



**Working with public
libraries to enhance
access to quality-assured
health information for the
lay public**

Healthinfo4u

**British Library Co-operation and
Partnership Programme No. 6:**

Final Report

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and David Ball**

2003



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Bournemouth University
Occasional Papers on
Library Information
Services

Abstract

This study provides the results of a 22-month project to research whether web technology can be used to provide the lay public with quality-assured, evidence-based journal literature previously only available to health care professionals. The study documents the development of the demonstrator product and the results of its trial and evaluation, using action research methodologies, in selected public libraries and health information points in the UK. The literature review provides the context for the development of the provision of health information for the lay public and considers the issues surrounding the provision of e-journals. The study also provides an assessment of the potential requirements for a viable future web-based resource to provide consumers with the full text of quality-assured health information selected from journals used by health care professionals.

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Executive summary

Introduction

This report documents the results of the British Library Co-operation and Partnership Programme No. 6: *Working with public libraries to enhance access to quality-assured health information for the lay public*, a 22-month study managed by Bournemouth University from June 2001 until March 2003.

The aim of the study was to explore the feasibility of re purposing quality-assured, evidence-based information currently available only to health professionals and deliver it, using existing web-based technologies, to the lay public. The majority of the access locations used during the study were public libraries. The award of additional funding from the British Library in 2002 supported the demonstrator sites in additional health information locations.

Literature review

The report documents, through an extensive literature review, the context within which consumers might be encouraged to seek health information and how that information might be provided. It is evident that health provision is undergoing a paradigm shift to self-care, with doctors and other health care professionals increasingly acting as brokers for health guidance. The review also reflects the importance and challenges of developing a web-based information tool suitable for the lay public. Patients are using new technology to access information about conditions and treatments, both conventional and complementary. The National Health Service agenda is firmly patient-centred; the emergence of the expert patient, demanding quality-assured professional information, has created the need for access to such information and supporting navigating tools.

Developing the demonstrator product

The development of the demonstrator product was informed by research into existing Internet-based consumer health information and was supported by quality assurance procedures for content selection. The selection criteria developed used peer-reviewed literature already selected for the *British Nursing Index (BNI)* and the *Allied and Complementary Medicine Database (AMED)*. The further selection of articles by experts followed guidelines established to ensure relevance of the content for the lay public.

The demonstrator product was developed and evaluated against the research project's aims and objectives. Technical, publisher and document supply partnerships enabled access to the selected articles. The lay public was provided with access to specially selected, quality-assured journal articles that were organised under 256 topics. Those who used the demonstrator product commented on the value they placed on the information provided as illustrated by the following:

I came across your website and lo and behold there were all these collated references that would have taken me a lot longer to find on an individual basis. I thought the site was excellent.

Methodology

The study adopted action research as the methodology for the project evaluation. This enabled users' views to be sought and considered throughout the development of the product, and provided the mechanisms for consultation with appropriate specialists including the project's Board and Steering Group and other health care professionals, information professionals and consumer health care information providers.

Project results

The results of the action research include: feedback from questionnaires returned during the project's three demonstrator cycles; comments obtained from focus groups and telephone interviews; and an analysis of document supply and document access data. The population sample is shown to be representative of health consumers who use public libraries and health information points.

In total 233 questionnaires were received and some of the key results are:

- 82% considered the product to be a "good idea";
- 66% would use the product again, rising to 87% once articles had been received;
- 66% considered the articles to be "easy" or "moderate – some medical terms but understandable";
- 63% considered that the articles had fulfilled their expectations, with another 28% being fairly or partly satisfied;
- 44% indicated the information was "indispensable", "valuable" or "significant", with a further 23% rating it as "helpful".

The results indicate that the project developed a demonstrator product that met the needs and gained the respect of consumers. Discussions with health care professionals indicated that the product should be made available to the lay consumer and one general practitioner commented "I would like to see this integrated into a surgery". The project Steering Group have endorsed *Healthinfo4u* and one member commented "providing accessible patient information is vital, you have conducted some sterling work".

Sustainability

The report discusses how document delivery was achieved free of charge during the project either through document supply provided by the British Library Document Supply Centre, or through different full-text on-screen arrangements provided by three publishers. The challenges of developing a future product that could be sustained in a commercial marketplace are discussed. None of the models for document access trialled and evaluated during the study would be suitable without modification for a future product. This is due in part to the unavoidable costs of the

copyright charges imposed by the publishers. For document supply from the British Library these copyright charges ranged from £0.13 to £52.00 per article.

Conclusion

The report concludes that there is evidence that web technology could be used to deliver a tool that could supply the lay public with accessible, quality-assured, evidence-based literature previously only available to health care professionals. However there are major impediments, in terms of technology, negotiating with and rewarding rights-owners and developing a sustainable payment model, to transforming the *Healthinfo4u* demonstrator into a viable product.

Acknowledgements

Our thanks go to the Project Board and Steering Group (whose names and affiliations are detailed in Appendices C and D). They all gave indispensable advice drawn from a depth of expertise across the areas of work.

We would like to acknowledge the work of the following public library authorities who helped write the proposal for the project, served on the Project Board, and made available demonstrator sites for the project: Bournemouth Borough Council Arts, Libraries and Museums Services; Essex County Council Library and Information Services; Poole Borough Libraries; Wiltshire County Library Service.

Our thanks go to the following in the development and facilitation of additional demonstrator sites: Bournemouth Primary Care Trust; Durham and Tees Valley Workforce Development Confederation; Poole Hospital (NHS Trust) Library Services; University of Birmingham Regional Library Unit.

We would also like to thank the project's two technical partners, Health Communication Network and Ovid Technologies, and the two secondary content providers, *British Nursing Index* and *Allied and Complementary Medicine Database*, for contributing to the bid and for making possible the selection of the demonstrator product's content.

Acknowledgement also goes to the following publishers who provided full-text access to a selection of journal articles contained in the demonstrator product: Blackwell Publishing; Lippincott, Williams and Wilkins; and RCN Publishing.

Last but not least our thanks go to the British Library who not only provided 50% of the funding, but also invaluable assistance from the British Library Document Supply Centre.

1 Introduction

This report documents the results of the British Library (BL) Co-operation and Partnership Programme No. 6: *Working with public libraries to enhance access to quality-assured health information for the lay public*, a 22-month study managed by Bournemouth University from June 2001 until March 2003. The original and additional project bids form Appendices A1 and A2.

The study was designed to explore the feasibility of re purposing quality-assured, evidence-based information currently available only to health professionals and deliver it, using existing web-based technologies, to the lay public.

The research study had the following objectives:

- to support lifelong learning and healthy living agendas by making existing quality-assured sources of health information available to the lay person through public libraries and patient information centres by both document delivery and full-text electronic access;
- to enhance health professionals' access to literature selected for its relevance to the lay person;
- to build on existing services and partnerships to create a new navigational tool to such literature;
- to investigate with publishers sustainable models for accessing specialist electronic information through public libraries;
- to recommend models for sustainable delivery, including the selection of content, web access to the secondary sources, web delivery of full-text and traditional document supply of content.

During the study the project team delivered five papers at conferences, published two articles and demonstrated at four health information events to disseminate the project findings and to promote the research study to the health care and information communities (Appendix B).

The report is organised into the following sections.

Literature review

The literature review has provided the context within which consumers might be encouraged to seek health information and possible means of providing that information. It discusses the development of UK and European health information policies, the consumer need for health information and the growing demand for health information over the Internet. It also reviews the methodology adopted for the project and developments in electronic document access.

Developing the demonstrator website

One of the first tasks was to develop the demonstrator website. This section discusses: the review of existing health information websites; the scope of the topics to be

included; the quality-assured content selection process; the build of the dataset; the website design; and the technical issues involved in setting up document access.

Project methodology

Action research was the methodology adopted for the project because the resulting triangulation of multiple data sources enables research to obtain diverse views. The methodology's participatory style encouraged the researchers to seek and consider users' views throughout the development of the product, and provided the mechanisms for consultation with appropriate specialists, including health care professionals, information professionals and consumer health care information providers. The project Steering Group (see Appendix C for membership) provided valuable comment and guidance on the project and the development of the product. The Project Board (see Appendix D for membership), comprising the Technical Group, the Publishers Group, the Demonstrator Site Planning Group and the Producers Group, addressed issues of product development and testing.

The study incorporated three cycles during which members of the public accessed the demonstrator product at selected public libraries and health information points. Respondents provided a representative population sample in the context of a web-based study conducted in the demonstrator sites selected. The project developed demonstrator site partnerships across five counties in the United Kingdom.

Project results

Two questionnaires, a series of interviews and a focus group were used to establish whether the product could provide quality-assured health care information to the lay public. The results obtained from the 233 questionnaires were analysed using SPSS and the conclusions from all feedback are presented.

Sustainability

The public demand for a viable future product is illustrated, and the challenges of product development, document access and eventual product delivery are outlined.

2 Literature Review

2.1 Scope of review

The literature review provides the context within which consumers might be encouraged to seek health information and possible means of providing that information. The literature reviewed covers:

- health information policies of the UK Government and the Commission of the European Communities (CEC);
- consumer need for health information;
- consumer demand for health information over the Internet;
- the research methodology adopted for the project;
- the quality assurance of consumer health information;
- the parameters for document access.

2.2 Health information policy

A new focus on health promotion was outlined by the UK Government's Department of Health (DOH) in the 1991 white paper *Health of the Nation* (DOH 1991), which included a recognition that lay people should have access to reliable information in order to contribute to their own health care. This policy was continued in *Information for Health* (DOH 1998) which outlined strategies for meeting patient and public information needs as follows: "access to the right information at the right time is a crucial ingredient of modern health care. Across the world there is a growing interest in information about health" (Ch5.9, p.79).

This document recognised the potential for health information to be conveyed over the Internet: "the latest information technology presents huge opportunities to improve the quality and accessibility of health services to patients and the public" (Ch5.1, p.77). It also included a reference to the service that would later become *NHS* (National Health Service) *Direct Online*.

The need for patients' contribution to their own health care was emphasised further by the UK Government in *Saving Lives: Our Healthier Nation* (DOH 1999), in particular the development of the "Expert Patient programme". This was designed to enhance the knowledge of patients with chronic conditions in order to help improve their quality of life (DOH 1999 p.39).

The publication of the *NHS Plan* (DOH 2000) endorsed the policy for public information, outlining the intention that new technologies would be used to enable access and delivery.

The provision of public health information was further emphasised in *Building the Information Core* (DOH 2001a): "people will be helped to navigate the maze of health and care information through the development of consistent information" (Ch3.5, p.13). The document suggests that "patients and the public will demand far greater information about how they can look after their health" (Ch4.2, p.23).

In regard to the use of modern technologies to convey health information Wanless (2002) comments: “through media such as the Internet and digital TV, people receive more information and interactive advice on the management of their and their family’s health” (Ch2.13, p.15).

The Expert Patient (DOH 2001b) articulates the concept of the “Expert Patient programme” developed by the DOH to promote increased patient knowledge and empowerment:

Today’s patients with chronic diseases need not be mere recipients of care. They can become key decision-makers in the treatment process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives. (p.5)

Concerning the potential tangible benefits of patients being able to “empower themselves with appropriate information”, that is, to exercise increased “self-care”, Wanless (2002) comments:

Department of Health estimates based on the above (self-care) research suggest that, for every £100 spent on encouraging self-care, around £150 worth of benefits can be delivered in return. (Ch3.49, p.50)

The recognition that the Internet is increasingly being used to access health information is documented in the CEC Action Plan *eEurope 2005: An information society for all* (CEC 2002a), and it outlines the requirement for efficient, accessible online health services:

By end 2005 Commission and Member States will ensure that online health services are provided to citizens (e.g. information on healthy living and illness prevention, electronic health records, teleconsultation, e-reimbursement). The Commission will monitor actions taken by Member States to make health information as accessible as possible to citizens. (3.1.1, p.13)

The Action Plan also recognised the need for instruments to measure the quality of web-based health information: “it is critical that e-health content and services are developed efficiently, are available for all and health related web sites comply with established quality criteria” (3.1.1, p.13).

Taken together these policies provide the drive and commitment to provide members of the public with quality-assured, accessible health information and reflect the value of doing so using Internet resources.

In predicting possible future policy drivers, Grimson and Grimson (2002) comment that:

Ensuring equitable access to health care for all citizens is likely to become a major political issue over the next decade which must inevitably bring with it fundamental changes in the health care system. (p. 28)

They highlight the emerging “need for global equity” and conclude:

It is hard to believe that major changes to the way health care is governed and delivered will not be necessary in the next decade and the way information technology is utilised will be shaped by these changes. (p. 28)

2.3 Consumer need for health information

Coulter *et al.* (1999) write that patients require reliable and appropriate information in order to express informed preferences. Charnock & Shepherd (2002) write that there has been a rapid increase in the involvement of patients in their individual health care decisions.

Wanless (2002) expands on patients’ informed preferences:

With access to better information, they are involved fully in decisions not just about treatment, but also about the prevention and management of illness. The principle of patient and user involvement has become ever more important and the health service has moved beyond an “informed consent” to an “informed choice” approach. (Ch2.10, p. 15)

Access to appropriate information and the ability to communicate with health care professionals are crucial elements to patient and user involvement. These elements have been described by Illman (2000) as “prerequisites for the expert patient”, referring to the “Expert Patient programme” developed by the DOH (2001b) for those with chronic conditions.

Inherent in this approach is the availability of quality-assured health care information to enable individuals to develop their knowledge and skills so that, if they wish, they can work in partnership with health and social care professionals.

Mackay (2000) notes that increased information-seeking behaviour from health consumers has the benefit of enhancing the position of the doctor and patient as partners in health care. Holmes-Rovner *et al.* (2001) articulate that the increasing amount of patient involvement in health care decisions, as encouraged by policy drivers, creates a higher demand for information.

Sowden & Forbes (2001) acknowledge that there are a number of factors that may affect involving patients in decision-making successfully, for instance the accessibility of the information and the individual’s desire to participate.

McKenzie (2002) has also analysed barriers in patient/practitioner communication and reflects on the value of patients who are well informed on their individual condition:

In many cases, these accounts portray information seekers as indispensable, if invisible, partners without whose active participation practitioners could not work effectively. (p. 43)

2.4 Consumer demand for health information over the Internet

Mackay (2000) demonstrates that the demand for consumer health information has seen a major growth and that patients and consumers obtain their information from a wide range of sources. Ferguson (2000) writes that in 2000 there were over 100,000 health information web sites and that 98 million adults have used the Internet to find health information; this represents one third of all Internet searches.

A US study (Congressional Internet Caucus Advisory Committee 2002) on expanding Internet use by Americans found that 54% of the population are online and 35% search for health information. In comparison, in 2001 49% of the UK population had Internet access (ICM, 2001).

The GP Committee of the British Medical Association (2001) recognise that patients use Internet information in consultation with health care professionals and acknowledge that this is a positive step towards partnership in individual health care decisions. Timmons (2001) writes that this can benefit both the patient and the health care professional by providing new opportunities for individual treatments.

Ball and Lillis (2001) describe how the relationship between health care professionals and consumers is developing, facilitated by the Internet, and outline the implications of the increased demand for information: “the empowered, computer-literate public is exerting tremendous influence on health care delivery” (p. 1). They continue:

This new breed of consumer is slowly redefining the physician/patient relationship. Such changes can effect positive results like improved clinical decision-making, increased efficiency and strengthened communication between physicians and patients. First, however, physicians and organizations that support them must fully understand their role in the e-health revolution. Both must advance their awareness of the new consumers and define specific actions that will help them realize the benefits of e-health. (p. 1)

Ball and Lillis (2001) also identify three elements that e-health consumers require of health information provision: convenience; control; choice. They write that new e-health tools will enable consumers and health care professionals to “achieve a new level of knowledge and connectivity, and the inefficiencies that bar them from fast access to crucial clinical answers will largely disappear” (p. 9).

As documented above Sowden and Forbes (2002) identified factors that would have an impact on the success of patients using health information to become partners in their individual treatments. Dickerson and Brennan (2002) analysed Internet use to suggest that provision of e-health tools alone will not be enough to empower patients:

examination of Internet use through critical social theory perspectives reveals how dominant ideologies can maintain traditional barriers to information-sharing in health care. (p. 195)

They suggest that:

widespread availability of health care information that can be accessed directly by patients may create a situation of perceived conflict when physicians contend that they hold the authority to determine the correctness of the information. (p. 198)

The risk of the suggested “perceived conflict” above may be reduced by patients using a specially developed, accessible health information tool that both consumers and practitioners can recognise as one that provides quality-assured literature.

Milewa *et al.* (2000) also suggest that it is crucial to analyse the impact of patient information whilst acknowledging socio-historical barriers in order to avoid “incomplete, a-sociological, understandings of how patient behaviour is influenced” (p.473).

In recognition of the Internet’s potential to correct the balance of power in the patient/physician relationship, Dickerson and Brennan (2002) comment:

online health information and support are available to assist patients in obtaining support, it is important to be cognizant of trends both historically and in the future that affect patient participation. (p. 202)

They conclude:

If the ideologies of egalitarianism and effective allocation of resources can be realized, then a more equitable provider/patient relationship can be realized that empowers patients and improves quality of care. (p. 202)

Sowden & Forbes (2001) have documented the inherent challenges of guiding consumers through the expanse of health care information to arrive at accessible, appropriate literature. Hammond (2001) writes that the demands of the health care consumer, notably the expert patient, have led to the need for access to quality-assured health care information and provision of the navigational tools to support this.

Ferguson (2001) proposes that some patients are, in his experience, capable of sourcing and reviewing health literature to such a degree that he describes them as “medical end user(s)” (p. 555). He writes that there are “patient driven online support networks” developed to help patients deal with information and that “the 21st century will be the age of the net empowered medical end user” (p. 556).

Coulter *et al.* (1999) also acknowledge that in the search for and review of health information, consumers know what kind of information may help them.

2.5 Methodology adopted for the project

The aim of the project was to research whether it is possible to repurpose professional, quality-assured, journal-based health literature to create an accessible web-based resource for the lay consumer. The cyclical development of the resource was to be informed by, and reflect on, data from consumers, health care professionals and health information experts. The methodology selected needed to include data collection methods that would direct product development throughout each project cycle. It was anticipated that the project would result in an innovative and unique resource for the growing community of health care consumers to increase their knowledge base.

Action research is a multi-disciplinary, experimental research method that relates knowledge to practice. It involves collaborative partnerships and is participative and grounded with practical concerns (Reason & Bradbury 2001).

Heron and Reason (2001) elaborate that action research is a method that connects the researcher with the experiences of the community and the people who are involved with the research. They describe this as “co-operative enquiry” (p.179) and write that the benefit of this approach compared with traditional research is that it is “conducted *with* people rather than *on* people” (p.179). They write that a second benefit in using action research is that it is concerned with practical methods of helping people discover how to address issues in their community, rather than simply expanding on a theory.

In consideration of its collaborative, participatory and multi-disciplinary approach, action research was chosen as the appropriate methodology for this social research project.

In reference to Lewin, a researcher who stresses the importance of conducting research to achieve practical change, Ottosson (2003) writes that social research should have the priority of undertaking “practical work to improve inter-group relations” (p. 90). He outlines that it is a process of joint learning to solve a problem, of “devising changes for the better” (p. 91) and continues that today action research “has its roots in solving social problems in society or in organisations and draws general scientific conclusions from the experience” (p. 91).

Ottosson (2003) also comments that participatory action research is particularly useful in “new and unpredictable situations common in early phases of innovation management and product development” (p. 91).

The community studied in the project is the UK health consumer in selected information provision environments. Black (2002) writes that survey results should indicate that purposive sampling had been used in order to achieve a typical UK population profile.

The increasing use of participatory research strategies in health research has been documented by Cornwall and Jewkes (1995), who claim these strategies “are gaining greater respectability and attention within mainstream health research” (p. 1667).

They write that action research methods have been used to assess needs in health promotion, and highlight the key characteristics and strengths of participatory methodologies:

characterized as being reflective and iterative, in contrast with the rigid linear designs of most conventional science. One of their key strengths is seen to reside in exploring local knowledge and perceptions. (p. 1668)

Concerning the participatory research method of the focus group, Nielson (1997) recognises the value of such groups, however he warns of the implications of only using this method in the evaluation of the usability of web systems:

Although focus groups can be a powerful tool in system development you should not use them as your only source of usability data. To assess whether users can operate an interactive system, the only proper methodology is to sit users down, one at a time, and have them use the system. (Online, URL: <http://www.useit.com/papers/focusgroups.html>)

It follows from this that those who attend a focus group should be recruited from users who have tested the resource being developed.

2.6 Quality assurance

Two of the issues involved in assessing and ensuring the quality of health information are explored; peer review of professional literature and the quality assessment of Internet-based health information tools.

2.6.1 Assessing quality through peer review of literature

Kohane and Altman (2000) describe how the quality of professional literature has traditionally been achieved through peer review, that is, “having qualified individuals read and evaluate manuscripts before they are released for general consumption by a larger community”.

Bingham *et al.* (1998) expand on the peer review process for medical papers, articulating that it exists “to identify the best scientific reports and to correct deficiencies in scientific reporting before publication” (p. 441).

