelines on antimicrobial prescribing and the issues surrounding those guidelines in an effort to reduce patient pressure on doctors and subsequently reduce inappropriate prescribing". The main content of the site is found in over 60 frequently asked questions, grouped into 22 categories. These FAQs provide short evidence-based answers, written by the NeLCD team, with links to the evidence and related questions on the site. Each FAQ is indexed using MeSH keywords to permit keyword searching. Each category is assigned a collection of relevant external resources, all catalogued using

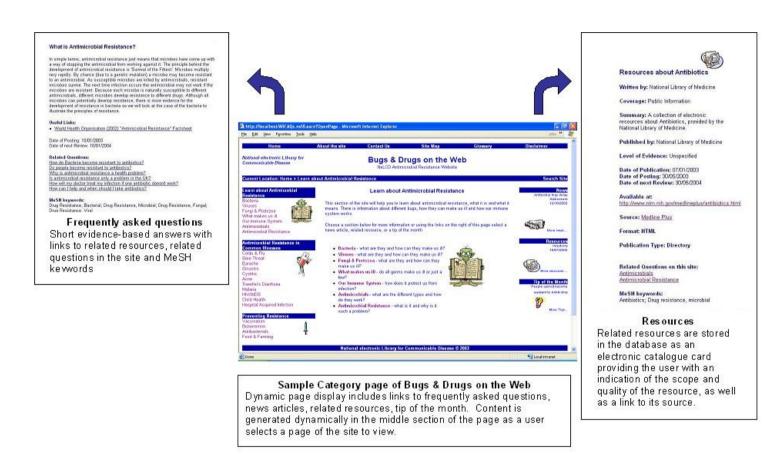


Fig. 1. Sample page of the Antimicrobial Resistance website with explanations of different areas of content

the NeLCD electronic catalogue card based on Dublin Core. A short summary of the resource is provided to indicate the target audience, content and level of quality. In addition the site provides links to antimicrobial resistance stories in the news, linking to sites such as the BBC and Netdoctor. Figure 1 shows a sample page of the website and example questions and resources.

Pre and post questionnaire evaluation methods

As already discussed, there are various methods to investigate user behaviour and self-reported use of online health information. However, there has been little, if any, investigation into the impact of this information on user knowledge and attitude. We wanted to conduct an initial study to investigate this impact. As the use of pre and post questionnaires testing user knowledge and attitude proved a useful method in previous studies evaluating the effectiveness of other forms of medical information (e.g. video and print media) on changing public or professional knowledge and/or attitude [17, 26, 27, 30] we adopted this methodology for this study. Pre and post questionnaires were designed to evaluate:

- General knowledge about antibiotics
- Attitudes to the use of antibiotics in a common ear infection (acute otitis media)
- Whether age, gender, experience with the Internet or level of education had any influence on the impact of the site on user knowledge and attitude changes i.e. does the site appeal to or is it more accessible to specific groups?
- The relationship between knowledge and attitude changes, and the usability of the site were also investigated but are outside the scope of this paper and are reported elsewhere [31, 32]

An expert in communicable disease validated the questions. Both questionnaires contained the same seven true/false statements about antibiotics and the same six likert scale questions (1 strongly disagree to 5 strongly agree) about antibiotic use in acute otitis media. These questions are shown in the appendix. The post-use questionnaire also collected demographic information about users. Participants were asked to complete the pre-use questionnaire, then encouraged to freely browse the website for around 10 minutes and asked to complete the post-use questionnaire when they left the site.

4. Results

Setting of the Study

The study took place in the Science Museum, London as part of 'live science' in February half-term 2003. Two hundred and twenty seven museum visitors were recruited opportunistically and of these 177 completed both questionnaires for which the results are discussed below. The study population recruited closely matched the Science Museum visitor statistics in gender, age, and highest level of education [33]. Results

were analysed and tested for statistical significance using an appropriate statistical test (paired t-test, McNemar's test or Fisher's Exact). The results are discussed below comparing changes in knowledge and attitude between different demographic groups. The seven true/false statements evaluating knowledge were marked by giving a score of one for each correct answer. A "don't know" answer was counted as incorrect. The six likert scale questions were on a scale of 1 (strongly disagree) to 5 (strongly agree) and these rankings were used as scores. When there was no ranking by the user they were left out of the analysis for that specific question, so the sample size was reduced accordingly.

Changes in knowledge and attitude

Overall there were significant improvements in knowledge (p<0.05) and a decreased expectation of antibiotics for acute otitis media (p<0.001). Differences between gender, age groups, education groups and confidence using the web are reported below.