Three main benefits of the process have been identified by Kohane and Altman (2000). Firstly “there are some assurances that the contents of the manuscript have been carefully assessed and are valid”; secondly “authors benefit from the knowledge that their colleagues have evaluated their work”; thirdly “publishers benefit because they can make claims about the quality of the contents of their publications” (p. 433).

Peer review is not without criticism and Ludbrook (2002) claims to have identified, during a study, the following weaknesses in the process:

- reviewer incompetence, which he suggests could be solved by publishing guidelines and running training programmes for reviewers;
- reviewer bias, which he writes could be combated through blind reviews signed by the reviewer;
- failure to detect plagiarism and fraud, which he suggests could be approached by specifically warning reviewers about this and asking them to make Internet searches for similar material. (p. 106-7)

Some of the issues surrounding making quality-assured health information available to consumers may be addressed by selecting from an existing, peer-reviewed literature base. In order to avoid Ludbrook's perceived weaknesses of the peer review process having an impact on the information provided to consumers, a secondary selection process that follows agreed criteria could be implemented (Beard & Madge, 2002). In this way consumers may be provided with re-purposed, accessible, quality, health information of an appropriate level and provenance.

2.6.2 Assessing quality of Internet-based health information tools

The issue of identifying trustworthy information on the Internet is highlighted by Ferguson (2002), "of those with Internet access, 82% say that they are concerned about getting online health information from an unreliable source" (p. 555).

As with information disseminated through other media the quality of information presented over the Internet varies widely. Referring to a study conducted in 1997, Purcell *et al.* (2002) write that there have recently been at least 80 studies reporting that health information over the web varies "widely in terms of accuracy, completeness and consistency" (p. 557).

Considering e-health services being developed for consumers, Forsstrom and Rigby (1999) write that "health care is one of the most crowded markets in cyberspace" (p. 173). They elaborate "as the Internet population continues to grow, steering patients away from sources of bad information may one day become a standard part of preventive medicine" (p. 173).

They suggest that a solution would be to have a "closed network" of health services where websites would have to be registered, or that a European regulatory authority could ensure the quality of health information.

The CEC (2002b) has drawn up a commonly agreed set of quality criteria to guide the development of health-related websites. The resulting quality criteria require a health-related website to possess the following: transparency; authority; privacy and data protection; updating of information; accountability; accessibility.

Silberg *et al.* (1997) write that issues of quality are important and valid, and that standards applied to web-based information should also apply across all information types and media. They note that "novice and savvy Internet users alike can have trouble in distinguishing the wheat from the chaff, the useful from the harmful" (p. 1244).

They conclude that the Internet is not a “special case” in the need to manage the information more carefully, however it may be seen as such because of the rapid access to, and wide dissemination of, health care literature.

In reference to quality assurance of Internet health information in particular, Charnock and Shepperd (2002) also suggest that web-based health information resources are scrutinised more closely than those delivered by other methods:

Health information in other media has not received the same degree of attention, even though the public is exposed to misleading and inaccurate information from a variety of sources. (p. 556)

Purcell et al (2002) suggest that the web interface directing users to the online information should have its own quality criteria, and that in measuring the effectiveness “it is users’ views we should be seeking” (p. 558).

The importance of quality assurance is illustrated by Sacchetti *et al.* (1999) in their survey of the data available over the Internet on a single health topic. They indicate:

We found that searching the Web for good quality, health-related information can be extremely time-consuming. Judging whether the information is applicable and credible presents an even greater challenge than locating it. (p. 1120)

They conclude:

As physicians do in their actual delivery of care, they must take an active role in helping their patients find Web sites that provide the best and most accurate information. (p. 1120)

The DOH (1998) recognised the requirement of quality assurance of health information on the web and outlined its vision for an accreditation process to be implemented through the Centre for Health Information Quality (CHIQ):

There is a need to signpost information sources, to give the public easy access to relevant information. There is also a need to develop, through a process of accreditation, access to information which the public and patients can rely on and which is presented in a clear and intelligible way. As part of its Patient Partnership strategy, the NHS Executive has already set up the Centre for Health Information Quality. The role of CHIQ is to work with the producers of information for the patient and the public to improve its quality, accessibility and evidence base. (Ch 5.17, p. 81)

The accreditation of consumer health information provisions offered by CHIQ presents a solution to the questions of quality-assurance of health literature for the lay-public. Conducting a secondary selection of peer-reviewed professional literature, using agreed criteria, may ensure the provision of quality health information to consumers. The CHIQ accreditation process is used to assess online services that provide access to health literature. The accreditation addresses issues of quality such

as accuracy, clarity and relevance of the web site information (*HiQuality* website, URL: http://www.hiquality.org.uk/producers_guidelines.htm).

2.7 Document access

The provision of access to electronic resources, as opposed to traditional document access, is increasing. Burden *et al.* (2001) illustrate the advantages in this development, writing that the British Library recognises that having e-journal content available to users electronically can provide “a much faster service (possibly instant, if combined with electronic delivery) and cheaper processing” (p.120).

The move to providing an information service to consumers, in the Internet environment, carries with it a number of challenges. Burden *et al.* (2001) note that the need for “licensing access to information” has increased following the shift from acquisition of physical material; they recognise that “complex licensing arrangements” are necessary in order to make electronic journals available as a traditional document supply resource alone (p. 117).

In reporting on public libraries’ consortium purchase of electronic resources, Ball (2002) comments that licences were “characterised as a minefield”. The licensing challenge may be indicative of the difficulties of making publishers’ e-content available to the largely indeterminable Internet market (Burden *et al.*, 2001).

Rowley (2000) comments that there are issues around publishers’ attitudes towards web availability of their publications “because they cannot predict what effect this will have on their revenues” (p. 51). The author reflects that it is challenging to develop e-journal pricing structures as it is difficult to “assess the potential level of sales”.

Ball (2002) discusses e-resource procurement models and illustrates the challenges involved in making publishers’ e-content available to service providers through aggregators or serials agents. In referring to the Californian State University (CSU) libraries project, Ball (2002) highlights that it:

is customised, based on a very tightly defined set of requirements. It seeks to evade one common problem: the packaging by publishers or intermediaries of the information made available. (p. 18)

The project had enabled a customized selection of journal titles based on consumer demand, rather than the e-content available being restricted to the usual “predetermined bundles of electronic journals packaged by publishers or aggregators”. The publishers’ or aggregators’ practice of only supplying bundles of journals, the titles of which have been predetermined by them, indicates an unwillingness to sell journals at the level requested by, for example, a library or user. Publishers’ caution of a model where content is sold at the level of demand may be illustrated by the fact that “no major publisher submitted a proposal” for the CSU libraries project.

A second project noted by Ball (2002) is the National Electronic Site Licence Initiative (NESLI). This appointed a Managing Agent (an aggregator) to negotiate with publishers for e-content, although this model does display a situation where there would be “an inherent conflict of interest”. Ball (2002) elaborates by noting:

What is the incentive for the MA [Managing Agent] (a commercial company) to negotiate the best deals for the HE [Higher Education] community when this could reduce its income? (p. 19)

The third project, UKB and Elsevier Science (a single publisher), provides a Dutch consortium with access to all Elsevier Science journals whilst UKB and Elsevier commit to explore, using jointly funded projects, ways to provide scientific information using future technology. Ball (2002) writes that in this situation the e-content has not been chosen by the service provider or user, and that Elsevier may gain “a further competitive edge” from the new products and services resulting from the projects.

Ball (2002) describes the final project – PEAK (Pricing Electronic Access to Knowledge) – as “an innovative experiment ... to demonstrate how the apparently conflicting interests of different elements of the supply chain may be accommodated” (p.17).

PEAK provided access to a selection of Elsevier Science journals and had three models of document access that allowed: subscription by institutions enabling unlimited access to bundles of any 120 articles for their authorised users; subscription by institutions and individual users enabling unlimited access to articles corresponding to a print journal; purchase of an individual article for a fixed price by an individual user. Following this model the publisher has some stability and predictability of income and institutions and individuals have an element of choice.

Ball (2002) concludes that if this model was:

extended to encompass other publishers the model would provide a completely new way of selling and buying information, suited to and enabled by the electronic medium, and not adhering to patterns of hard-copy commerce. (p.20)

In reference to the provision of e-content Rowley (2000) predicts that that there will be “changes in the means of access to journals and the agencies involved in providing that access” (p. 52); also that in this context publishing can be seen as “preparation and packaging of information that is easily accessible to the user” (p. 51).

Aggregators, as intermediary subscription agents of e-journals, have been preparing and packaging the information from publishers to customers to make it “easily accessible”. Pedley (2002) recognises that such “access and content, i.e. helping users mine the content and enabling them to find it in the first place, are critical ingredients to success” (p. 16).

However Berinstein (1999) notes that there has been a “surprising development” in that aggregators no longer hold e-journal content and that instead they “merely pass users through to publishers’ sites” to obtain full text. The author adds that publishers are:

exercising more and more control over their creations than they did in the all-ASCII world, while aggregators are formatting less and facilitating more. Many publishers format their own material according to their own needs and drives, and many now maintain their own Web sites and hosts. This trend means that documents have become less standardized than before, though aggregators smooth over the bumps by providing common interfaces. (p. 38)

Berinstein (1999) elaborates that the various models involved, i.e. where aggregators provide front ends and act as processors, content holders or a combination of these, the situation can lead to “pain for both vendors (aggregators) and users” because of the disparate document formats and lack of continuity of access.

A number of concerns expressed by public libraries relating to e-resources are noted by Ball (2002). They include: the issue of remote access by the user (for example, from the home or office); supporting concurrent use; authentication of the user (for example, through IP address or username and password); licensing; intellectual access concerns, in that interfaces are designed for the academic or specialist rather than the general public; speed of delivery of e-content through a modem (p. 10-11).

Rowley (2000) uses the example of Blackwell’s Electronic Journal Navigator to illustrate how subscription agents, in the context of providing libraries with content, can manage the access and delivery of e-journals. The author outlines that the service includes:

Both subscription access and pay-per-view access for articles from electronic journals which libraries do not subscribe. A single access and authentication point for all electronic journals, on multiple servers, including simplified password and access management. A single interface to support browsing and searching. (p.46)

Concerning the development of new search and delivery models to tackle publishers’ concerns surrounding e-journal access, Berinstein (1999) describes the UnCover model:

UnCover, which delivers documents in unreal time (up to a 24-hour turnaround), encrypts full-page articles for viewing with its proprietary software, CARLview. This disciplinary of a programme deletes the entire article from your disk once you’ve printed it. (p. 39)

In this way the author claims that “users use and publishers profit”.

A recent initiative is concerned with enabling free electronic access to journals containing recent academic and scientific research and seeks to avoid the challenges of publishers concerns as discussed above. The initiative derives from one of the

activities conducted by the Open Society Institute (OSI) regarding access to information and public health. Launched in February 2002, the Budapest Open Access Initiative (BOAI) has developed strategies for economically sustainable publishing that would support free electronic access to the latest research and aims to “accelerate progress in the international effort to make research articles in all academic fields freely available on the Internet” (online, URL: <http://www.osi.hu>).

A number of projects have been supported during the BOAI’s first year, including support for authors to publish articles in the forty open access journals that have been developed so far. The aim is for the academic community to have equal access to the most current research and the initiative is working towards:

world-wide electronic distribution of the peer-reviewed journal literature and completely free and unrestricted access to it by all scientists, scholars, teachers [and] students. (Online, URL: <http://www.soros.org/index.html>)

The BOAI is evidence of the wider, international open access movement that recognises the value of disseminating professional knowledge using Internet technologies to promote widespread, free distribution. It aims to provide the academic community with the most recent research. Due to the intended audience, the open access journals will not have had the relevance of their article content for the lay public considered.

2.8 Conclusion

The health policies of the UK Government and CEC indicate a commitment to using the Internet to provide consumers with accessible health information. There is therefore the need for corresponding development of partnerships between patients and health care professionals. These partnerships will be supported by access to quality-assured health information. The result will be the emergence of more “expert patients”.

Consumers are increasingly using the Internet as a source of health information and this has led to the requirement for reliable tools to measure and assure the quality of the information. This is illustrated by the development of quality criteria by CHIQ and the CEC.

Providing access to electronic professional health journal information presents a number of challenges including publishers’ caution to provide access for an “indeterminable” market and their unwillingness to provide a customised content service.

3 Developing the demonstrator product

3.1 Introduction

The following section discusses the development of the demonstrator product during the project's three cycles and includes comments on the methods used to inform content selection and site design. The ultimate project aim was to use good site design to provide the lay public with a clear, simple and fast route to the selected quality-assured journal articles.

3.2 Review of existing health information websites

In order to assess whether the demonstrator product would be a meaningful contribution to the provision of Internet-based health information, existing health information websites aimed at the consumer were reviewed in the project's preliminary stages, for example:

- *NHS Direct Online* – a fast, reliable gateway to high quality health information on the Internet which specialised in brief descriptions of over 200 conditions. In November 2001, an encyclopaedia was launched, the web site was redesigned, and the site now incorporates a personal web enquiry service for individual health conditions;
- *National electronic Library for Health* – provides clinicians with evidence-based information on the best current practice. In 2002 NeLH was extended to use by members of the public, however the information is not presented with the lay public in mind and might be considered to be more accessible for those who are already expert patients;
- *BBC Health* – provides introductory information under a range of health topics and incorporates personal services, for example, *Ask the Doctor*;
- the websites produced by organisations and groups concentrating on a particular disease or condition, for example, the *British Heart Foundation* and the *Cancer BACUP* sites.

The review identified that there was a gap in the health information continuum between general information on health conditions, for example *NHS Direct Online*, and detailed clinical information, for example the *Cochrane Library* now available from the *National Electronic Library for Health (NeLH)*. It confirmed that, by providing quality-assured accessible articles from professional health journals, the demonstrator product would offer the lay person information not previously available and would complement the health information already offered by the Internet.

3.3 Topic selection

To ensure the relevance of the demonstrator product it was first necessary to choose a list of topics to be covered. This was achieved by reviewing the scope and content of existing consumer health information sources including:

- *NHS Direct Online*;
- *Health Canada*;

- National Service Frameworks (NSFs) developed by the DOH;
- *The Patient's Internet Handbook*;
- *CancerBACUP* website.

The first and second cycles of the demonstrator study provided more feedback on the relevance of the topics; by the third cycle the final A-Z topic list was linked to from the website home page (Screen Shot A) and appeared as illustrated by Screen Shot B, C and D below.

Screen Shot A.

Healthinfo4u
 Search Help Encyclopaedia About Feedback Home

Help
[Search](#)
 Use this link to take you to the topics available.
[Help?](#)
 If you are unsure of how to use this site
[Encyclopaedia](#)
 Use this for a brief introduction to a health topic.
[About](#)
 Information about this project.
[Feedback](#)
 For you to tell us what you think about the product

Sponsors

 Blackwell Publishing

 Royal College of Nursing
 Royal College of Nursing

Welcome
 to Healthinfo4u, a project to explore giving you access to [quality assured journal articles](#) normally only available to health professionals.

Topics
 Access the site by choosing a topic, then see a set of recently published articles written for the healthcare community, but understandable by all.
 Use the [link](#) to see all the topics you can search through, or click on one of the examples below. Please note that Healthinfo4u articles will arrive in clear packaging

Cancer
 We carry articles relating to many different forms of cancer.

Arthritis
 30% of the population suffer from this condition.

Mental Health
 Is an issue that will affect some people through their lives. Whether directly or indirectly.

Heart Health
 Information on conditions that may affect your heart and its health

Hot Topic
Diabetes
 30% of the population suffer from this condition.

Hot Topic
Asthma
 Affects 3 million people in the UK.


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[Copyright, Scope & Disclaimer](#)

Screen Shot B.

Healthinfo4u

[Search](#) [Help](#) [Encyclopaedia](#) [About](#) [Feedback](#) [Home](#)

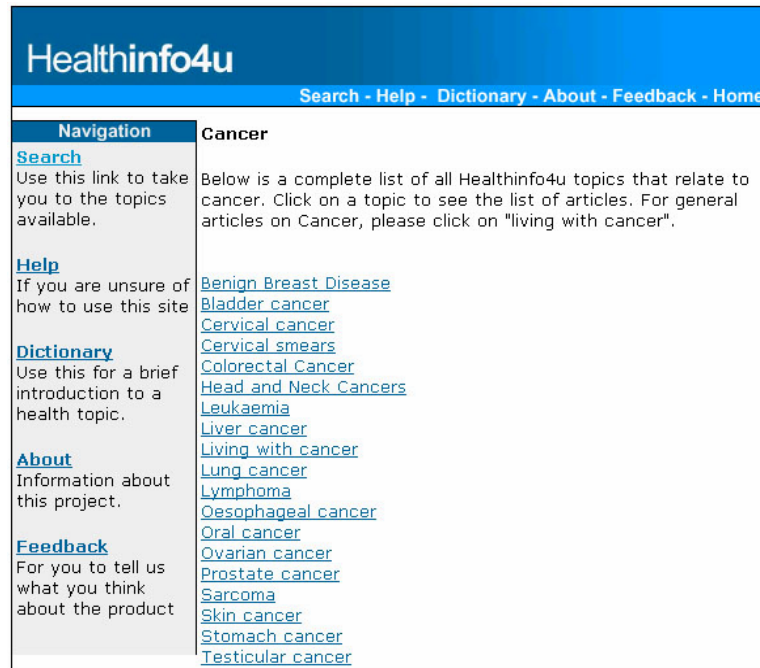
Navigation							
<p>Search Use this link to take you to the topics available.</p> <p>Encyclopaedia Use this for a brief introduction to a health topic.</p> <p>About Information about this project.</p> <p>Feedback For you to tell us what you think about the product</p> <p>Help</p> <p>1.) Scroll down the list using the mouse to find the topic.</p> <p>2.) OR use the alphabet by clicking the initial letter of the topic.</p> <p>3.) Find the topic in the list, then click on it.</p> <p>4.) Read the list of articles.</p> <p>5.) Click on "Link to this Article" to read the article on screen.</p> <p>You will need a password to view the full article.</p> <p>To use the password click on the full text - HTML link and enter a username and password in the top right hand box.</p> <p>6.) Or click the "Order this Article" box</p> <p>7.) To remove the selection, click in the box again.</p> <p>8.) Read the conve-</p>	<div style="display: flex; justify-content: space-between;"> <div style="width: 60%;"> <p>The health topics are listed in alphabetical order below. Either look down the complete list or click on the letter of the alphabet your topic begins with. Find your topic in the list and click on it to see the full list of articles available.</p> <p>Example: For 'fever' choose 'f' from the alphabet. You will see all topics beginning with 'f' in alphabetical order. Look down the list, click on 'fever' to see the articles available.</p> <p>Please note that Healthinfo4u articles will arrive in clear packaging.</p> <p>If you need any help in the process then check out the 1-13 help steps on the side of this page.. or you could try the more detailed help.</p> </div>  </div> <p style="text-align: center; margin-top: 20px;"> A - B - C - D - E - F - G - H - I - J - K - L - M - N - O - P - Q - R - S - T - U - V - W - X - Y - Z </p> <table style="width: 100%; border: none;"> <tr> <td style="vertical-align: top; width: 33%; padding: 5px;"> <p>A</p> <p>abortion acne acupuncture addiction ageing AIDs alcohol misuse allergies alzheimer's disease anaemia anaphylaxis angina anorexia nervosa anxiety aromatherapy arrythmais arthritis aspergers asthma autism</p> </td> <td style="vertical-align: top; width: 33%; padding: 5px;"> <p>B</p> <p>back pain bed wetting benign breast disease bereavement behavior problems bipolar disorder bladder cancer blindness blood disorders blood pressure body image bone disorders bone marrow transplantation bowel disorder brain tumours breast cancer breast disorder bronchitis bulimia burns</p> </td> <td style="vertical-align: top; width: 33%; padding: 5px;"> <p>C</p> <p>cancer cardiovascular diseases cataract cerebral palsy cervical cancer cervical smears childbirth chlamydia cholesterol chromosomal disorders chronic fatigue syndrome chronic illness cleft lip + palate coelic disease colds colorectal cancer congenital disorders conjunctivitis constipation contraception compulsory treatment Common complications of diabetes cradle cap CJD crohn's disease croup cystic fibrosis cystitis</p> </td> </tr> <tr> <td style="vertical-align: top; padding: 5px;"> <p>D</p> <p>deafness dementia depot drug administration depression dermatitis</p> </td> <td style="vertical-align: top; padding: 5px;"> <p>E</p> <p>ear disorder eating disorder eczema emphysema endocrine disorder endometriosis</p> </td> <td style="vertical-align: top; padding: 5px;"> <p>F</p> <p>fatigue fertility fever fibroids fibromyalgia foot problem</p> </td> </tr> </table>	<p>A</p> <p>abortion acne acupuncture addiction ageing AIDs alcohol misuse allergies alzheimer's disease anaemia anaphylaxis angina anorexia nervosa anxiety aromatherapy arrythmais arthritis aspergers asthma autism</p>	<p>B</p> <p>back pain bed wetting benign breast disease bereavement behavior problems bipolar disorder bladder cancer blindness blood disorders blood pressure body image bone disorders bone marrow transplantation bowel disorder brain tumours breast cancer breast disorder bronchitis bulimia burns</p>	<p>C</p> <p>cancer cardiovascular diseases cataract cerebral palsy cervical cancer cervical smears childbirth chlamydia cholesterol chromosomal disorders chronic fatigue syndrome chronic illness cleft lip + palate coelic disease colds colorectal cancer congenital disorders conjunctivitis constipation contraception compulsory treatment Common complications of diabetes cradle cap CJD crohn's disease croup cystic fibrosis cystitis</p>	<p>D</p> <p>deafness dementia depot drug administration depression dermatitis</p>	<p>E</p> <p>ear disorder eating disorder eczema emphysema endocrine disorder endometriosis</p>	<p>F</p> <p>fatigue fertility fever fibroids fibromyalgia foot problem</p>
<p>A</p> <p>abortion acne acupuncture addiction ageing AIDs alcohol misuse allergies alzheimer's disease anaemia anaphylaxis angina anorexia nervosa anxiety aromatherapy arrythmais arthritis aspergers asthma autism</p>	<p>B</p> <p>back pain bed wetting benign breast disease bereavement behavior problems bipolar disorder bladder cancer blindness blood disorders blood pressure body image bone disorders bone marrow transplantation bowel disorder brain tumours breast cancer breast disorder bronchitis bulimia burns</p>	<p>C</p> <p>cancer cardiovascular diseases cataract cerebral palsy cervical cancer cervical smears childbirth chlamydia cholesterol chromosomal disorders chronic fatigue syndrome chronic illness cleft lip + palate coelic disease colds colorectal cancer congenital disorders conjunctivitis constipation contraception compulsory treatment Common complications of diabetes cradle cap CJD crohn's disease croup cystic fibrosis cystitis</p>					
<p>D</p> <p>deafness dementia depot drug administration depression dermatitis</p>	<p>E</p> <p>ear disorder eating disorder eczema emphysema endocrine disorder endometriosis</p>	<p>F</p> <p>fatigue fertility fever fibroids fibromyalgia foot problem</p>					

Screen Shot C.

<p>7.) To remove the selection, click in the box again.</p> <p>8.) Read the copy-right statement at the end of the article. Click here for an explanation.</p> <p>9.) To continue with the order click AGREE</p> <p>10.) Complete the name and address form.</p> <p>11.) Click submit to complete your order.</p> <p>12.) Your article(s) will arrive within 10 days.</p> <p>13.) Complete feedback</p>	<p>Diabetes and Diet Diabetes and Insulin diabetes mellitus Diabetes and Pregnancy diarrhoea digestive disorders down's syndrome drug misuse dyslexia dyspraxia</p> <p>G gallstone mmr motor neurone disorder multiple sclerosis munchausen syndrome muscular dystrophy</p> <p>P pancreatic disorder panic paralysis parasites parkinson's disease personality disorders</p> <p>phobias pituitary disorder pneumonia polio polymyalgia rheumatika postnatal depression post traumatic stress pre eclampsia pregnancy premenstrual syndrome prostate cancer prostate disorders psoriasis psychosis psychiatric drugs</p> <p>S salmonella sarcoma scabies schizophrenia seasonal affective disorder (SAD) sexual abuse sexually transmitted diseases shingles shock sickle cell anaemia sjorgen's syndrome skin cancer skin disorders sleep smoking cessation speech disorders spina bifida spinal cord injury stillbirth stoma stomach cancer stress stroke sudden infant death syndrome suicide sunburn</p> <p>V varicose veins vasectomy virus infection vision</p>	<p>ENT disorder Enuresis epilepsy eye disorder</p> <p>H haemophilia</p> <p>Q</p> <p>T terminal care testicular cancer thrush thyroid tinnitus tooth problems transplants tranquillisers tuberculosis</p> <p>W whooping cough</p> <p>Z</p>	<p>fracture fungal infection</p> <p>I immune disorder</p> <p>R respiratory disorder rheumatoid arthritis rubella</p> <p>U ulcerativecolitis ulcers urinary tract disorder urticaria</p> <p>X</p>
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Major topics that had a number of related conditions ('Cancer', 'Arthritis', 'Mental Health', 'Heart Health', 'Diabetes Mellitus' and 'Asthma') appeared on the home page with a link to a second page of related topics to aid location of relevant articles (Screen Shot E opposite).

Screen Shot E.



3.4 Content selection

During the demonstrator study the article references for the dataset were selected from two existing premier bibliographical databases used by health care professionals; *BNI* and *AMED*. The information sources for the demonstrator study were chosen for their currency and because they were peer-reviewed and evidence-based, ensuring the quality of the articles. The complexity and relevance of articles written for the nursing and allied health professions was assumed to be more likely to be accessible to the widest possible range of the lay public. The literature was also more likely to describe reviewed best practice rather than innovative and yet to be proven treatments. The secondary content selection from *BNI* and *AMED* was undertaken on a cyclical basis and included:

- the development and review of selection criteria to enable a team of expert searchers to identify suitable content for the lay public;
- the development and review of a rationale to enable edit of the content;
- the review and edit of content by subject specialists.

3.5 Dataset build

To deliver the demonstrator product the project worked with two technical partners. During the first cycle in 2001 the technical partner was Health Communication Network (HCN) who facilitated access to the initial dataset of articles. During the second and third cycles in 2002/3 a new technical partner, Ovid Technologies, provided scripts that enabled the import of the selected content from *BNI* and *AMED* to create the dataset used in the demonstrator product. Perl scripting was used to interface the dataset to the web pages.

3.6 Website design

The website design was developed in parallel with the content selection. During the project's first cycle the technical partner *HCN* developed and implemented the prototype website design. During the project's second and third cycles the website was redesigned by the project team to provide a clear, simple and fast route to the selected quality-assured journal articles (online, URL: <http://www.healthinfo4u.org/>).

The development of the website used to access the dataset was informed by respondents' feedback and by consulting with the project Steering Group and Project Board. Tools developed to measure the quality of health information over the Internet were also considered in the development of the website design, in particular *e-Europe 2002: quality criteria for health related web sites* (CEC 2002b) and the *HiQuality* website (online, URL: http://www.hiquality.org.uk/producers_guidelines.htm). The resulting demonstrator website enabled users to access content within three clicks of the mouse from the home page.

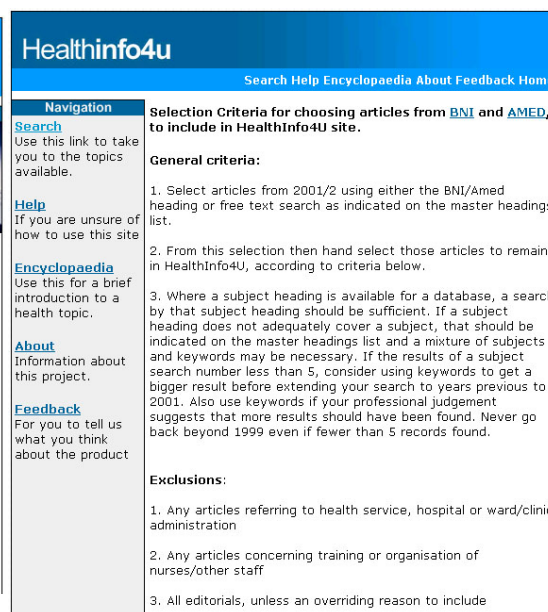
A selection of Screen Shots is given to illustrate the final design of the demonstrator website.

The home page (Screen Shot A above) gave information on how to: search the site; access selected priority topics (for example, 'Cancer' and 'Asthma'); link to the A-Z list of health topics for users to select from (Screen Shot F); link to an explanation of how the quality-assurance of the content was achieved (Screen Shot G).

Screen Shot F.



Screen Shot G.



Users were then shown a number of articles they wished to order (Screen Shot H and Screen Shot I) and they could link to an electronic copy of the

Screen Shot H.

HealthInfo4U
Search Help Encyclopaedia About Feedback Home

Topic: Blood Pressure

Last Updated: February 2003
Results 1 - 10 of 10

Help
To order a article if you cannot view it now, please tick the check box next to the article you want and complete the form at the bottom of the page.

To link to an article and view it immediately on the screen, you will need this [password](#)

Order this article:

Title: High blood pressure (hypertension). (Patient Education Series).
Author: Woods, A.
Source: Nursing. 2002 Apr. 32(4). p54-5.

Order this article:

Title: Medical and complementary management of hypertension. (23 refs).
Author: Harbron, E.
Source: Nursing Times. 2002 10 Jan. 98(2). p32-4.

Order this article:

Title: High blood pressure. (In the elderly. 9 refs).
Author: Jarvis, S.
Source: Practice Nurse. 2002 31 Jan. 23(2). p27-32.

Order this article:

I declare that:

- (a) I have not previously been supplied with a copy of the same material by you or any other librarian.
- (b) I will not use the copy except for research or private study and will not supply a copy of it to any other person; and
- (c) to the best of my knowledge no other person with whom I work or study has made or intends to make, at or about the same time as this request, a request for substantially the same material for substantially the same purpose.

I understand that if the declaration is false in a material particular, the copy supplied to me by you will be infringing copy and that I shall be liable for infringement of copyright as if I had made the copy myself.

Agree Disagree

Name

Address

Submit

HealthInfo4U is not responsible for the content of the articles obtained as a result of using HealthInfo4U.

Screen Shot J.

HealthInfo4U
Search Help Encyclopaedia About Feedback Home

Topic: Childbirth

Last Updated: February 2003
Results 1 - 20 of 29

Help
To order a article if you cannot view it now, please tick the check box next to the article you want and complete the form at the bottom of the page.

To link to an article and view it immediately on the screen, you will need this [password](#)

Go to page... 1 2

Order this article:

Title: Aromatherapy in childbirth. (Prospective observational research on the effect of essential oil use in reducing later uptake of epidural anaesthesia. 22 refs).
Author: Burns, E.
Source: MIDIRS Midwifery Digest. 2002 Sep. 12(3). p349-53.

[Link to this article](#) Please note you will need this [password](#)

Title: Experiences of fears associated with pregnancy and childbirth: a study of 329 pregnant women. (Research. 31 refs).
Author: Melender, H.
Source: Birth. 2002 Jun. 29(2). p101-11.

Order this article:

Screen Shot K.

Blackwell Synergy Home Browse Search My Synergy Register Help
Username: Password: Athens Login Logout

You are at: Home > List of Issues > Table of Contents > Full Text
Bournemouth University

Full Article [View/Print PDF article \(136k\)](#)

[Download to reference manager](#)

Birth
Volume 29 Issue 2 Page 101 - June 2002

Experiences of Fears Associated with Pregnancy and Childbirth: A Study of 329 Pregnant Women

Hanna-Leena Melender, RM, MNSc

Background: Women may experience a variety of fears in association with pregnancy and childbirth. The purpose of this study was to describe their objects, causes, and manifestations, and to identify factors associated with the fears.

Methods: The study sample comprised 481 pregnant women in western Finland, of whom 329 (response rate 68%) completed a questionnaire. It was developed on the basis of semi-structured interviews and previous studies and had a 4-point scale and a dichotomous scale. Data were subjected to rotated factor analysis, and sum variables were produced. The effects of various demographic variables were calculated using the Kruskal-Wallis and Mann-Whitney U tests.

Results: Of the 329 respondents, 78 percent expressed fears relating to pregnancy, to childbirth, or to both. Specific fears concerned childbirth, the child's and mother's well-being, health care staff, family life, and

QuickSearch Inc
Synergy for
Authors:
 Hanna-Leena Melender, RM,

Search

Affiliations
Hanna-Leena Melender is a project coordinator at the Centre for Extension Studies, University of Turku, and doctoral candidate in the Department of Nursing, University of Turku, Turku, Finland

3.7 Document access

Having established the procedures for selecting citations for quality-assured journal articles, access to the full text of the articles was negotiated. It was important to facilitate full-text access to all of the articles selected, however no single method could provide for this during the demonstrator study. The use of different methods of

full-text access was acceptable during the study as it was important to obtain feedback on the possible methods of providing full text.

Document supply for the complete dataset content up to the value of £4,000 was agreed and established with the British Library Document Supply Centre (BLDSC) as part of the research project's matched funding; this was facilitated through the BL ARTWeb online document order service. The order process was supported by Bournemouth University administrative staff and the articles were dispatched free of charge to the users.

Agreement was reached with three publishers with significant content to link to the full text of their articles at no cost to the users. Each publisher facilitated different access models:

- full-text display of articles using PDF (Portable Document Format) files provided by a publisher;
- full-text display of articles using a direct link to the full-text article on the publisher's website;
- full-text display of articles using a link to a search results page in a bibliographical database that contained a link to the full-text article on the publisher's website.

3.8 Conclusion

Early research into the availability of consumer health information over the Internet enabled the demonstrator product to be developed into a resource that was complementary to existing web-based health information.

The strong technical and document access partnerships facilitated the delivery of the demonstrator website's content, the document supply of articles, and the full-text availability of articles.

The cyclical development of the demonstrator product enabled the research project team to evaluate, reflect on and enhance the product.

4 Methodology

4.1 Study design

The study used an action research design to develop and evaluate a web-based health information tool for the lay-public. It had six defining action research elements.

- i. Potential users' comments were sought to inform design and content of the demonstrator product.
- ii. The study focused on participation in health decisions. The empowerment aimed for by government policy (DOH 1999) is in part achieved through the patient's access to original, recent, peer-reviewed information.
- iii. The Steering Group (see Appendix C) met three times during the life of the project and reviewed the research. It also acted as a select "virtual" focus group and suggested opportunities for dissemination. Members represented a wide range of national experts and leaders in the field of patient information provision and senior health care professionals.
- iv. Design goals, content decisions and review of the pilot trials were informed through the work of partnership sub-groups of the Project Board (see Appendix D).
- v. Health professionals were invited by interview and focus group to give their opinions about the usefulness of the product articles as a resource for patients.
- vi. Three consecutive evaluation and reflection cycles took place during the life of the study. The data collected and experience gained in each cycle informed the product design and the next cycle's evaluation criteria and format.

4.2 Population profile

The survey used purposive sampling to present a typical UK population profile in the 11 demonstrator site locations during the project's three cycles (Curtis *et al.* 2000). The profile considered age, sex, education, ethnicity, existing health knowledge and information-seeking behaviour.

The selection of public libraries and health information points for the project cycles enhanced the likelihood of meeting the appropriate cross section of the population. The third cycle tackled questions of achieving ethnic diversity. Gaps in the population profile were addressed by targeting questionnaires, for example in the first cycle working-age men and young people were specifically sought.

The demonstrator sites, detailed in Table 1 below, offered a variety of potential interviewees. For example, two sites used by the lay public to make health enquiries are HealthPoint, where 11,784 were made in 2000-2001, and The Michael and Ilse Katz Health Information and Resource Centre, Poole Hospital NHS Trust, where 1,796 were made in October to June 2001.

Table 1. Healthinfo4u demonstrator sites

First Cycle	Birmingham	Bournemouth	Durham	Essex	Poole	Wiltshire
Public Library	—	1. Boscombe 2. Charminster	—	Chelmsford	—	Trowbridge
Health information point	—	—	—	—	1. Healthpoint 2. Poole NHS Hospital Resource Centre	—
Second Cycle	Birmingham	Bournemouth	Durham	Essex	Poole	Wiltshire
Public Library	—	1. Boscombe 2. Charminster	—	Chelmsford	—	Trowbridge Salisbury
Health information point	—	—	—	—	1. Healthpoint 2. Poole NHS Hospital Resource Centre	—
Third Cycle	Birmingham	Bournemouth	Durham	Essex	Poole	Wiltshire
Public Library	Birmingham Central Library	1. Boscombe 2. Charminster 3. Bournemouth	Redcar & Cleveland	Chelmsford	—	Trowbridge Salisbury
Health information point	—	Bournemouth Health Information Shop	—	—	1. Healthpoint 2. Poole NHS Hospital Resource Centre	—
Clinical setting	Birmingham Childrens' Hospital	—	—	—	—	—

4.3 Recruitment of participants

Publicity materials (bookmarks, posters and flyers) were designed by the project team and were used by the demonstrator sites to recruit participants.

4.3.1 First Cycle

Participants were recruited through six demonstrator sites' general advertising of the web site and through being identified as a potential user by site staff. Participants were invited to use the prototype site and complete the first cycle questionnaire (Appendix E) in a single mediated session at the demonstrator site. The results of this questionnaire were used to refine the product, for example, the inclusion of additional home page links including one to an existing medical dictionary, and the use of a larger font throughout the site.

4.3.2 Second Cycle

The six demonstrator sites were extended to seven, all of which offered free Internet access to the product during the second cycle. Careful thought was given to creating appropriate environments for users to feel comfortable seeking potentially sensitive health information.

The Easter period (25th March to 26th April 2002) was chosen to give the greatest choice for a random cross-section of the population. The working population was targeted through local authority e-mail in the Wiltshire public library area.

Participants were recruited through demonstrator sites' general advertising of the web site and by publicised "special interest days", which included mediated sessions at each demonstrator site. Each site targeted fifty questionnaires (Appendix F) during the second cycle, using naturally occurring health enquiries where library staff perceived the product had potential for use.

4.3.3 Third Cycle

Recruitment of participants occurred as in the first two cycles. The seven demonstrator sites were extended to twelve and again offered free Internet access. The third cycle ran from 1st July 2002 to 28th February 2003. The five additional demonstrator sites included:

- one to address issues of ethnic diversity (Birmingham Central Library);
- one in a clinical setting (Birmingham Childrens' Hospital Patient Information Centre);
- one in a wider, consumer-based health information setting (Bournemouth Health Information Shop, Asda shopping complex);
- one to extend cultural and social diversity (Redcar and Cleveland Central Library);
- one to extend the Bournemouth Borough Libraries demonstrator sites (the new Bournemouth Central Library).

4.4 Data collection

Methods for collecting both quantitative and qualitative data were used. Triangulation of multiple data sources was employed to obtain diverse views and different dimensions of the research study.

Data were gathered from respondents using the following methods:

- first cycle mediated questionnaire (Appendix E);
- second and third cycle self-administered and mediated questionnaire (Appendix F);
- second and third cycle self-administered follow-up questionnaire (Appendix G);
- focus groups;
- telephone interviews;
- Steering Group and Project Board meetings.

Online surveys were not used as many questions required the participants to be looking at the product whilst answering. However the product website did include an online form to collect general feedback.

4.4.1 First cycle mediated questionnaire

The first cycle used a questionnaire (Appendix E) in a mediated setting in the six demonstrator sites.

4.4.2 Second and third cycles self-administered and mediated questionnaire

The second and third cycle questionnaire (Appendix F) was both self-administered and mediated. A mediated setting was used when required by the participant or as part of a “special interest day” at a demonstrator site. This resulted in useful contextual comments, for example, discussion on a preferred choice of searching form a category list or free text searching. The risk of incomplete self-administered questionnaires was minimised by the demonstrator sites promoting the questionnaire and product.

The questionnaire provided information about progress towards delivery of the objectives listed at the start of this report.

Questions on the following topic areas were identified to measure the objectives.

- Does the product provide access to relevant information about health for someone without medical or health care training, either for their own use or as a tool for learning about health?
- Does the product provide access to e-document full text or postal document delivery of a requested article?
- Does the product provide information that can be used by health professionals to share with their patients?
- Can users of the product navigate the web site?
- Is the web site accessible to all users (disabled access, educational level, web experience)?
- Can users of the product find information on topics of interest to them?

The opportunity to indicate interest in attending a focus group was also offered.

Entry into a prize draw to win a £25 book token was used to provide the incentive for participants to complete the questionnaire.

4.4.3 Second and third cycle self-administered follow-up questionnaire

A questionnaire was designed to gain participants’ views on the perceived usefulness of the articles received (Appendix G). The questionnaire was sent to participants through the post following dispatch of the article(s) by the BLDSC. One questionnaire was sent for each article requested and an SAE was provided for postal return of the completed questionnaire(s).

The questionnaire responses provided information about progress towards the objectives of providing accessible quality-assured health literature to the lay public and recommending models for sustainable delivery. The following questions were identified to measure the objectives.

- How was the article obtained?
- How useful was the article?
- How difficult to read was the article?
- To what extent has the information satisfied expectations?
- What was the information used for?
- What is the preferred method of article delivery?

4.4.4 Focus groups

Focus groups were used to examine issues in more depth, for example indicators of quality assurance such as “what makes you think a health information source is trustworthy?” A user focus group was held at the end of the second cycle. This reflected on the data received concerning the use of the web site and the health information gained by participants during this cycle.

An independent facilitator from CHIQ led the focus group discussion to enhance objectivity.

The Steering Group, whose expertise encompassed accident and emergency nursing, physiotherapy, carer support, patient representation, general practice, mental health, NHS libraries and social work, were invited to contribute to an e-mail focus group.

4.4.5 Telephone interviews

These were conducted to enable the collection of in-depth feedback from those participants who were interested in attending a focus group, but were unable to do so. They included discussion on issues that had been raised during the focus group but had not been resolved, for example, the preference for free-text searching or using a category list.

4.4.6 Face-to-face interviews

These were conducted at conferences and exhibitions to collect in-depth feedback from health care professionals working in the field of patient information. They included discussion on issues such as the usefulness of *Healthinfo4u* as a resource for patients to use in partnership with health care professionals.

4.4.7 Steering Group and Project Board meetings

The project invited and secured the eminent expertise of health information and health care experts (see Appendix C) to serve on the Steering Group. The membership brought together leading health care strategists including: a representative of the

Royal College of General Practitioners; the NHS Library Advisor; and executives from CHIQ, Mind, NeLH and the Patients Association. The Group met three times during the life of the project and provided comments and suggestions on all aspects of the project.