Gender

There were almost equal numbers of both genders taking part in the study, with 86 males (49%) and 91 females (51%). Both genders significantly increased their knowledge scores after using the site and significantly changed their attitude ranks for all but one of the attitude statements. However, whilst females scored slightly, but not significantly, higher both before and after using the site than the males on the knowledge questions (an average score before using the site of 4.42 compared to 4.22 and 5.03 compared to 4.8 after using the site), there was no significant difference between the knowledge changes of each group (p=0.9). There were also no significant differences between the proportions of males and females agreeing or disagreeing with the statements in question two.

Age

Dividing users into age groups allows us to see if the site impacts different groups in different ways. For example, do children learn from the site as much as, or more than adults? Or is the site tailored more to adults? Do different age groups come with different levels of knowledge and attitudes? Are the age groups that are more likely to be parents more likely to expect antibiotics for AOM?

Table 1. Changes in knowledge scores by age. (N= number of participants, Pre= mean score before using site, Post= mean score after using site, Change= mean change in score, p= statistical significance of change using paired t-test)

	< 18	18-24	25-34	35-44	45-54	55-64	65-74
N	29 (16%)	17 (10%)	45 (25%)	44 (25%)	24 (14%)	10 (6%)	8 (4%)
Pre	3.48	4.35	4.36	4.49	4.96	4.44	4.2
Post	4.17	4.47	4.93	5.4	5.16	5.33	4.2
Change	+ 0.69	+ 0.12	+ 0.58	+ 0.91	+ 0.2	+ 0.89	0
p	0.02	0.39	0.004	< 0.001	0.18	0.005	N/a

There were significant increases in knowledge scores after using the site for four of the six age groups: under 18, 25 to 34, 35-44 and 55-64. Table 1 shows these changes and figure 2 shows the changes in pre and post scores of the different age groups.

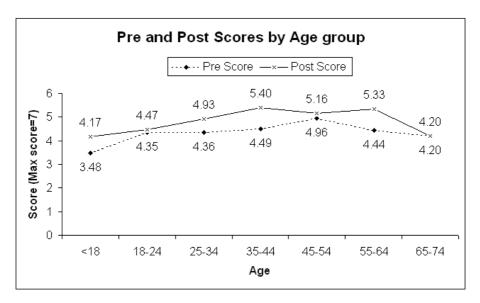


Fig. 2. Pre and post scores of different age groups.

There is variation across groups both before and after using the site. However, the noteworthy differences between groups were as follows:

- Between the total scores of the under 18 group and all other ages before using the site (p values: 18 to 24 =0.03, 25 to 34 =0.01, 35-44 = 0.006, 45-54 <0.001, 55-64 =0.03)
- Between the total scores of the under 18 group and the 25 to 34 group (p =0.03), the 35 to 44 group (p<0.001), the 45 to 54 group (p=0.02), and the 55 to 64 group (p=0.01) after using the site

For the attitude statements the only group to show no significant change in attitude to any of the statements was the 18 to 24 group. The 35 to 44 group showed significant changes in attitude to all but one of the statements. Those in the under 18 group, the 25 to 34, 35 to 44 and 55 to 64 groups were less likely to expect antibiotics for acute otitis media after using the site than before.

Education

The issue of whether level of education of users is related to the impact the site has on their knowledge and attitudes can help to indicate the suitability of the site for different groups. The use of antibiotics in acute otitis media is an area where the evidence-base is not clear and the limitations of current evidence is indicated on the website.

The level of knowledge of different education groups before and after the site and changes in their expectations of receiving antibiotics for AOM will help to indicate whether the information on the site is too basic or too detailed.

All groups showed significant increases in knowledge except the group with PhDs. The sample size of this group was too small (n=6) to allow it to be compared with the other groups. Figure 3 shows the pre and post scores of each group with the corresponding p value.

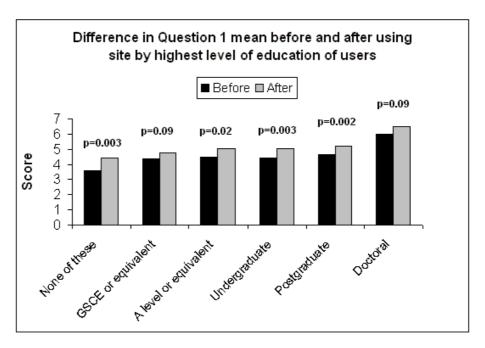


Fig. 3. Changes in knowledge scores by education group

The only significant differences in scores between groups (excluding the doctoral group because of the small sample) were:

- Between the "none of these" group and the GCSE group (p=0.02), the A level group (p=0.004), the undergraduate group (p=0.006), and the post-graduate group (p=0.002) before using the site.
- Between the "none of these" group and the A level group (p=0.03), the undergraduate group (p=0.02), and postgraduate group (p=0.01) after using the site

Only the postgraduate and doctoral groups saw no significant decrease in their expectation of receiving antibiotics for acute otitis media. The other groups were all less likely to expect antibiotics after using the site than before (p values: "none of these" =0.007, GCSE =0.05, A level =0.03, undergraduate =0.008)

Confidence using the Web

Although use of the web is increasing and more and more people are becoming confident web users, it is important to know that the site is not only impacting on those users that are confident with the technology but also on those who are not so familiar with it. Users were asked to rate their confidence using the web on a scale of one (not at all confident) to five (very confident). There was no significant difference in the proportions of users increasing their knowledge score between these five groups. Figure 4 shows the proportions of users in each group increasing and decreasing their score.

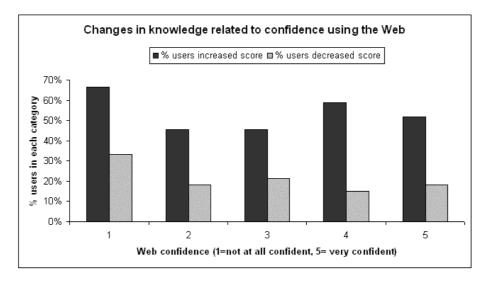


Fig. 4. Proportion of users increasing and decreasing their knowledge score by web confidence group

5. Discussion

These results suggest that for this group of users gender has no effect on knowledge and attitude either before using the site or after. Users under the age of eighteen can be expected to know less before and after using the site than the adults. While the site may not be particularly suitable for children, under 18 group did improve their scores significantly. The least impressionable age group was the 18 to 24 group. With respect to level of education, those without any of the qualifications listed had less knowledge before using the site than other groups. Although this group did improve their knowledge sufficiently for there to be no significant difference between them and the GCSE group after using the site. The fact that changes in knowledge were not related to confidence using the web could suggest that the site is easy to navigate for all levels of computer users. These results suggest that the impact of the site on user knowledge and attitudes is not dependent on demographic factors such as gender, age or level of education, or even confidence in using the technology.

But what does this mean for future evaluation of the NeLCD? This paper has presented a methodology that can be applied to evaluate the impact of the NeLCD on user knowledge and attitude. We have already discussed the value of analysing web logs in monitoring site usage and in personalising websites. If we can encourage users to register as "members" of the NeLCD and track their use of the library we can begin to collect more reliable data about user behaviour. By combining this with data collected at registration such as job title and grade, location, we can begin to build up a picture of how users behave within the library. We can evaluate user knowledge and attitude changes after using the site and compare this information to web logs, personal data about users and their perception of how the site has impacted on their work. This will help us to see how users best learn from the site and whether this varies between groups of professionals. Another important aspect of the NeLCD is the online community of communicable disease professionals. Will people who are more active in the community feel that they are learning more from the library or do they already come with a higher level of knowledge than other users? Does the site have more impact on those who are involved in every part of it or on those who focus on specific features e.g. the quality appraisals, the discussion fora etc. Can the NeLCD then be personalised for different groups of users or individuals, registered or not, and does this increase the impact of the library on users? And what about familiarity with the technology? Does that affect how much users learn from the site and why? Do those who come with less knowledge about a subject before using the site learn more than those with a greater knowledge?

Although not the primary aim of the library, there is a key role for the NeLCD in providing consumers with more in-depth, quality-appraised, evidence-based information than is currently easily available to them. We would like to investigate whether the public learns more from an NeLCD tailored for their use rather than a generic NeLCD for all users, what types of information public users want to access and how they expect to find this information within the NeLCD.

Conclusion

This paper has discussed the availability and user of consumer health information on the Internet and consumer online behaviour. It provides evidence that, in an initial study online health information was shown to change user knowledge and attitudes, but that these changes did not appear to be dependent on demographic factors or confidence using the Internet. The paper has discussed the potential of analysing web logs and personalising the library to increase the impact the NeLCD has on its users. It has presented a methodology that can now be further developed and applied to the NeLCD for evaluating the impact of the library on its users', their knowledge and attitudes and subsequent behaviour.

Future research will involve combining data from different sources in order to provide a better picture of user behaviour, preferences and learning. We hope to investigate the impact of the NeLCD on professionals and patients, comparing differences between these groups and within them. This paper presents the base on which this future research will be developed.

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