The day-to-day developments of the *Healthinfo4u* project was undertaken by the project team under the guidance of the Project Board (see Appendix D). The Board appointed sub-groups to consider the demonstrator sites, publicity, promotion, site design, access to full text and document supply. Product refinements, informed by data collection and in consultation with the project groups, were conducted at the conclusion of each project cycle.

4.5 Conclusion

The action research methodology adopted for the project facilitated the cyclical development of the product. The study design provided mechanisms for the data collected to inform each of the product's three development cycles. It enabled the various data collection methods to target specific sections of the population in order to obtain a sample that was representative in the context of a web-based study conducted in the demonstrator sites selected. The different data collection methods also facilitated data collection from health care and information professionals. The expertise of the Steering Group was utilised to provide guidance on the project and product development and to determine the future sustainability of the resulting health information tool.

5 Project results

5.1 Introduction

This section presents the results obtained from the varied data collected during the first, second and third demonstrator cycles of the project. Firstly the results from the first cycle that underpinned the development of the product are discussed. This is followed by a discussion of the combined results of the second and third cycle obtained from 223 questionnaires (Appendices F and G) returned during this period. It also incorporates comments obtained from the Steering Group, focus groups, telephone interviews, and an analysis of document supply and document access data.

5.2 First cycle results

The first cycle of the project involved the use of the prototype site in a single mediated session by users who had been identified by the demonstrator sites (see Table 1 on page 26). The first cycle questionnaire (Appendix E) was completed during the mediated session and the questionnaire results informed the development of the prototype site.

The following key results were obtained from the first demonstrator cycle:

- the home page design should be developed further;
- additional links should be added to the home page (for example, “Feedback”, “Help”, “About us”);
- a link to an existing medical dictionary or glossary of medical terms should be added;
- wording should be added to the site to indicate the status of the product as a research in progress;
- a link to the project site should be added;
- larger font should be used;
- the number of topic sub-categories should be increased;
- search results should be viewed in batches of 10;
- a check box should be added to each record to clearly mark those for document retrieval.

The analysis and implementation of the first cycle results enabled the product to be further developed into the site used in the project’s second cycle.

5.3 Second and third cycle results

The results from the second and third cycle are organised into sections covering: population profile; site impressions; perceptions about the name; site design, topics and searching; article access; and perceived value of articles.

5.4 Population sample profile

The project aimed to obtain feedback from a population profile that included the working and retired population. In addition some feedback was sought from young people aged 15-18 years.

The project sought to achieve the sample profile by selecting appropriate public libraries and health information points as project demonstrator sites. The *Healthinfo4u* web site was promoted in the demonstrator sites and was used by people who had naturally occurring health enquiries. The users were asked to complete the first and second/third cycle questionnaires following use of the web site (Appendix E and Appendix F).

The following results led to the conclusion that the population sample was representative within the context of a web-based product accessed in public libraries and health information points.

Chart 1 below indicates the distribution of respondents' gender (Appendix F, q.A4). The results show that two thirds of users were female and one third were male. This result reflects those of a US study conducted in seven family-based practices to determine the use of the Internet for health information by female (63.1%) and male (36.9%) patients (Smith-Barbaro *et al.* 2001). Indications are therefore that the *Healthinfo4u* project has not resulted in an unexpected bias towards use from either gender.

Chart 1.

Gender of Healthinfo4u users

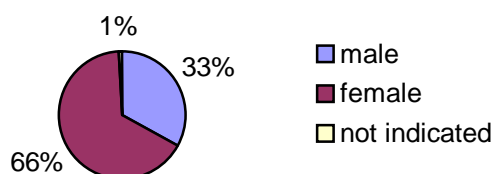
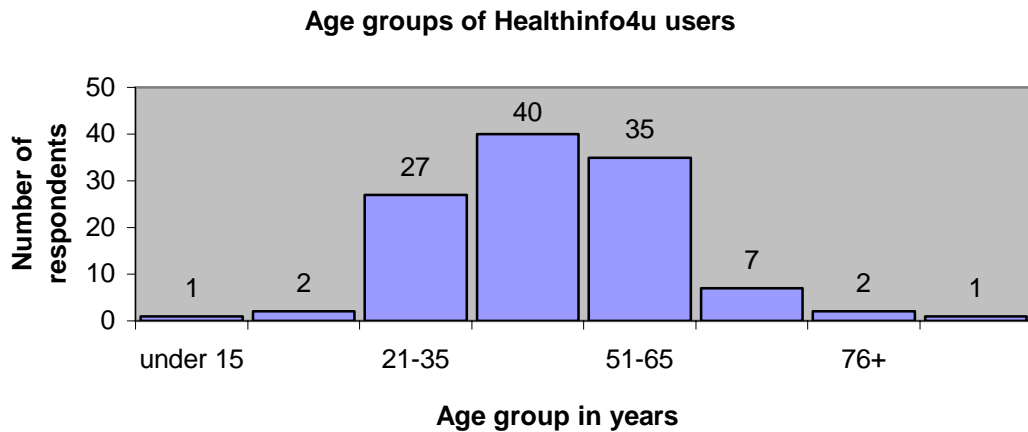


Chart 2 opposite shows that the distribution of age groups (Appendix F, q.A3) across the sample profile presents a result that is representative of the working population, but indicates that 8% of respondents were aged 66 years and over. This is a somewhat lower response rate than hoped for as national statistics indicate that 18% of the population are of this age range (Branigan, T. 2002).

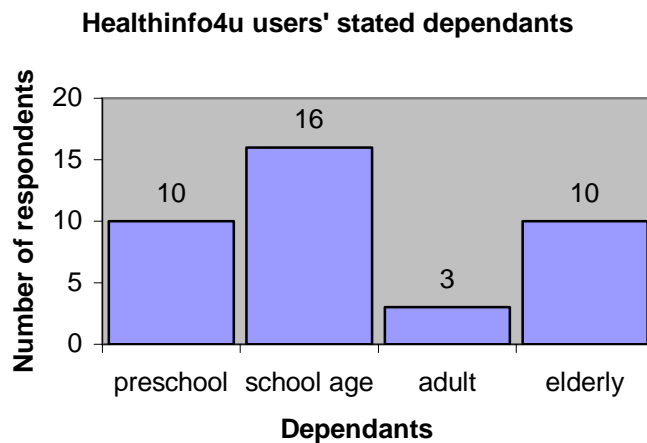
Chart 2.



Potential anxiety for using new technology in an open environment may have contributed to a relative under-representation of users from the oldest age groups. However the figures do reflect a reasonable percentage of web users in this age group. A study by the Office for National Statistics (ONS, 2001) indicates that 23% of the population aged 65 years or older have accessed the Internet at least once.

It is possible that the respondents declaring elderly dependants were searching for information for them. Chart 3 below indicates how many respondents considered themselves to have dependants of particular age groupings (Appendix F, qs.A11 and A12).

Chart 3.



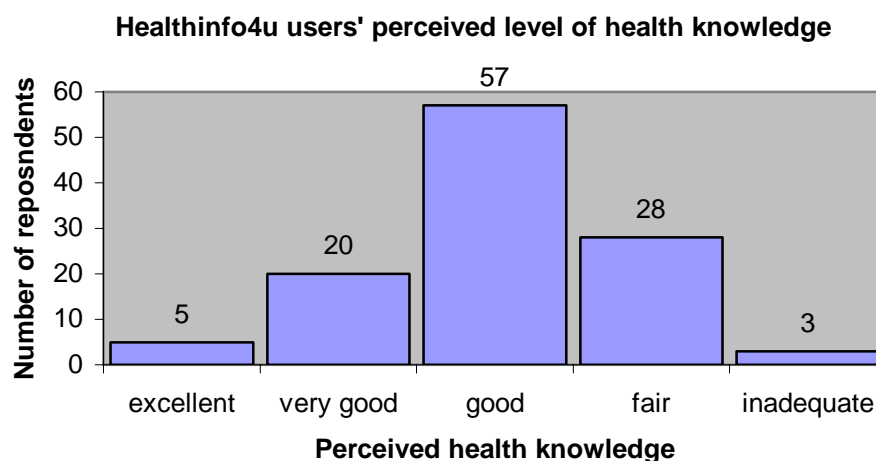
Respondents were asked to indicate their ethnicity (Appendix F, q. A7). 80% of respondents classified themselves as “White British” and 10% classified themselves as from backgrounds other than “White British”. The remaining 10% of users chose not to indicate their ethnic origin. Following the results of pilot 2, a demonstrator site partnership was developed with the University of Birmingham Regional Library Unit to address the limited ethnic diversity of respondents. This has resulted in a 0.4% increase in users from an ethnic origin other than “White British”. The ONS (2002)

reports that 7.6% of the UK population come from an ethnic minority and define “minority” in the same way as the project’s questionnaire, indicating that the project had a good representation of respondents from ethnic minorities.

To establish any bias from perceived levels of health knowledge or expertise in using the Internet, questions were asked about users’ perceptions of their own levels of health knowledge and experience of using the Internet (Appendix F, q. B1 and B5).

Chart 4 below indicates that the most common levels chosen for health knowledge were “very good”, “good” and “fair”. These results display a “normal distribution curve” (Calzada & Scariano, 1999), which helps confirm the validity of the sample population profile obtained.

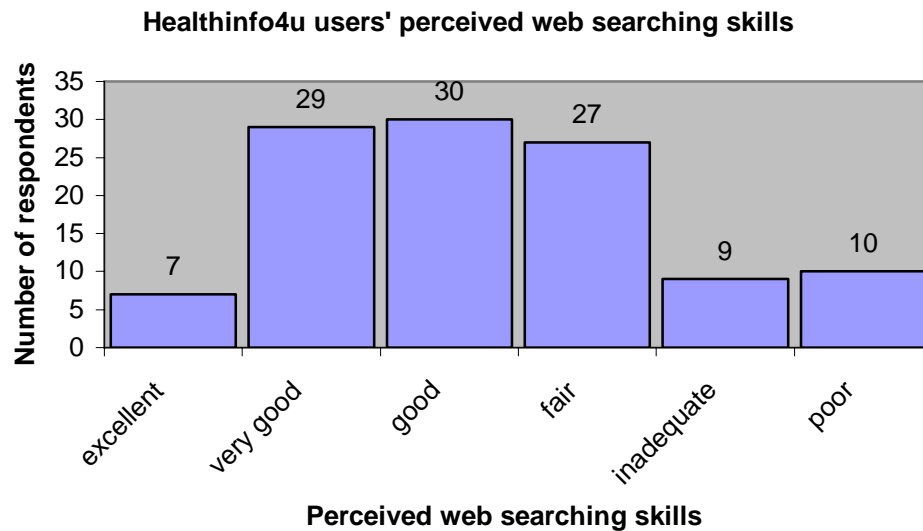
Chart 4.



It could be suggested that respondents’ comments and critique concerning the health information provided by *Healthinfo4u* are meaningful because of their perceived knowledge base. It is recognised that these questions are subjective, for example a doctor gave his health knowledge as “very good” and not “excellent”.

Chart 5 opposite illustrates that the most frequently chosen levels for perceived Internet experience were “very good”, “good” and “fair”. Although 58.9% consider they have high search skills (“excellent”, “very good”, or “good”), 41.1% express reservations about their skills (“fair”, “inadequate” or “poor”).

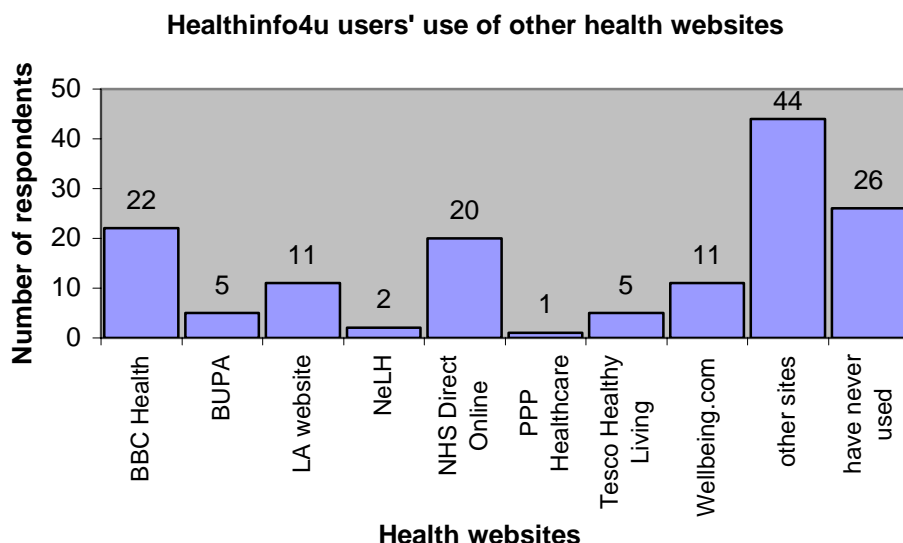
Chart 5.



It must be recognised that the respondents came from a public library user population and as such may have been expected to have better than average searching skills, and may have been likely to self-select to take part in a web-based study. Those with less confidence in using the Internet may have been less likely to self-select. As the majority of questionnaire respondents perceive they have “very good” to “fair” web searching skills, it can be assumed that the feedback received has originated from the target audience of Internet users.

Respondents were shown a list of websites and were asked to indicate whether they had used any of them as a source of health information, or whether they had never used the Internet as a source of health information (Appendix F, q. B8). Chart 6 on the following page shows the range of websites used by respondents who had sought health information from the Internet and also the number of respondents who had never used websites as a source of health information.

Chart 6.

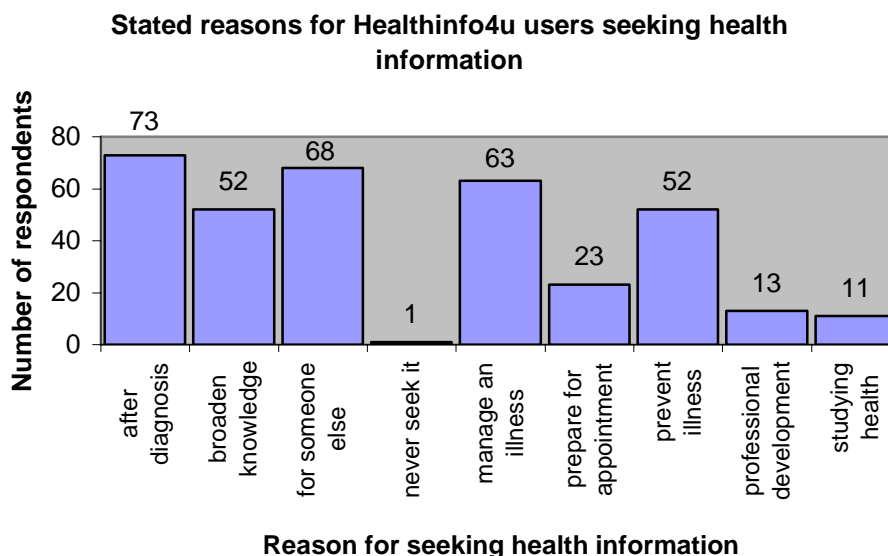


The most prominent individual websites that respondents indicated they used as sources of health information were BBC Health (15% of expressed usage) and *NHS Direct Online* (13.7% of expressed usage). The next most popular websites indicated were LA (Local Authority) and *Wellbeing.com* (both at 7.5% of expressed usage), followed by *Tesco Healthy Living* and *Bupa* (both at 3.4% of expressed usage). In addition respondents indicated that they had used “other sites” as sources of health information (30% of expressed usage). Chart 6 above also shows that before using *Healthinfo4u*, 26 respondents (representing 17.7% of expressed usage) had never used the Internet as a source of health information.

The product’s intended use is for people who are seeking health information presented over the web. As illustrated by Ferguson (2000) seeking health information over the web is very popular as it represents one third of all Internet searches. Presenting *Healthinfo4u* as an option for health information on the Internet was therefore likely to generate interest. The research would determine whether the site would be successful in providing information that consumers would value.

It was important for the project to consider users’ reasons for seeking health information on the Internet. The results in Chart 7 opposite indicate that most use was for obtaining knowledge to enable respondents to manage health conditions for themselves or others.

Chart 7.

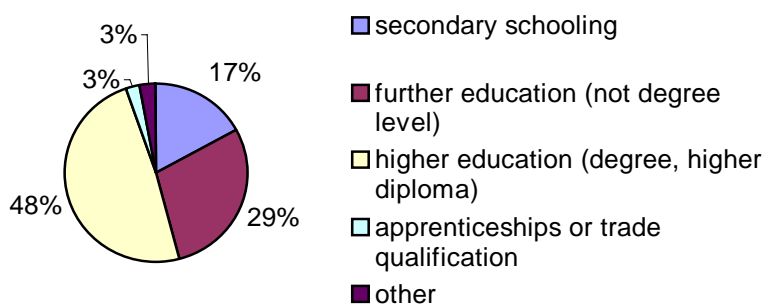


The results show that few respondents (6.5%) declared they were using the information for professional or study reasons.

The educational profile of the respondents was analysed (Appendix F, q. A6). Chart 8 below shows that 29% described themselves as having studied up to secondary school level; 48% had followed a level of higher education; further education had been followed by 17% of respondents; 3% had studied for apprentice or trade qualifications.

Chart 8.

Highest level of education attained by Healthinfo4u users



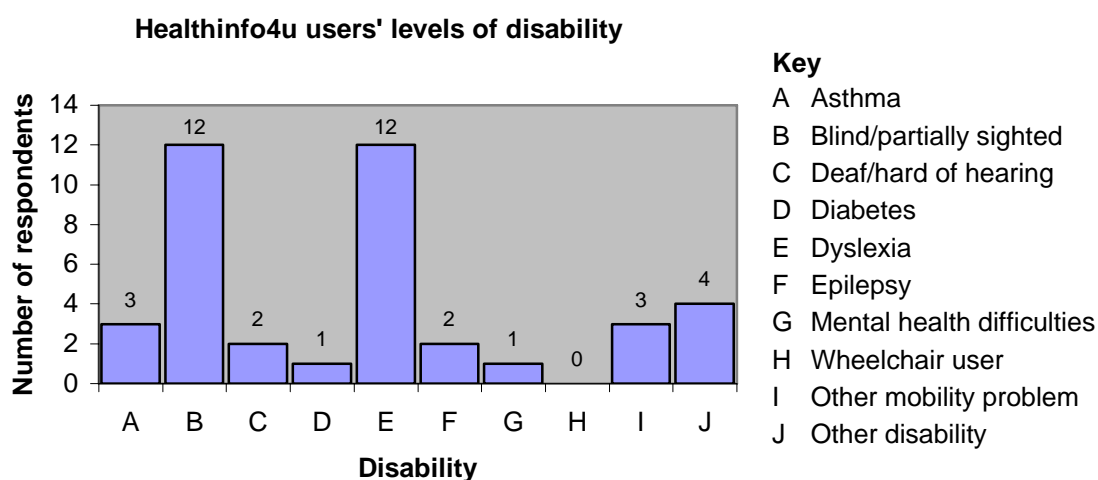
This was the expected audience to be found in public libraries and the research would establish whether *Healthinfo4u* would be accepted as a valued tool by this target audience.

To complete the sample population profile, questions were asked about perceived disabilities (Appendix F, q. A8, A9, A10). 11% of respondents were registered disabled or were disabled in terms of the 1995 Disability Discrimination Act. This

result compares to 20% of the UK population (Department for Work and Pensions, [1998]).

Questions were asked about respondents’ disabilities to establish what might be needed of the site design. Chart 9 below indicates that two considerations for site design have emerged from the results from 12 respondents who were blind/partially sighted and 12 who had dyslexia. The categorisation of topics reduces some of the difficulties that free text searching for medical terms may present. During the study care was taken to ensure clarity of the website design for those with visual impairment, and of the 12 respondents with visual impairment 10 rated the site as “very good”.

Chart 9.



5.5 Impressions of the Healthinfo4u site before and after use

The following section reports on the results of respondents’ overall impressions of the *Healthinfo4u* site and their “descriptions” of it. Both questionnaires sought respondents’ opinions of the site before and after use of the web site and following article delivery. The project wished to establish whether the concept of *Healthinfo4u* was sound and likely to satisfy some of the health information needs of the lay public. Did perceptions change after reading the articles and would respondents intend to use the site again (Appendix F, q. C1, C16, C17 and C19; Appendix G, q. 9, 10)?

Chart 10 opposite indicates that 81% of *Healthinfo4u* respondents, when first using the site, perceived it to be “excellent”, “very good” or “good”. 13% considered it “fair” and 6% considered the site to be “inadequate” or “poor”. Chart 11 opposite indicates that after using *Healthinfo4u* there was a 125% increase in those viewing the site as “excellent”. The remaining results for “overall first impressions” shift from the enthusiastic first impressions to a significantly positive normal distribution of impressions where 67% of respondents consider the site “excellent”, “very good”, or “good”.

Chart 10.

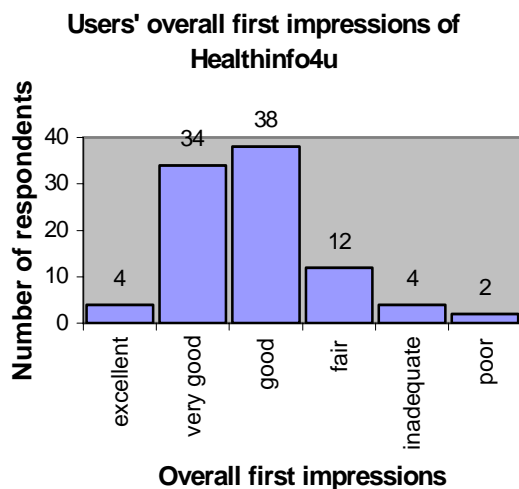
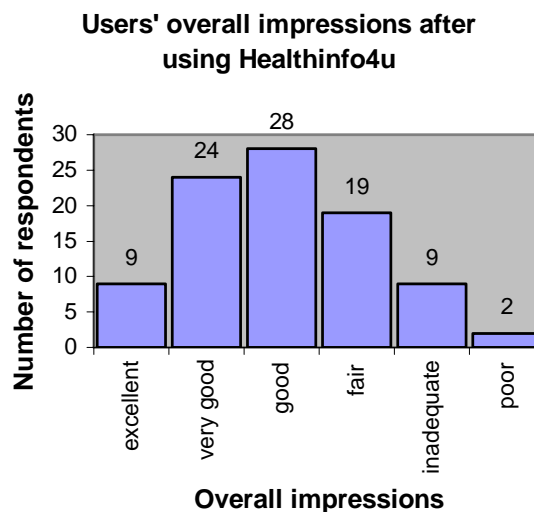


Chart 11.



One respondent commented on their general impression of the site:

A good idea - often doctors don't have time to spend explaining the wider picture for a patient. Having access to information would allow the patient or carer to ask relevant questions once a bit more informed.

In order to establish whether perceived health knowledge and/or web searching skills influenced perceptions of the site, the “overall impression” results were cross-tabulated against the perceived health knowledge and perceived web searching skills results (Appendix F, q. B1, B5). Chart 12 and Chart 13 below indicate that the site was well received regardless of these perceived skills.

Chart 12.

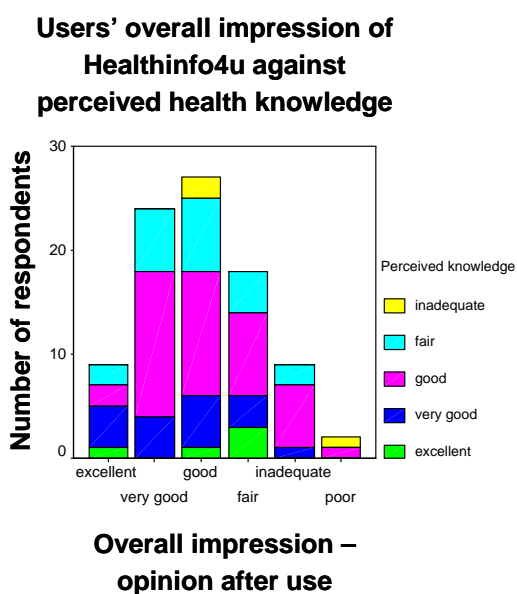
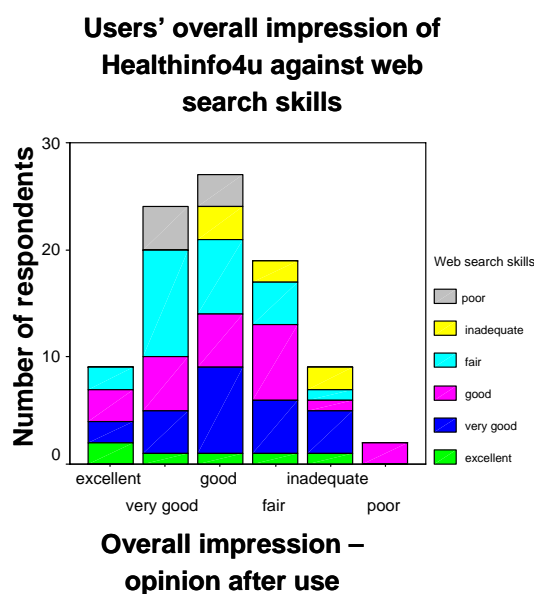


Chart 13.



A further measure of satisfaction with *Healthinfo4u* was to ask respondents to indicate their intentions to use the site again both prior to (Appendix F, q. C19), and after article delivery (Appendix G, q. 10).

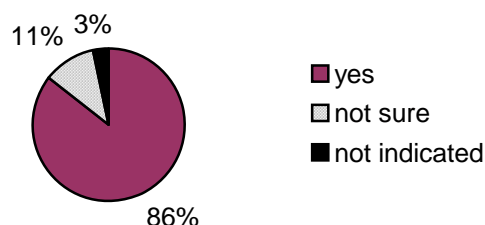
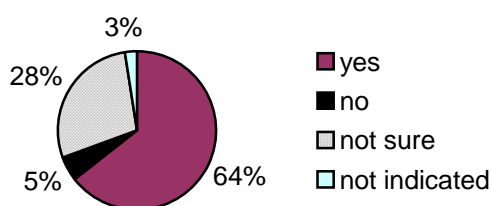
Chart 14 and Chart 15 below indicate that the intention to use *Healthinfo4u* again has increased from 64% after first accessing the site to 86% after receipt of the articles chosen. This is a rise of 34%, and it should also be noted that there has been a 61% reduction of the “not sure” responses after the articles have been received.

Chart 14.

Chart 15.

Users' intended future use of Healthinfo4u after first accessing site

Users' intended future use of Healthinfo4u after receipt of articles



In addition none of the respondents to the follow-up questionnaire considered that they would not use *Healthinfo4u* again and one respondent commented:

I will use this site more and more I should think. Looking forward to seeing how it develops.

Both the questionnaires in the second and third cycles (Appendices F and G) sought respondents' opinions of *Healthinfo4u* before and after use. Both questionnaires offered a range of phrases and respondents chose the phrases that, in their opinion, best described the site (Appendix F, q. C17; Appendix G, q. 9). Table 2 opposite indicates the frequency of descriptions chosen from each questionnaire and presents them in order of combined popularity from both questionnaires.

Table 2. Frequency of comments chosen by respondents to describe Healthinfo4u.

Description of Healthinfo4u	Appendix F. after site use only	% respondents	Appendix G. after receipt of articles	% respondents	Total frequency	Total %
A good idea	93	81.0%	103	87.3%	196	84.1%
Useful for anyone interested in health care	50	43.5%	73	61.9%	123	52.8%
A promising product	52	45.2%	60	50.8%	112	48.1%
Useful for anyone studying health care or medicine	42	36.5%	66	55.9%	108	46.4%
Useful information about disorders	48	41.7%	54	45.8%	102	43.7%
Gives specific health information	37	32.2%	60	50.8%	97	41.6%
Somewhere to get the latest research	40	34.8%	56	47.5%	96	41.2%
A route to information not available elsewhere	34	29.6%	59	50.0%	93	40%
Good for general health information	39	33.9%	40	33.9%	79	33.9%
Educational	29	25.2%	49	41.5%	78	33.4%
A mine of information	26	22.6%	34	28.8%	60	25.8%
Useful for school projects	33	28.7%	24	20.3%	57	24.5%
Somewhere to look for information about syndromes	22	19.1%	23	19.5%	45	19.3%
Needs a bit of work but a good idea	30	26.0%	13	11.0%	43	18.5%
I was surprised by what I could find	16	13.9%	16	13.6%	32	13.7%
Looks exciting but cannot take the information away	24	20.9%	6	5.1%	30	12.9%
Needs a lot of work but a good idea	17	14.8%	12	10.2%	29	12.4%
A place for diet and exercise advice	11	9.6%	9	7.6%	20	8.6%
Difficult to find what I want	14	12.2%	1	0.8%	15	6.4%
Confusing	5	4.3%	0	0	5	2.1%
Too difficult to use	5	4.3%	0	0	5	2.1%
I don't like it	3	2.6%	0	0	3	1.2%
Too detailed information for me	1	0.9%	0	0	1	0.4%
Useless	1	0.9%	0	0	1	0.4%
Respondents to each questionnaire	115		118		233	

The results from the 2 questionnaires indicated in Table 2 above reflect the positive feedback obtained from many of the questions asked throughout both questionnaires. The choice of descriptions included opportunities to rate the product poorly.

The description most frequently chosen, by 84.1% of all respondents to both questionnaires, indicates that *Healthinfo4u* is perceived as “a good idea”. The next most popular choices were “useful for anyone interested in health care” (52.8%) and “a promising product” (48.1%). When viewing all 24 statements the 10 most frequently chosen are positive acclamations of *Healthinfo4u* and its possible uses. The following 8 most frequently chosen descriptions indicate a level of usefulness, and the 6 least frequently chosen phrases are all critical comments. Of these,

“difficult to find what I want” was chosen by 12.2% of respondents after use of the site; however the selection of this comment reduced to 0.8% of respondents following receipt of the information. The last five critical comments were not chosen by any of the respondents following receipt of their information.

The response that displays the largest increase in popularity once the articles have been received is “a route to information not available elsewhere”, which has increased by 73.5%. “Gives specific health information” has also shown a significant increase of 62% once articles have been received. These results support the hypothesis that selecting quality-assured journal literature previously only available to health care professionals does add perceived value to the lay person’s quest for health information.

In addition, respondents’ choice of “needs a bit of work” reduced by 57% once their articles had been received, and “difficult to find what I want” decreased by 93% from 12.2% to 0.8% once respondents read their articles.

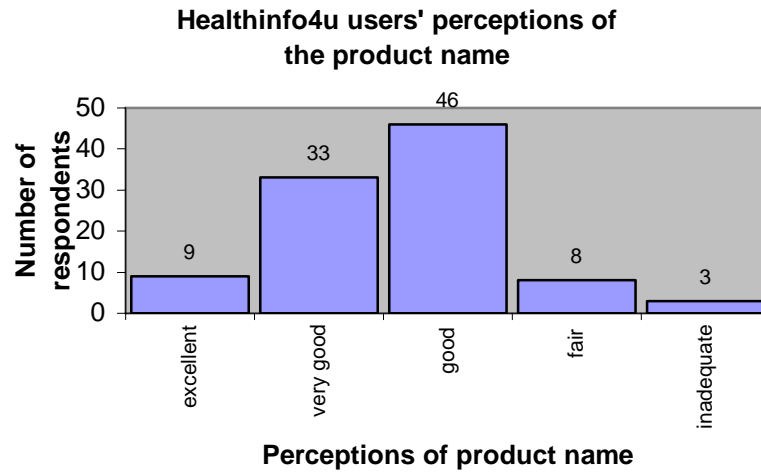
The results also show that none of the respondents to the follow-up questionnaire perceived *Healthinfo4u* to be “confusing”, “too detailed information for me”, “too difficult to use”, “useless” or that they “don’t like it”. One respondent to questionnaire one perceived *Healthinfo4u* to be “useless”.

Table 2 and Charts 5 to 8 all reinforce the view that the site is being perceived in a positive way, which increases after use, and that users would like to continue to obtain health information from *Healthinfo4u* in the future.

5.6 Perceptions about the name “Healthinfo4u”

It was important to consider respondents’ opinions of the name “*Healthinfo4u*” as it might have presented barriers to the product’s use and not portray what the product could deliver (Appendix F, q. C1). Chart 16 opposite indicates that 89% of respondents rated the name either “good”, “very good”, or “excellent”. This suggested there was no need to change the proposed product name during the research project.

Chart 16.



5.7 Site design, topics and searching

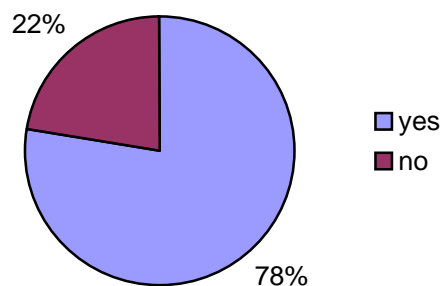
Descriptions of the product development are given in Chapter 2. The following section explores how successful *Healthinfo4u* was at satisfying the ultimate aim of providing users with a clear, simple and fast route to the journal articles. It also considers how users may wish to search for information, the desirability of including a dictionary or encyclopaedia, and the options for display of search results.

5.7.1 Range of topics on search page and success rates for finding the desired topic

Respondents were asked to indicate whether they found the topic that interested them (Appendix F, q. C3). Chart 17 below indicates that 78 % of users immediately found the topic they were interested in.

Chart 17.

Healthinfo4u users who found their topic immediately



This result illustrates that finding topics from a list was a successful route to the desired information. During the development of the demonstrator product additional topics and groups of topics (see Screen Shot B, C, D and E on pages 19, 20 and 21)

were added following analysis and careful consideration of user feedback received. The progressive development of the *Healthinfo4u* topics and the organisation of them enhanced the “click and find” approach to the information.

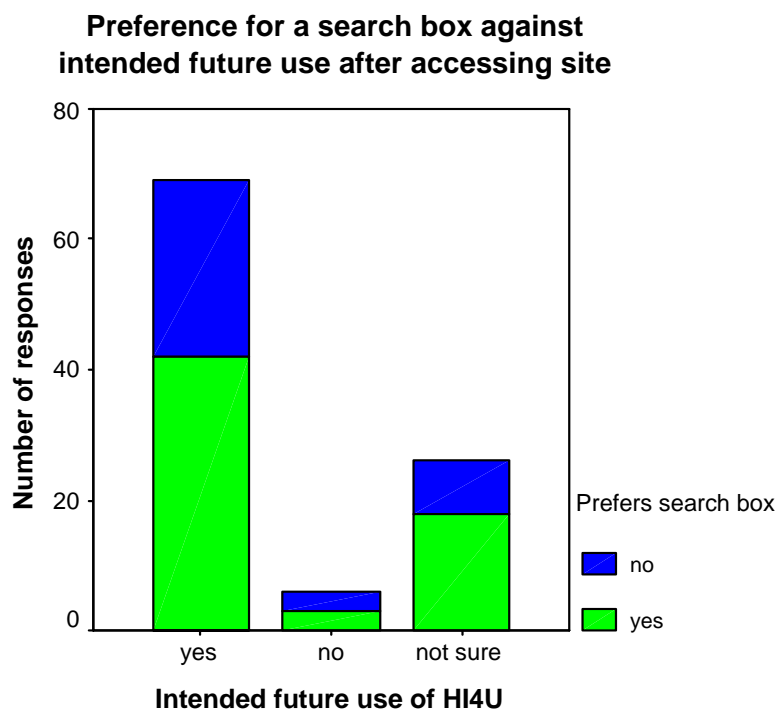
5.7.2 Preference for free text search feature (search box)

To research the future design of searching *Healthinfo4u*, questions were asked on the type of search feature users might prefer (Appendix F, q.C12). An example of a respondent’s feedback concerning this feature is:

Should be able to type in keywords which are contained in article and title, and also search by more lay terms as well as medical.

When the high percentage of users who found the desired information at the first attempt is considered alongside the positive response to using *Healthinfo4u*, the lack of free text searching was not a disadvantage to the product during the study. However just over 50% of respondents had suggested a search box would be useful. In order to identify whether there was a trend in the desire for a search box, elements of respondents’ profiles (age group, perceived health knowledge, perceived web searching skills, information industry work or study, health sector work or study) were analysed against their search box preferences. There was not a significant difference in the desire for a search box when these elements of the respondents’ profiles were analysed; it can therefore be assumed to be an issue of personal preference. It is evident that the preference for a search box did not significantly affect the user’s choice of whether to use *Healthinfo4u* in the future, as Chart 18 opposite indicates.

Chart 18.



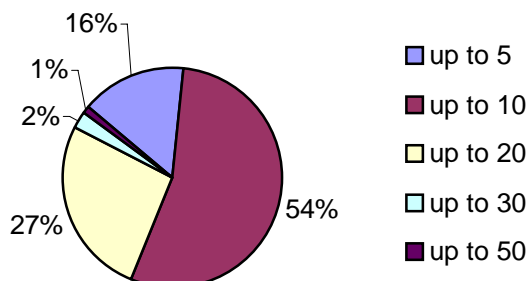
The focus group recognised that the provision of a search box is a complex issue and it considered the perceived advantages to having this feature on the site. The group discussed the use of a search box from a user's perspective and remained undecided on whether the availability of the feature would add value to the product. There were concerns that the addition of a search box may lead to misspelling of search terms that would decrease the success rates for finding information. However adding a search feature is something that should be considered for any future version of *Healthinfo4u*.

5.7.3 Preference for number of search results to be displayed

It was important to establish users' preferences for the number of search results to be displayed on each page. Respondents were asked to choose from a range of numbers of articles to be shown (Appendix F, q.C5). Chart 19 on the following page shows that there was a clear preference for 10 search results to be shown on each page, as indicated by 54% of respondents. This was incorporated into the development of the product.

Chart 19.

Healthinfo4u users' preferred number of search results to be shown on each page



5.7.4 Desirability of having access to medical dictionary or encyclopaedia

Respondents were asked for their opinions on the desirability of having a link to an existing medical dictionary or encyclopaedia (Appendix F, q. C14), 90.4% indicated they would like to see such a link. One respondent suggested:

a general summary of the illness would be helpful.

Another respondent remarked that:

it would be useful to incorporate links to approved health sites elsewhere.

Potential benefits of including an online dictionary or encyclopaedia were identified during the project. Throughout the development of *Healthinfo4u* links were maintained with the producers of *NHS Direct Online* to ensure maximum synergy and avoid duplication of information. As a result when the *NHS Direct Online Encyclopaedia* was launched the project obtained agreement to link to it from the demonstrator website and provide *Healthinfo4u* users with that resource. The steering group also welcomed the link with *NHS Direct Online* and expressed desire that this might be strengthened in any permanent version of *Healthinfo4u*. Future collaboration of this kind with web-based health information providers would have the potential to facilitate the products' integration into the spectrum of health information.

5.8 Article access

A range of questions was asked about the preferred format for output of the articles and preferred methods of obtaining the articles (Appendix F, q.C10, C11; Appendix G, q.3, 4). It should be noted that, during the project's three cycles, articles were free at the point-of-use and the principal route of access was through postal document supply. However there was no research undertaken to establish whether the same result would have been received if respondents had been asked to pay for the information.

The document supply element of the project was provided by BLDSO, up to a maximum budget of £4,000 including VAT. To ensure the project remained within this budget requests were only accepted from users in demonstrator area postcodes.

612 requests for articles were received from within the demonstrator areas where *Healthinfo4u* was promoted. In addition the appeal of the free product extended beyond the project boundaries as evidenced by the 821 requests that were generated from outside of the demonstrator areas:

- 367 requests from outside of the demonstrator areas but within the UK;
- 315 international requests;
- 139 requests with e-mail address supplied instead of postal address prohibiting postal document supply.

The product had not been promoted outside of the demonstrator areas and the above requests indicate that the demonstrator product generated interest from health consumers. However these out-of-area requests could not be satisfied by the project. The following comments are examples of the comments received from consumers who had placed orders from outside the demonstrator areas:

when your project is distributing more widely, can you let me know what charges are applicable for what would be a most valuable service;

I was very happy to find these articles. Free full articles containing this theme [very low birth weight children] are very rare. Maybe there will be the possibility to read them in the future ... thanks for your efforts;

I would greatly appreciate the possibility of obtaining articles in the future and look forward to the expansion of the site to permit this once the necessary funding is available.

5.8.1 On-screen access

During the 34 weeks of the second and third cycles, 12% of the site's article content was available to view on screen. Three publishers, Blackwell, Lippincott, Williams & Wilkins and RCN Publishing, made content available free of charge during the project. Access was by a link either to a specially created PDF file of the individual article, or to a publisher's web site that displayed the full text in either PDF or HTML (Hypertext Markup Language) format. The following access statistics have been made available by one publisher who provided 8% of the on-screen *Healthinfo4u* article content:

- 213 article abstracts were viewed;
- 50 articles were viewed in PDF full text;
- 72 articles were viewed in HTML full text.

5.8.2 Document supply

Where an article was not available on screen the user indicated the article(s) they wished to receive by clicking in the "order this article" box and completing the order

form at the bottom of the display of search results (see Screen Shot H and Screen Shot I on page 23). The order was sent to the project team who then completed an ARTWeb online order form to enable the article(s) to be dispatched to the user by the BLDSC.

The results of document supply are:

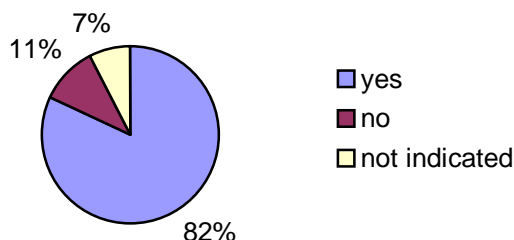
- 132 individual users requested 612 articles to be dispatched during the project cycles;
- 70.8% of the potential budget was used;
- cost of total articles requested @ £4.69 per unit is £2836.20;
- average number of articles requested per user is 4.6.

Towards the end of the project, as promotion was being scaled down in demonstrator sites, requests declined more rapidly than had been anticipated leaving an under-spend on document supply. However the requests from outside the demonstrator areas displayed a steady increase during the project.

Chart 20 below indicates that in the free at the point-of-use environment of the project, 82% of respondents were prepared to accept postal delivery (Appendix G, q. 4).

Chart 20.

Expressed acceptance of postal delivery after articles had been received



Preference for on screen access for articles may be indicated by respondents' choice of the phrase "looks exciting but you cannot take the information away" (see Table 2). On first using the site 20.9% of respondents chose this phrase to describe *Healthinfo4u*. After articles had been received only 5.1% of respondents had this view, a reduction of 75%, which may indicate that despite a desire to see the information on screen it is acceptable to receive the information by post. However this may not have been the case had charges been involved. One respondent's satisfaction with the document delivery element led to the comment:

The article I requested to be sent to me by post arrived very quickly – impressive.

Qualitative comments regarding the packaging of the articles were received from two respondents. They were concerned that the use of clear plastic packaging may not be appropriate as the articles relate to personal health enquiries.

5.9 Perceived value of articles received

Feedback was sought to gain respondents’ opinions on the level of difficulty of articles received, how far the articles had satisfied expectations, and the perceived usefulness of them (Appendix G, q. 8,7,5).

Chart 21 below illustrates that 74% of respondents indicated that the articles had an “easy” or “moderate – some medical terms but understandable” level of reading difficulty. It is reasonable to assume from these results that the selection criteria used during the project provided articles that are generally accessible to members of the public. This assumption is supported by the following online feedback from a respondent:

interesting and useful site for obtaining in depth articles about Rheumatoid Arthritis.

Chart 21.

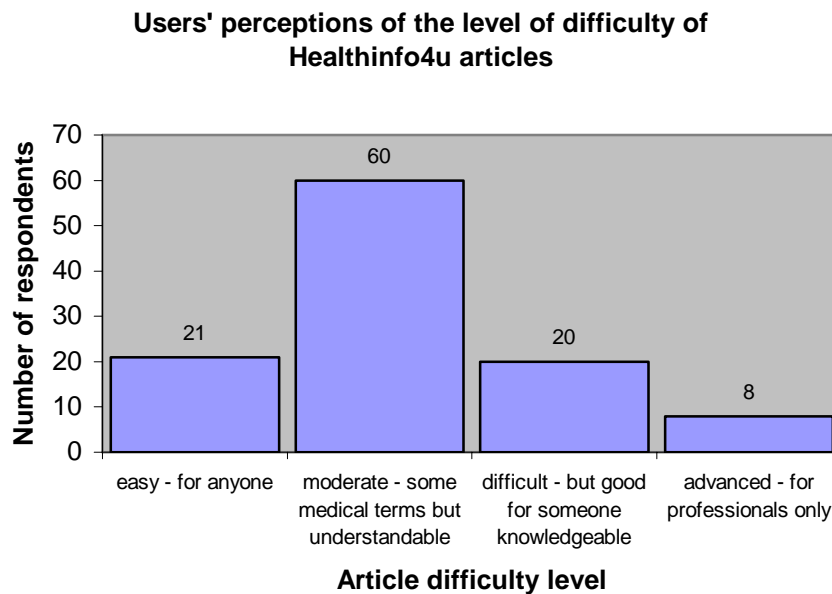


Chart 22 on the following page indicates that 66% of respondents considered the information they received from *Healthinfo4u* had “exceeded”, “completely” or “mainly” satisfied their expectations. 28% were “fairly” or “partly” satisfied and 6% were not satisfied.

Chart 22.

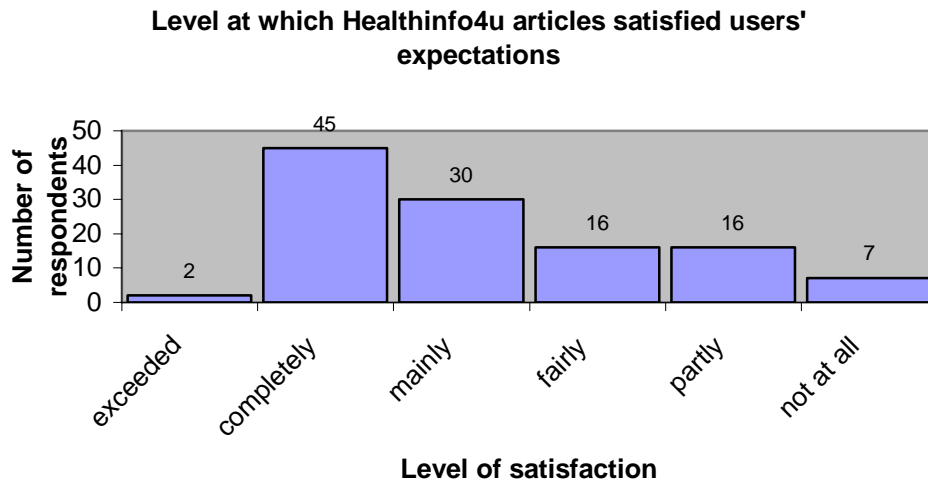
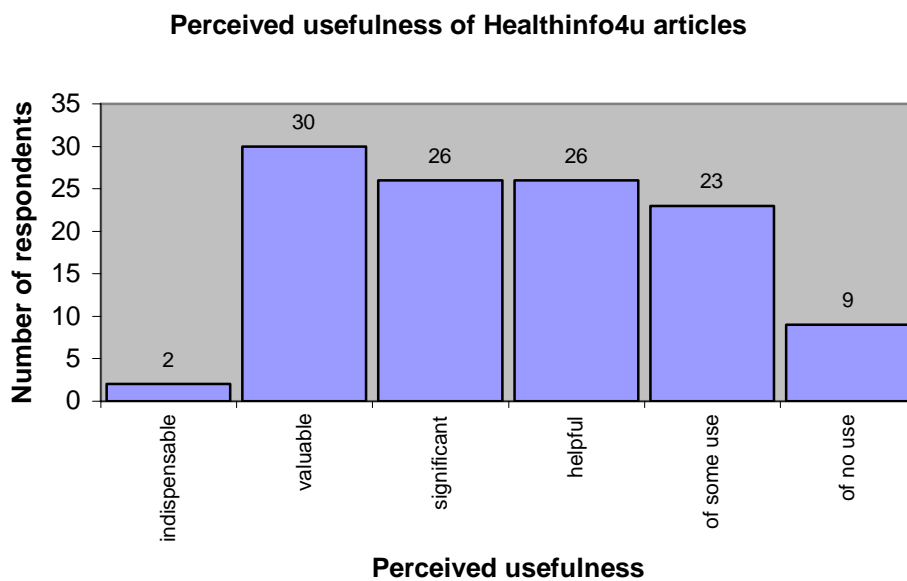


Chart 23 below illustrates that 50% of respondents viewed the articles to be “indispensable”, “valuable” or “significant”. A further 22% perceived that they were “helpful”.

Chart 23.



One respondent stated:

there are many useful points made as to information about various treatments and side effect profiles and the need to make sure women understand that it is a recurrent chronic condition.

Another respondent gave this general comment concerning the usefulness of the articles:

if the information is kept up-to-date this will be a useful tool, especially for those people suffering from a specific illness/allergy/condition.

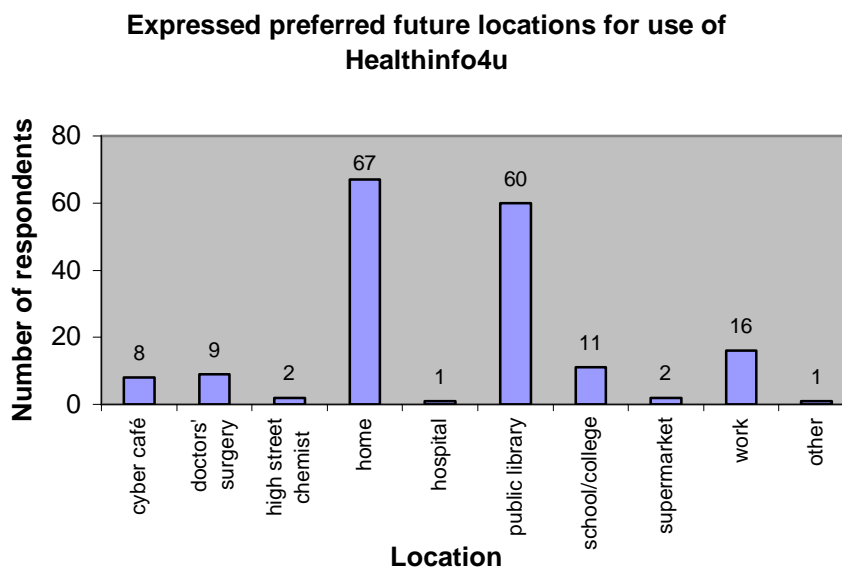
One respondent commented that the site:

gives lots of info on the topic that has been chosen. Informative.

5.10 Preferred locations for future use of Healthinfo4u

Consideration of where users might use the Internet was relevant to the future viability of a *Healthinfo4u* product (Appendix F, q. C20). As might have been expected with a pilot held in public libraries, Chart 24 below indicates that 60 respondents (34% of the expressed preferences) would like in the future to use *Healthinfo4u* in “public libraries”. More surprisingly, 67 respondents (38% of the expressed preferences) also chose “home” as one of their preferred future locations. These two locations were overwhelmingly the most popular preferences out of ten options suggested for future use. “Work” was the third most popular choice indicated by 16 respondents (9% of the expressed preferences), followed by school or college indicated by 11 respondents (6% of the expressed preferences) and doctor’s surgery indicated by 9 respondents (5% of the expressed preferences). This illustrates potential opportunities for developing the product for access from home, work and clinical health care settings whether in hospital or the doctor’s surgery.

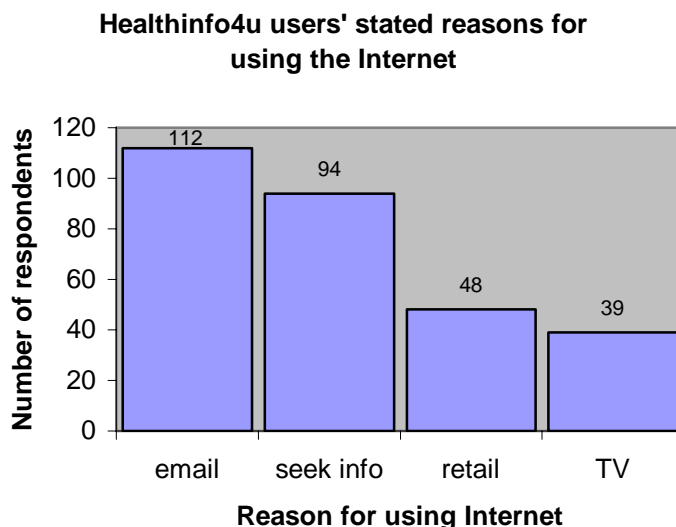
Chart 24.



5.11 Use of the Internet

Questions were asked about why people use the Internet. Chart 25 on the following page indicates that the most popular use of the Internet by *Healthinfo4u* respondents is e-mail access, followed closely by seeking information (Appendix F, q.B6, B7).

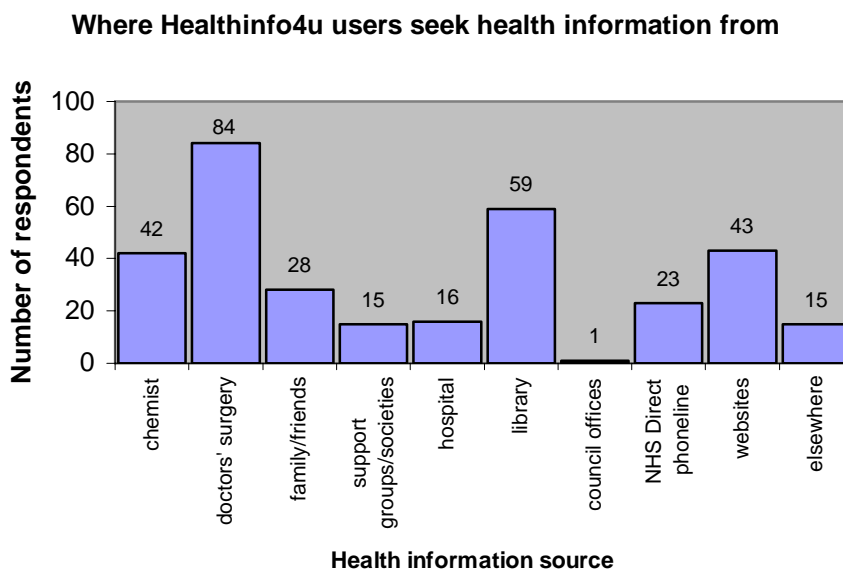
Chart 25.



5.12 Seeking health information

Also relevant to the potential viability of *Healthinfo4u* is what sources respondents already use to locate health information (Appendix F, q. A2). Chart 26 below indicates the preferences for health information sources as chosen by 115 respondents. 84 respondents (25% of the expressed preferences) chose going to a “doctors’ surgery” as one of their preferred methods of obtaining health information. The next most popular choice from 59 respondents was “library” (18% of expressed preferences) and the third was “websites” chosen by 43 respondents (13.2% of expressed preferences). 42 respondents (12.8 % of expressed preferences) indicated that they used a chemist to obtain health information.

Chart 26.



These results indicate that *Healthinfo4u* respondents already use the Internet as a source of health information and, as indicated in Chart 26 opposite, 37% seek information from websites.

Ferguson (2002) comments that one third of all Internet searches are for health information. If 37% of the survey population already use the web for health information it would suggest there would be a strong market for *Healthinfo4u* as a web-based product.

During the project 74% of respondents found the website in public libraries, 9% discovered the website through word-of-mouth recommendations and 7% found the website by reading an e-mail bulletin. These use statistics reflect the marketing and promotion of the demonstrator product during the three evaluation cycles.

5.13 Conclusion

Results indicate that the population sample was representative within the context of a web-based product accessed in public libraries and health information points.

Users' overall impressions of the site, including the product name, are positive and are not affected by their perceived health knowledge or Internet search skills.

The development of the site design, the topics and searching methods have enabled users to find the information of use to them.

The results of article access indicate that users received their articles through a combination of document supply and on-screen access, and that the perceived value of the articles was high. There was a significant increase in users' intentions to use *Healthinfo4u* again once the information had been read. There was also a significant increase in the selection of positive statements to describe *Healthinfo4u* once the information had been read.

Users indicated that the most popular locations for future use of the product were "home" and "public library". This result however might have been affected by the context of the study demonstrator sites, that is, predominantly public libraries.

The results suggest that *Healthinfo4u* would be a valuable resource for those who use the Internet to find health information and also that the number of articles required by each consumer might not exceed five per search.

6 Sustainability

6.1 Future product access

The demonstrator study results have indicated that the lay public would like to use the product in the future from a variety of access locations. One user commented during a telephone interview:

I thought it was first class to have available to the general public. It's very difficult to get access to articles otherwise. It's an absolutely vital service. The articles I asked for on heart conditions were very good and I wish you good luck with the project.

Results also suggest that there would be a demand from health care professionals who would like access to a quality-assured product to which they could refer patients. One GP commented, "I would like to see this integrated into a surgery" and a health visitor described the product as "a wonderful tool for those who would like to use it. People would know where to go for the information they want. I'm impressed."

As discussed in the literature review a future product could have the potential to contribute to the development of the expert patient. This has also been illustrated in the feedback from health care professionals. A regional co-ordinator of an Expert Patients Programme indicated they would like to make the product available as part of the training programme and noted:

this is a valuable resource for those who wish to develop their knowledge to manage certain chronic conditions. It had a positive response from the group, and I would be keen to have this resource available as part of future training for expert patients.

A Patient Advice and Liaison Service (PALS) co-ordinator commented that:

it would be a useful resource for expert patients as more people are developing computer skills and are more interested in getting health information. I'd like to be able to tell people they can use this.

Comments were received not only from health care professionals; an expert patient also provided the following online comment on the product:

it seems integral to the concept of self-management that information such as is provided here be easily obtainable by as many people as possible. I'm excited to see this kind of information becoming more widely available and hope it will inspire other health authorities to follow suit. So thank you to the organisers and to you as a pioneer in this regard.

The advantages of providing good quality health information were described by a local authority staff member involved in health promotion:

it would be great to have people going to their doctors with this information. I'm surprised that nothing like this, with a health consumer focus, has been available before. Promoting good health needs to be tackled from a number of angles.

There would be inherent challenges in making a future product available in a variety of locations visited by the public. For example, the availability of necessary on-site Internet access technology, the web knowledge of the potential user and the willingness to browse for and request information of this nature in a public location. Facilities for the print and download of information would be necessary, or the capability to e-mail the results to enable printing at a later date.

These challenges could be overcome, for example:

- by increasing the knowledge and confidence of those using the Internet;
- by retaining the simple-to-use interface that has been developed and by ensuring an element of privacy in access locations;
- by the availability of on-site fast printing, or by the facility to e-mail the results or download them to a disk for printing elsewhere;
- by the introduction of authentication protocols to enable access from home computers.

6.2 Product development

The demonstrator study with its use of action research facilitated the development of a quality-assured tool that could underpin a sustainable future product.

Maintaining the quality assurance would be one of the most important aspects for any future product. The project results suggest the following criteria would need to be adopted:

- the use of professional peer-reviewed journals as the source for content selection;
- the use of selection criteria to identify articles with appropriate content at an appropriate level for the lay public;
- the selection, editorial and review processes to be undertaken by leading information and health care professionals;
- a simple web-based search and retrieval interface to facilitate rapid download or printing of the chosen articles.

The issue of quality assurance of the demonstrator website was addressed during the project in consultation with CHIQ; their guidelines for the accuracy, clarity and relevance involved in the design of health information websites would need to continue to be followed. The award of Partnership status to the *Healthinfo4u* demonstrator website by CHIQ reflected the recognition the project achieved for developing a high quality, health information tool for the lay public. CHIQ indicates the value of the award of Partnership status with their organisation:

partner organisations are health information providers whose research and editorial processes and information meet CHIQ standards.

The CHIQ partnership mark on a future product could therefore not only alleviate fears about using the Internet as a source of quality-assured health information, but could also contribute to the level of confidence that consumers and health care professionals would have when using it.

6.3 Document access

The demonstrator study facilitated the trial of three models for full-text document access and one model for document supply. These were dependent on the technologies available to and offered by the publishers or aggregators who were providing full-text access, and by the document supply sponsoring provider. Without modification none of the models used in the demonstrator study would provide a sustainable future model for delivery of the product.

The first full-text document access model involved the conversion of the journal articles into PDF files by the publisher. The articles were subsequently supplied on CDROM and were loaded on to a server by the project team. The user clicked on the full-text link on the demonstrator website and the appropriate PDF file was immediately displayed. For a publisher, an advantage of using PDF files to provide full-text in a future product would be that the consumer would access only the full text of the single article supplied as that PDF file. This would mean the publisher would not have to provide access to a full-text article contained in their website. An advantage of using PDF files for the producer of a future product would be that the articles would be held in a server that would be in the control of the producer. The challenge in using PDF files would be firstly that the process could be time-consuming for the publisher and the producer (as it was during the demonstrator study where the number of PDF files supplied was relatively low at 32), and secondly that those users who access the product through for example a digital television would not be able to download the necessary Adobe Acrobat Reader software to view the article. One user noted:

I do not have a computer but rely on cable tv for access to the web (and for e-mail) This means, of course, that I cannot print out any of the info I read, but it is frustrating to see a document of interest restricted to pdf format so that I can't even open it (because I can't "add" Adobe to my system).

The second full-text document access model involved the publisher enabling trusted proxy server and remote username and password access to the full text of journal articles on the publisher's site. The project team used a Perl script to create the link to the relevant article on the publisher's site. To view the article the user clicked the full-text link on the demonstrator website and entered a username and password; these had been instantaneously displayed by a pop-up box. The advantage of this model for a future product would be that once the Perl script had been developed the links to full text would be created quickly. The challenge in using this model would be that if the publisher experienced problems with their server or if there were problems with the Perl script, the full text link would not operate. There would also be authentication challenges for a future product to ensure only those entitled to use the service could do so.

The third full-text document access model involved the use of a non-open URL and a Perl script to link to the search results page of an aggregator's database of articles. The user was directed by the demonstrator website to click on the full-text link on the search results page to view the article. Despite instructions being incorporated into the demonstrator product, this process was less than intuitive. The challenge of this model for the producer of a future product and an aggregator would be to provide an alternative to the user having to navigate the aggregator's search results page to locate the full-text link. As with the second model an advantage to this model would be that once the Perl script had been developed the links would be created quickly. However this model would also present authentication challenges for a future product intended for use by the lay consumer particularly in non-library settings.

The model followed for document supply involved the user ticking an on-screen box next to the chosen article(s) from the demonstrator website and completing an online order form at the bottom of each search results page. The orders were submitted by e-mail to the project office where they were entered into an existing online order form for the existing document supply service (part of the ARTWeb service) provided by the BLDSC. The articles were dispatched by the BLDSC and received by the user within five days. The challenges in following this model for a future product would include:

- subscribing organisations or the producers would need to re-enter the orders into the ARTWeb online form;
- the postal delivery costs involved would have to be funded;
- clear plastic packaging currently used would be unsuitable for the receipt of possibly sensitive health data;
- articles would by necessity of the BLDSC processes be dispatched individually even if a number were ordered by the same person.

In addition the most significant challenge for the lay public using postal document supply or electronic document delivery in a future product would be the disparate copyright fees that are set by individual publishers for each journal title; these currently range from £0.13 to £52.00. This unavoidable element of the document supply model for individual requests not mediated through library document supply schemes would make the cost of each article unpredictable. With the choice of articles not being fixed for subscribing organisations they would not be able to budget satisfactorily the costs of providing the product to their lay public. The alternative could be to pass payment to the end-user. However, access to those articles with higher copyright fees would be restricted to those individuals with sufficient disposable income. End-user payment would also present the challenge of ensuring that the costs of obtaining articles were understood clearly before purchase, especially where the disparate cost of the articles would not relate to the quality of the content but to the decision of the publisher owning the intellectual property rights (IPR). The challenges of current document supply models, which are constrained by the publishers' copyright charges, would prohibit use in a future product.

6.4 Challenges of making the product available

Although the selection of content would not be problematic if the quality assurance processes outlined were adopted, the demonstrator study has identified challenges in making a future product available.

There would be challenges deriving from technology, the access locations, authentication of accredited users, and the subscription models.

Public locations, for example public libraries or health information kiosks in shopping complexes, would require suitable privacy, fast and reliable Internet connections, and print and download capability. All access locations would require suitable simple authentication protocols to ensure use of the product was restricted to the clients of the subscribing organisations.

The greatest challenge would be securing the delivery of full-text access for all of the content selected as being appropriate for a future product.

It would be time-consuming to negotiate with individual publishers agreement and remuneration for access to the chosen content commensurate with the likely use of the material. To transform the current demonstrator product into a future product would involve approaching 188 publishers of 352 journals containing the 3,100 articles referenced in the product.

Research included in the literature review suggested publishers would be cautious to make their e-content available to a market that is difficult to predict. During the demonstrator study one publisher in particular, who held a significant proportion of the articles selected by the project team, voiced concerns about making the information available to consumers and would not take part in the study. Some of the concern was about the potential for litigation as the articles would have been originally intended for health care professionals, not the lay public. This concern in particular would need to be addressed. The quality-assurance methods used for content selection would perhaps contribute to allaying the above concern.

However another concern expressed by publishers is one of losing existing revenue: they fear that existing subscribers would use *Healthinfo4u* as a substitute for their journals. The overwhelming opinion of those involved in the project, however, is that the market for this product would be additional to the institutional or personal, professional subscriptions that already exist. Publishers and aggregators might wish to participate in a service that would empower the health information consumer, albeit for a return that is difficult to quantify. The document supply figures from the demonstrator study, with the average of 4.6 articles per requester, might suggest that demand for full text would be relatively limited and would therefore be acceptable to the publisher as a small additional new market and not one that would detract from existing revenues.

The use of aggregators may provide the solution to the challenge of negotiation with large numbers of publishers, as they might be able to offer access to e-content based on negotiating extensions to existing agreements. The new market that the product

could realise may not, at first, be perceived as one that would immediately justify aggregator involvement, due to a relatively small financial return. However, as with publishers this would be a new market that might allow for sales in health care and public library settings in the UK and abroad. This was illustrated by the success of the demonstrator product in the public library and health information demonstrator sites.

The potential of a market for the product was illustrated by the 821 requests generated during the ten-month demonstrator period from outside the demonstrator areas without any promotion of the site. 315 of these came from outside the UK; a further 139 requests were received from users who supplied only an e-mail address and these may have been from anywhere in the world. In addition to modest sales returns there might be potential for spin-off public relations benefits from participating in the patient empowerment agenda promoted by governments around the world.

Currently no one aggregator would have the potential to enable access to more than 34% of the articles currently referenced in *Healthinfo4u*. However there might be potential for more content customisation and for additional content to be negotiated so that the product could continue to provide information on the NHS “target” areas: cancer, coronary heart disease and stroke, accidents and mental health (DOH 1999).

The options for different funding models might encompass subscription, sponsorship and pay-per-view. The public sector, and individual or grouped organisations or services, could subscribe to enable free access to a future product for their members or customers for a defined period of time. Suitable commercial organisations might sponsor the product in order to enhance the products or services they offer to consumers and could make it available to a specified group of people or the general public free of charge. Individual consumers or organisations could access a future product on a pay-per-view basis, enabling each article to be paid for individually.

6.5 Conclusion

The demonstrator study results indicate that the health consumer would like to use this product in the future. However there are major impediments, in terms of technology, negotiating with and rewarding rights-owners, and developing a sustainable payment model, to transforming the *Healthinfo4u* demonstrator into a viable product.

7 Conclusion

This report has presented evidence to answer whether it would be feasible to re-purpose quality-assured, evidence-based information currently available only to health professionals and deliver it, using existing web-based technologies, to the lay public.

The study was grounded in the prevailing UK and CEC health strategies to empower the patient; results have suggested that a future product would have the potential to contribute to the development of “expert patients”. Results also indicate that health professionals perceive value in making *Healthinfo4u* available to the lay public.

The literature research has identified that consumers are increasingly using the Internet as a source of health information and that this has led to the development of tools to measure and assure the quality of information, for example the quality criteria from CHIQ and the CEC. If *Healthinfo4u* were developed into a viable product it would have the potential to support the growing trend for using the Internet as a source of quality-assured, kite-marked health information.

The development of the demonstrator product and the results from Chapter 5 suggest that the resource had relevance to the health consumer. The choice of topics, selection of content, simple website design and availability of the full text of the articles enabled users to access information that they perceived had a high level of usefulness. The result was a website that provided the lay public with a clear, simple and fast route to accessible, quality-assured journal articles previously only available to health care professionals.

User feedback from the Steering Group and Project Board provided clear indication of the value of *Healthinfo4u* in varied health care settings. The award of the CHIQ Partnership mark provided the public statement of the quality assurance of the information provided. User comments describing their overall perceptions of *Healthinfo4u* were overwhelmingly positive. After first accessing the site a high proportion of users indicated they would like to use the product again. Following the selection and receipt of articles the number of respondents wishing to use *Healthinfo4u* again had increased significantly, indicating the high value users placed on the information obtained. One respondent’s feedback illustrated how valuable they considered the demonstrator product to be:

I came across your website and lo and behold there were all these collated references that would have taken me a lot longer to find on an individual basis. I thought the site was excellent.

During the project document access was free at the point-of-use and was provided predominantly by the BLDS. However the study has shown there would be a major challenge in providing health consumers with a sustainable product that involved postal or electronic document supply which was free at the point-of-use. The range of fees set by publishers from £0.13 to £52.00 would prevent the producers of a future product from being able to propose a document supply inclusive subscription. An

open-ended subscription with all document supply costs to be met by subscribers would present difficult budgetary decisions for organisations that might subscribe. Charging the end-user would involve the challenge of ensuring the costs of obtaining *Healthinfo4u* articles were understood clearly before purchase, especially where the disparate cost of the articles would not relate to the quality of the content but to the decision of the publisher owning the IPR.

The alternative model to document supply would be to provide on-screen access to the selected journal articles. However for a future product to have access to the appropriate content would require negotiation with over 180 publishers. This negotiation would be time-consuming and difficult, as would arriving at agreed remuneration for these IPR holders. In addition dealing with 180 or more publishers would compound the technological challenge of arriving at a simple access platform.

It would appear that if there were to be a sustainable product a method would be required that could build on the access that might be provided by aggregators. During the project aggregators had the potential to provide up to 34% of the content available. With further product refinement it might be possible to deliver a product that would have 100% available on screen.

The project results have provided evidence that web technology could be used to deliver a tool that could supply the lay public with information about accessible, quality-assured, evidence-based literature previously only available to health care professionals. However, there are major impediments, in terms of technology, negotiating with and rewarding rights-owners and developing a sustainable payment model, to transforming the *Healthinfo4u* demonstrator into a viable product.

APPENDICES

Appendix A1 Original project bid

THE BRITISH LIBRARY CO-OPERATION AND PARTNERSHIP PROGRAMME

Working with public libraries to enhance access to quality-assured health information for the lay public

1. Proposal for a demonstrator study

1.1 Introduction

This bid addresses the aims of *Working with public libraries to widen access to collections and to support lifelong learning*. By virtue of the partnerships involved it also fulfils some of the objectives of *Working with the higher education (HE) sector to extend developments in HE to other sectors*.

This project uses existing web technology in public libraries to deliver to the public high-quality information based on that already available to health care professionals.

Health is currently undergoing a paradigm shift to self-care, with doctors and other care professionals increasingly acting as brokers for health guidance. Patients are using new technology to access information about conditions and treatments, both conventional and complementary. The National Health Service (NHS) agenda is firmly patient-centred; the emergence of the expert patient, demanding quality-assured professional information, has created the need for access to such information and supporting navigational tools.

The medical information required is:

- both clinical and complementary;
- quality-assured and evidence-based;
- available to the health care professional, the patient, their advocates and representatives;
- publicly accessible in appropriate formats;
- mediated and set in context.

This information is currently contained in collections held by the British Library, the Royal College of Nursing (RCN), the NHS and university libraries. It is mediated for the health care professional and students through two complementary databases *Allied and Complementary MEDicine Database (AMED)* and *British Nursing Index (BNI)*.

The project will use these resources to:

develop and deliver a new database combining quality-assured health information from clinical and complementary sources;

extend access for the lay public to both the database and the primary sources.

The bid is supported by contributions from:

- primary content providers - electronic publishers;
- secondary content providers - *AMED, BNI*;
- technical partner - Health Communication Network (HCN);
- intermediaries – BLDSC;
- access sites - the public library authorities of Bournemouth, Essex, Poole and Wiltshire; patient information services in the NHS South West Regional Library Service.

All the organisations are used to collaborative working across the sectors and are seeking, through practical co-operation, to produce a sustainable service that satisfies both the Government's healthy living agenda and consumer needs.

The relevance of the project will be enhanced by the involvement on the steering group of the NHS Library Advisor, a health professional and a consumer representative.

The project leadership provided by Bournemouth University also brings expertise in negotiating licences with electronic publishers, which will enhance the sustainability of the proposal.

2. Aims and objectives

To support lifelong learning and healthy living agendas by making existing quality sources of health information available to the lay person through public libraries and patient information centres by both document delivery and full-text electronic access;

To enhance health professionals' access to literature selected for its relevance to the lay person;

To build on existing services and partnerships to create a new navigational tool to such literature;

To investigate with publishers sustainable models for accessing specialist electronic information through public libraries;

To recommend models for sustainable delivery, including: the selection of content; web access to the secondary sources; web delivery of full-text; traditional document supply of content.

3. Work packages and deliverables

WP = Work Package D = Deliverable

3.1 WP1 Project management

Including: report writing; partnership group meetings; and steering group review.

The partnership group will provide advice both in group meetings and one-to-one with the project worker (further details of expertise are given in sections 8 and 12). The group will agree the content of all the deliverables including the reports to be presented to the steering group.

The steering group (see section 11) will review the project outcomes and endorse any recommendations for scaling the project beyond the pilot. Members will take part in the dissemination programme and nominated representative(s) of the British library will be invited to attend.

D1.1 Interim project report

Documenting the agreed format of the pilot product, the models of document delivery to be tested, the mode(s) of delivery to be used and the mechanisms to be used for evaluation. The agreed report will be sent to a nominated representative of the British Library.

D1.2 Final report

Documenting the methodology and results of the study, including review of all deliverables. Particular emphasis will be given to the models proposed for sustainable document access to the primary literature for the lay public and to the model(s) proposed for the secondary tool that is to be used to navigate to this quality assured literature. The agreed report will be sent to a nominated representative of the British Library.

3.2 WP2 Product definition and design

Including: resource identification; database specification and build; web interface design and build.

WP2.1 Product definition

Documenting the scope of the secondary navigation tool: specification of the range of journals to be included from the 300 plus currently available in the separately owned *BNI & AMED*; scope of the index/abstract entries to be included from *BNI & AMED*, including quality and accessibility criteria; identification of and arrangements to add any primary sources of information not currently indexed or abstracted by *BNI* or *AMED* for example patient information leaflets; the thesaurus to be used to facilitate navigation; the name, specification and pilot business model for the newly created secondary navigation tool; the models to be used for document delivery and full-text access to the primary literature.

D2.1 Product specification

WP2.2 Product design

Documenting: the software to be used for the secondary navigation tool; the format of delivery to be used in the pilot (web access but possibly also print and CD-ROM); the web design to be used to access the secondary tool and subsequent primary document access; the processes, including workflow, required to submit data to the technical partner; the processes, including workflow, required to build the product; the process required to distribute the product to the pilot access sites.

D2.2 Design specification

WP2.3 Product build

Delivery of: a specially created, quality assured, web based secondary indexing and abstracting tool; full text access option will be linked from the tool.

D2.3 Pilot product

3.3 WP3 Licence negotiation

Including: publisher negotiations; access design and build.

The investigation of new models of full text delivery will lead to an access strategy that can be applied during the pilot using project funding where necessary to cover any costs.

D3 Pilot electronic document access strategy

3.4 WP4 Pilot product delivery, testing and evaluation

WP4.1 Beta testing

Including: access for the public to the secondary navigation tool; access for the public to primary documents through library websites and mediated services, patient information centres in hospitals, other NHS direct outlets within the public library authorities of Bournemouth, Essex, Poole and Wiltshire; assessing both traditional and electronic document delivery options; lay and professional user perceptions of content and accessibility; access site evaluation; The British Library through the Health Care Information Service (HCIS) will provide document supply to end-users during the life of the project based on the secondary tool; the potential of local access schemes will be explored.

D4.1 Operational pilot product

WP4.2.1 Design promotional materials for health care and information professionals

D4.2.1 Promotional materials for health care and information professionals

WP4.2.2 Design promotional materials for lay consumers

D4.2.2 Promotional materials for lay consumers

WP4.3 User feedback from focus groups and questionnaires

Focus groups will be held in all access locations and questionnaires and selected follow up interviews will be used to gauge lay, information and health professional feedback on the relevance, usability and accessibility of the secondary tool and the primary literature contained in the pilot product.

D4.3 Interim feedback report

Documenting the testing of a hybrid model exploiting local collections from NHS and HE and public libraries, alongside British Library document delivery and full-text options direct from publishers.

WP5 Potential sustainable delivery models

This documentation will make recommendations about the possible sustainability of the project.

WP5.1 Documentation of sustainable database delivery models

The British Library through the HCIS will be tasked with documenting a possible model for access of full text material by the end-user in a public library setting. It is expected that the model documented will be applicable to other projects where full text delivery is required. It is expected that the project will continue in the pilot areas and that it will be scaleable to other areas.

D5.1 Model(s) for sustainable delivery of the product***WP5.2 Documentation of sustainable full text access models for lay consumers***

The investigation of new models of full text delivery should lead to models that can be applied to organisational or index subscriptions instead of journal subscriptions.

D5.2 Models(s) for sustainable full text access models for lay consumers**3.6 WP6 Dissemination programme planning.**

D6 Section 10 gives more details of proposed dissemination vehicles

Timetable

Month 1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	
WP1	WP1 PG	WP1	WP1 PG	WP1 SG D1.1	WP1	WP1 PG	WP1	WP1 PG	WP1	WP1 SG	WP1	WP1 PG	WP1	WP1 PG	WP1	WP1 SG	WP1	WP1 PG D1.2	
WP2.1	WP2.1 D2.1	WP2.2 WP2.3 D2.2	WP2.2 WP2.3 D2.2	WP2.3	D2.3														
	WP3	WP3	WP3	WP3	WP3	WP3	WP3	WP3	WP3	D3									
					WP4.1 WP4.2.1 WP4.2.2	WP4.1 D4.1 D4.2.1 D4.2.2	WP4.1	WP4.1	WP4.1	WP4.1	WP4.1	WP4.1	WP4.1	WP4.1	WP4.1 WP4.3	WP4.1 WP4.3			
											WP5.1 WP5.2	WP5.1 WP5.2	WP5.1 WP5.2	WP5.1 WP5.2	D5.1 D5.2				
							WP6	WP6	WP6	D6		D6		D6		D6			D6

WP = Work Package D= Deliverable PG = Partnership Group SG = Steering Group

National and International standards

All database development will conform to international protocols including that of Z39.50.

Relationship to other projects, programmes and strategies

6.1 National healthy living agenda

The NHS is committed to developing and delivering a number of healthy living initiatives in order to reduce health inequalities and improve the health of the nation. These include Health Action Zones, Health Living Centres, NHS Direct Online 24-hour services and new models of consumer involvement in their own health and in decision-making processes. Local Health Improvement Plans target specific objectives within a broader framework of health improvement. These plans and strategies are dependent on the public being knowledgeable about health matters and on local activities that bridge traditional sectors of NHS and local authority services.

6.2 Local health initiatives and strategies

The Project will support and dovetail with a number of local initiatives. Two of the Project's proposed pilot areas are primary targets for improving healthy living, being located within wards listed in the DETR Index of the 2000 most deprived wards in England. (Out of the 2000 Boscombe West is 83rd, Wallisdown (known as West Howe) 630th and Kinson 1283rd.) Kinson and West Howe have high levels of unemployment and a high incidence of long-term illness. Recently areas within the two wards were designated as a Surestart area. Boscombe West has high levels of unemployment, single households and houses in multiple occupancy, and drug abuse.

A Healthy Living Centre project (OASIS) is under way in Boscombe, which aims to promote community group partnerships and involves both Bournemouth University and Bournemouth Libraries. The project will support these partnerships.

Poole Healthpoint service is currently involved in health/disability information projects with the health authority, voluntary organisations and other professional agencies. One of these, Poole Community Wise, commissioned by Poole Social Services as a database of local community groups and contacts, is awaiting final preparation for distribution on the Poole Borough intranet.

Poole Healthpoint and local NHS Trusts are involved in a project for provision of information to patients and the public under the Dorset-wide Implementation of the Information for Health Strategy (P6).

6.3 National information initiatives

The People's Network strategy for public library infrastructure, staff training and content will provide and promote the necessary skills development to underpin the use of ICT as an integral part of information provision within the public library network. Essex is entering into investigations with the British Library to establish how the BL *Inside* service might be best adapted for public library use.

6.4 Local information strategies and initiatives

Within the Wessex partners the enhancement of health information is a key objective of the **Conurbation Library and Information Plan**.

Bournemouth Libraries wish to build on the historical links with *Healthpoint* in Poole.

In **Poole** the access will complement information currently provided through the existing Healthpoint co-located in the Central Library.

Wiltshire access will be through a link to the existing website, which has been significantly redesigned for 2001, taking account of website guidance for visually impaired people. Currently the site includes a comprehensive directory of sources of health information but does not provide access to quality-assured literature.

Essex Libraries are a major contributor to *SEAMLESS*, a partnership of local, regional and national organisations, including health authorities providing a web-based, interactive, citizens' information service for the people of Essex which is distributed and based on common standards.

The **South West Regional Library Service**, as part of NHS Plan (2000), is looking at ways of facilitating access to Patient Information Services particularly those in local hospitals in Poole, Bournemouth and Wiltshire.

7. Access Policies

7.1 Project leader

Bournemouth University includes in its mission the facilitation of scholarship through applied research and consultancy, including collaboration with regional, national and international partners. The Library, in support of this, provides access for the University community to the widest range of facilities, resources and systems possible within budget. In addition it seeks to foster access to collections through collaboration, partnerships and negotiated agreements within the conurbation and beyond.

7.2 Primary content providers

Journal publishers such as Blackwells have expressed a commitment to the investigation of new models of full-text delivery mediated through subscriptions to secondary sources.

7.3 Secondary content providers

Both the secondary content providers *BNI* and *AMED*, have made commitments in their business plans to their quality-assured information being made available to the lay public. The project will provide the opportunity to complete the loop and add access to the primary documents indexed by *BNI* and *AMED*.

7.4 Technical partner

HCN has a proven track record in facilitating timely access to appropriate and relevant health information that supports evidence-based approaches to service delivery and in the longer term will impact on patient outcomes. The delivery of the product will be a web-based service developed by HCN, the project's technical partner, a company experienced in health care information systems.

7.5 Intermediaries

The Health Care Information Service of the British Library acts as the focus for all health-related activities within the national library of the U.K. The emerging strategy for the British Library includes “digital library services, new partnerships with other institutions and making our nationally important collections available to the widest possible audience...The Web will be central to everything that we do. It will enable us to provide better services in support of scholarship, research and innovation and to expand our services to the general public.” Lynne Brindley, October 2000, <http://bl.uk/concord/otherpubmisc2.html>.

7.6 Access sites

Public libraries have a unique role in the community offering a neutral access point to a wide range of information for all members of the public. Each of the access sites has policies that underpin the project proposals to extend access through practical co-operation.

Bournemouth and **Poole** public library authorities focus health information through the Healthpoint service and are committed to extending access through the use of internet technology available in their libraries. Bournemouth has made a commitment to provide printed resources of appropriate material for the public to borrow to support the information provided through this project. This will build on existing provision for carers and parents.

Wiltshire County Council has a network of 31 libraries and maintains a database of community information, comprising in excess of 15,000 items. This database is freely available on their website and is maintained by a team with the help and support of individuals and voluntary organisations. It has a strong core of health information and is promoted at events in the county, e.g. Over-50s Health Days, and Carer Fayres. The library teams also help people to source health information for which there is a growing demand.

Essex Libraries has a network of 74 libraries large and small serving a population of over 1.25m people. All libraries have internet capability through 116 (increasing to 516 during 2001) library terminals. It has a central health collection (Health Zone) at Chelmsford Library (one of the busiest libraries in the country) which is supported by a health information specialist. Essex Libraries also offer a direct-line enquiry service that handles a significant number of health enquiries, which arrive by phone, fax, email and personal visit.

NHS South West Regional Library Service works very closely with local higher education institutions in order to deliver integrated access to library and information services for health care staff and students. These partnerships are being extended to include local government and private sector agencies, in order to support the whole spectrum of health care provision.

In line with the NHS Plan (2000), NHS librarians are keen to explore ways in which patient empowerment can be supported through access to health care information. The creation of patient information centres provides a route for extending access and this project provides the next step in taking this forward.

8. Resources

Project funding is essential to manage the practical co-operation required, to direct the product creation, delivery and evaluation and to present a sustainable model.

A project worker is required to facilitate the product definition, liaison with the contributing agencies, product specification and subsequent pilot and evaluation. They will also be involved in researching and documenting the possible delivery models beyond the pilot and for co-ordinating the dissemination.

Bournemouth University, the lead institution and provider of licence and procurement model expertise, will manage the project worker. The project worker will also liaise with the entire partnership group for all aspects of project delivery, monitoring and evaluation. HCN will lead all aspects of the technical delivery. *BNI* and *AMED* will provide guidance to the project worker on product content.

The partners have been able to secure significant funding for the project infrastructure, including the waiving of any British Library Document delivery costs in the pilot phase. All pilot sites will host focus group evaluation sessions and provide support for the pilot delivery. The costs requested will fund the project worker, equipment, materials and consumables, evaluation and dissemination costs.

9. Sustainability

The project will research possible models of sustainability, including NHS Direct subsidy, NHS regional library subsidy, EARL funding, public library subscription and permutations of all of these. The project will detail the recommended product sustainability and will have sought to have secured funding for one year to provide continuation of the service to the pilot access sites plus the inclusion of some options to extend to national delivery.

The project will deliver electronic full-text information from at least one publisher. The negotiation with the publisher(s) and resulting usage statistics will form the basis, together with specialist knowledge within Bournemouth University of procurement of electronic information, for recommendations on sustainability as an electronic service.

10. Publicity and dissemination

10.1 Interim report

There will be an interim report documenting the project definition and pilot phase to be published six months after project start.

10.2 Conferences

Suitable conferences will be sought to publicise the pilot project. Conferences in both the library and health sectors will be targeted - including the Healthcare Computing conference in March 2002, the Health Libraries Group conference in mid-2002 and the Medinfo conference in late 2001.

10.3 National seminar

The NHS Library Advisor will host a national seminar at the Department of Health London office, Skipton House, to promote the potential of the service and the lessons learned.

10.4 Web site

The project will maintain a website where project and sample product information will be made available to health information experts.

10.5 E-mail lists and articles

The interim and final report will also be publicised through e-mail lists and articles will be submitted to relevant professional journals.

10.6 Final report

The final report will be published, presented to the British Library, and disseminated as outlined above.

10.7 Pilot sites

The pilot sites will provide an ongoing programme of promotion aimed at the target audience.

11. Monitoring and evaluation

11.1 Project Steering Group

The establishment of a project steering group is seen to be an essential element for ensuring the relevance of and for monitoring the research. It will formally sign off the work packages twice during the life of the project. We have secured the commitment of Veronica Fraser (NHS Library Adviser, NHS Executive Policy Unit). We will be seeking to appoint a representative of the health professionals who work closely with patient information needs and a lay consumer of health information.

11.2 Project evaluation

The project evaluation will look at relevance of the product content and the success of the delivery model.

Each pilot site will host a user focus group and questionnaire feedback will be gathered from a sample of lay users, clinicians and information professionals.

Access figures will be used to gauge volumes of use.

11.3 Dorset-wide Implementation Plan for Information for Health: Project on Information for Patients and the Public (P6).

Through discussion with the advisory panel this plan will be used to provide information on relevance.

11.4 External verification of the evaluation findings

If successful the project will approach Resource: the Council for Museums, Archives and Libraries and NHD Research and Development to contribute to the assessment of the evaluation.

12. Expertise

12.1 Bournemouth University

A high value is placed on research, consultancy and other forms of professional engagement, recognising that these functions have a central role in the development of the University's standing and fulfilment of its mission.

The University is home to a number of specialist centres that serve to enhance the learning experience. These include the unique and prestigious National Centre for Computer Animation, the Centre for the History of Defence Electronics, the Worshipful Company of Cooks Centre for Culinary Research and the International Centre for Tourism and Hospitality Research.

The University Library has a good record of research, including the BLRIC/LIC-funded project on library purchasing consortia (*RIC/G/403*) and the current Resource-funded project on outsourcing and externalisation (*LIC/RE/108*). Three projects, in partnership with Bournemouth Media School, are in receipt of AHRB funds in the area of media archives, specifically focusing on: BBC Radio 4 *Analysis* a current affairs documentary series; *This Week* an Independent Television documentary and current affairs series; and Independent Local Radio Programme Sharing Archive digitisation project in partnership with the National Sound Archive.

Specialist expertise in negotiating with publishers for electronic licences will be provided by David Ball, who chairs the Libraries Group of the Southern Universities Purchasing Consortium, and is currently leading negotiations with publishers to develop new business models for electronic information.

12.2 The British Library Health Care Information Service (HCIS) and Allied and Complementary MEDicine Database (AMED)

HCIS acts as the United Kingdom Medlars Centre, which gives it a unique link to the National Library of Medicine in Washington. HCIS staff index 25% of the UK input into the *Medline* database and consequently are experts on medical indexing. The service also produces the *Allied and Complementary MEDicine Database (AMED)* which indexes the literature on complementary and allied medicine and HCIS is therefore seen as a leading information provider in the field of complementary medicine.

AMED covers the areas of complementary medicine, physiotherapy, occupational therapy, rehabilitation medicine, palliative care, podiatry and speech and language therapy. Its coverage extends back to 1985, when the database was initiated due to the lack of coverage of these topics on *MEDLINE*. It has its own thesaurus of terms based on *MeSH* and since 1993 has included abstracts. Each of the topics is available as print, and the complete database is available on CD-ROM through SilverPlatter and OVID as well as on the Web via EBSCOMed.

12.4 British Nursing Index

BNI provides references to journal articles from all the major British nursing and midwifery titles plus other English language titles. Over 9000 records are added each year. Its coverage extends back to 1994, although the print version has been available since 1991. It has developed a thesaurus based on British practice and terminology, which is subject to constant review. Abstracts are being added to the database in 2001 as part of the development of *BNI+*, which includes more international references to complement the British material. *BNI* is updated monthly, and currency of content is given high priority. The database is available in print, on CD-ROM via SilverPlatter and there are web-based versions on both SilverPlatter and OVID platforms. *BNI's* partner in electronic published versions is HCN. *BNI* Publishing itself is a partnership between organisations in higher education, the NHS, and a nursing professional body, and the partnership seeks to extend its content to the widest possible audience to provide opportunities to enhance health care.

12.5 Health Communication Network (HCN)

HCN's considerable experience in multiple public/private stakeholder and complex programs is best evidenced in its involvement in Australia in the internationally known, Integrated Care Program (ICP). The ICP, now in its third funding year, seeks to implement an evidence-based best practice approach using information technology for general practitioners. Other program partners have included the Commonwealth Government, Divisions of General Practice and The Pharmaceutical Alliance.

12.6 Bournemouth Libraries

Bournemouth Libraries has experience of successful cross-sectoral partnership working. Partners include commercial organisations, voluntary and statutory bodies. The library service has a strong community focus and local staff are positively encouraged to network with other workers and agencies. It is intended to build on the high levels of volunteer support provided by the Bournemouth Council of Voluntary

Services, Help and Care, and Age Concern to help mediate access to the information alongside library staff in the Bournemouth pilot.

There are staff employed who have particular interests and skills in the health information field. These include a senior manager with relevant experience and an ex-Healthpoint employee who will be involved in the project. Other staff who could be directly involved in this project include two with additional communication skills i.e. British Sign Language and Makaton.

12.7 Essex County Council Libraries, Heritage & Cultural Services

Essex Libraries is a large and innovative public library service and their work in the *SEAMLESS* project partnership described in section 6 provides expertise in the design, and operation of interactive citizens' web-based information services.

12.8 Poole Healthpoint

Healthpoint is funded by Dorset Health Authority, Poole, Bournemouth and Dorset Social Services and Poole Library Service. It has a drop-in centre at the main library but also answers health information enquiries throughout Poole, Bournemouth and Dorset from the public and health care professionals, and is the contact for Dorset Health Information Services via Dorset Healthline and NHS Direct South West.

Healthpoint is also a member of SWRLIN and has had close links with the Help For Health Trust over several years. With all the above organisations Healthpoint has been part of ICT and public/patient projects.

12.9 Wiltshire County Library Service

In developing their database of community information which comprises in excess of 15,000 items, Wiltshire have developed expertise in designing, maintaining and promoting accessible websites which comply with all relevant guidelines.

12.10 NHS Executive Information Policy Unit

The NHS Information Policy Unit was established following the publication of the NHS Information Strategy Information for Health in 1998. As its title suggests the IPU is developing information and communication policies to support the NHS Plan, and commissioning projects and programmes in electronic health records, a National electronic Library for Health, and better information provision for patients and the public via NHS Direct Online and nhs.uk. The NHS is committed to exploring ways of working with other public sector partners so that accurate and relevant information on healthy living and treatment options is within the reach of all.

12.11 NHS South West Regional Library Service

The NHS South West Regional Library Service co-ordinates health library and information services across the following counties: Cornwall, Devon, Somerset, Gloucestershire, Dorset, Wiltshire (including the former County of Avon) – a

population of almost 5 million. There are 99 members of staff working in 30 different service points. All libraries have public access to the internet, and their staff are skilled in facilitating access to electronic resources for end-users. In some areas dedicated internet facilitators are employed, and many staff are acquiring teaching qualifications. The service has already worked with HCN to establish new models for funding database and full-text access to health literature and, with HCN, will make available its joint NHS/internet server to host the web-based product during the pilot.

13. Roles and responsibilities

Bournemouth University, the lead institution and provider of licence and procurement model expertise, will manage the project worker. The worker will also maintain liaison with the project team for all aspects of project monitoring and evaluation with HCN for all aspects of the technical delivery, with *BNI* and *AMED* for product content, and with the NHS South West Regional Library Service and the public library authorities of Bournemouth, Essex Poole and Wiltshire for the pilot scheme delivery.

There will be a project board made up from representatives of all the partner institutions who will meet regularly to monitor the work packages and their delivery. Twice during the project they will meet with the steering group to report, receive advice and guidance and to sign off appropriate work packages. The Head of the British Library Health Care Information Service will act as an additional reporting route into the British Library.

14. Costs and Contributions

14.1 Costs

<i>Staff</i>	
Project Worker 12 months (including on-costs)	*£25,000
Administrative support 12 days	£2,160
Web site and database creation 100 days	£10,000
Total Staff Costs	£37,160
<i>Travel and subsistence</i>	
There will be travel and subsistence costs within the UK for: project management, interviews, attendance at conferences and seminars where relevant. Standard Bournemouth University rates are: £22 per day car hire (excluding petrol); £60 Maximum B&B; £5.00 lunch; £6.00 dinner; 2 nd class or cheaper rail travel.	
Total Travel and Subsistence Costs	£6,000
<i>Non-recurrent costs</i>	
These include:	
Communications	†*£500
Focus Group meetings (administration, travel, refreshments, meeting space)	†*£1,500
Public Library infrastructure support (staffing; stock; training)	£6,090
Volunteers' expenses & training	£1,000
Clerical assistance	£750
Licences to enable full-text access to literature	£3,000
Document delivery	£4,000
Total Non-recurrent Costs	£16,840
<i>Recurrent costs</i>	
The University requires a contribution to consumables, telephones and postage.	
Total Recurrent Costs	*£750
<i>Other costs</i>	
The University requires a contribution to recruitment and computing costs.	
Total Other Costs	*£1,450
Total Project Costs	£62,200

14.2 Contributions

<i>Contributions from the applicants' institution</i>	
The contribution comprises: time of the Project Leader; library facilities and office space.	
Estimated Contribution by Bournemouth University	£3,000
<i>Contribution from collaborative partners</i>	
The contribution comprises: financial contribution, services and time of Partners	
Estimated contribution by HCN to web and database construction	£10,000
Contribution to project funding from HCN	£5,000
Contribution to project funding from <i>BNI</i>	£5,000
Estimated contribution of BLHCIS to document delivery and AMED costs	£4,000
Example contribution from access libraries to library staff in pilot sites; additional stock resources; staff training; volunteer management/ co-ordination and focus group evaluation	£6,000
Total Contributions	£33,590
<i>Summary of Costs and Contributions</i>	
Staff Costs	£37,160
Travel and Subsistence	£6,000
Non-recurrent costs	£16,840
Recurrent costs	£750
Other Costs	£1,450
Total Project Cost	£62,200
Contributions from the applicants' institution	£3,000
Contribution from collaborative partners	£30,590
Total Contribution	£33,590
Total grant requested is	£29,200

* breakdown of CPP grant requested on application form

† £2,000 from grant

Appendix A2 Additional project bid

THE BRITISH LIBRARY CO-OPERATION AND PARTNERSHIP PROGRAMME

No. 6: Working with public libraries to enhance access to quality-assured health information for the lay public

Healthinfo4u

Proposal for additional funding, 2002

1. Introduction

The original award (http://www.healthinfo4u.org.uk/html/bid_text.html) enabled the project partners to explore methods of providing the lay public with information previously only available to health care professionals. This information is currently contained in collections held by the British Library, the Royal College of Nursing (RCN), the NHS and university libraries, and is mediated for the health care professional and students through two complementary databases *Allied and Complementary MEDicine Database (AMED)* and *British Nursing Index (BNI)*.

The project has developed publicly accessible information that is quality-assured, evidence-based and both clinical and complementary in nature. It is selected and presented for patients, their advocates and representatives, and for mediation by health care professionals.

The project research process has identified three key sustainability issues that need further exploration and development. This proposal summarises project achievements and outlines the additional work packages, deliverables and costs.

2. Lead institution

Project leadership will continue to be provided by Bournemouth University (see http://www.healthinfo4u.org.uk/html/bid_text.html). The project head is David Ball, University Librarian.

3. Partners

The project partners are used to collaborative working across the sectors. They are seeking, through practical co-operation, to produce a sustainable service that satisfies both the Government's healthy living agenda and consumer needs.

The project partners, and their roles, are:

Blackwell Publishing (primary content provider)

BNI Partnership (secondary content provider) – Bournemouth University Library;

Poole Hospital (NHS Trust) Library Services; Royal College of Nursing Library and Information Services; Salisbury Healthcare (NHS Trust) Library Services

Bournemouth Borough (public library access site)

Bournemouth University Library (project management)

British Library – *Allied and Complementary MEDicine Database* (secondary content provider)

Document Supply Centre (BLDSC) (intermediary)

Health Care Information Service (HCIS) (steering group)

Essex County (public library access site)

NHS Executive South West Information and Library Service (access site)

Ovid Technologies (technical partner)

Poole Borough (public library access site)

RCN Publishing (primary content provider)

Wiltshire County (public library access site)

4. British Library involvement

A strong partnership exists with the British Library for the content and delivery elements of Healthinfo4u. *AMED*, produced by the BL HCIS, is one of the project's two secondary content providers.

In the first phase of the project, BLDSC waived charges of up to £4,000. Unexpectedly the project established that over 85% of content will be available only as hard-copy through BLDSC, which has increased the level of partnership activity by the BL in the project.

The project team will explore marketing opportunities with Bruce Madge of the BL, and develop models for sustainability jointly with the BL.

The project will work closely with Stephanie Kenna of the BL to disseminate the lessons learnt during the project stages.

5. Aims and objectives

The aims and objectives of the original project are as follows:

- to support lifelong learning and healthy living agendas by making existing quality sources of health information available to the lay person through public libraries and patient information centres by both document delivery and full-text electronic access;
- to enhance health professionals' access to literature selected for its relevance to the lay person;
- to build on existing services and partnerships to create a new navigational tool to such literature;

- to investigate with publishers sustainable models for accessing specialist electronic information through public libraries;
- to recommend models for sustainable delivery, including: the selection of content; web access to the secondary sources; web delivery of full-text; traditional document supply of content.

The extended project will have an additional aim:

- to investigate with the British Library sustainable models for document delivery for Healthinfo4u in public libraries and medical settings.

6. Summary of work completed to date

Project deliverables in support of the original aims and objectives have all been met (see http://www.healthinfo4u.org.uk/html/bid_text.html, Section 3).

Two web sites have been launched: the project web site at <http://www.healthinfo4u.org.uk> and the product web site at <http://www.healthinfo4u.org>.

The Steering Group is a valuable part of the project and membership has been drawn from:

- CHIQ;
- general practitioners;
- health care information specialists;
- health promotion specialists;
- mental health information specialists;
- the NHS including the NELH and NHS Direct;
- nursing practitioners;
- patients' and carers' organisations.

The Steering Group, focus groups and questionnaire responses all have given overwhelming support to the concept and development of the product. This is illustrated by the following extracts from the *Draft Interim Feedback Report*:

- 89% of all respondents rated Healthinfo4u a good idea.
- 80.5% questionnaire respondents rated the name Healthinfo4u a suitable choice.
- 74.4% of respondents found their topic of interest at the first attempt.
- 65.1% of respondents said they would definitely use the site again after their first use; this increased to 81.5% of respondents who, after using the site, had selected and received articles. No users indicated they would definitely not use the site again.
- 72.7% of respondents were satisfied with the postal delivery of their chosen articles, however the majority of all the feedback indicates a long-term preference for access to the full text on screen.

The first and second pilot phases enabled the inclusion of references to 3000 quality-assured journal articles. CHIQ is working with the project to enable the award of their *Triangle Mark*, an accepted label of quality assurance. Respondents assessed quality as follows:

- 85% of respondents indicated that the articles were of an easy, moderate or understandable level of difficulty.
- 59% of respondents considered the information they received fulfilled their expectations, with another 32% being fairly or partly satisfied.
- 52% of respondents viewed the articles to be indispensable, valuable or significant. A further 24% perceived they were helpful.

This demonstrates both definite acceptance of the project's concept and endorsement of the content.

7. Additional work proposed to achieve sustainability

7.1 Issues

The two pilot phases have informed the *Interim Report* (<http://www.healthinfo4u.org.uk/html/reports.html>) and the *Draft Interim Feedback Report*. These have identified a number of issues that require further research and investigation in order to move towards a sustainable electronic service that meets user needs:

- *Balance of print and electronic availability*
Recent analysis by Bournemouth University of serials subscriptions showed three publishers providing 30% of content to academic libraries. Contrary to expectation, this pattern decisively has not been replicated in *Healthinfo4u*: only 9.5% of content is available from two of the top three publishers identified. The sustainable product will therefore have a hybrid nature in terms of having to provide information in both hard-copy and electronic forms.
- *Need for additional access channels*
Feedback has shown that primary care and clinical settings will be key access channels. To be viable and acceptable in such settings, the credibility of the product will have to be established for GPs and clinicians.
- *Need for additional content*
Feedback has confirmed the need for additional non-journal free content (e.g. leaflets, links to web sites). Research by the project head for Resource on procuring electronic content for public libraries corroborates the requirement for hybrid sources comprising free and paid-for information (<http://www.resource.gov.uk/information/research/re178-01.pdf>).

It is also evident that there is a need for additional accessible content from medical journals not covered by *AMED* or *BNI*. Such content will help to establish credibility in the primary care and clinical settings. It will also eliminate what for

the user is an artificial distinction arising from the coverage of the two parent publications.

7.2 Work packages and deliverables

WP = Work Package D = Deliverable

WP1 Hybrid document access

WP1.1 Technical development

Particularly given the extension to non-library settings, work will be required to develop an interface to BLDSC as the supplier of hard-copy documents.

Resources required: software developer time; travel and subsistence.

D1.1 Hard-copy document delivery interface

WP1.2 Hybrid economic model

Subscription to online full-text resources is relatively easy to fund and deliver. The significant transactional element of the hybrid print and electronic model poses considerable problems. Few organisations, particularly those with public clienteles, will be willing to fund unlimited access. Payment by end-users and by non-library intermediaries in medical settings will be investigated, as will alternatives such as digitisation.

Resources required: project leader; project worker; administrative support time; travel and subsistence.

D1.2 Hybrid economic model

WP2 Additional content

WP2.1 Journal content

With advice from clinicians and GPs, and building on the content-usage patterns from the pilots, criteria for non-AMED/BNI journal content will be developed and appropriate content indexed.

Resources required: project leader; administrative support; indexing time.

D2.1.1 Criteria for additional content

D2.1.2 Additional content

WP2.2 Free content

With advice from information providers and intermediaries, and building on the content-usage patterns from the pilots, criteria for free content will be developed. Appropriate web sites will be indexed and linked. Other content (e.g. leaflets) will be procured and made available as appropriate.

Resources required: project worker; administrative support; software developer time; document acquisition.

D2.2.1 Criteria for additional content

D2.2.2 Additional content

WP3 Additional access sites

A trial will be made in appropriate primary health care and clinical settings.

Resources required: document supply; project worker; administrative support time.

D3 Pilot in additional sites

WP4 Promotional materials

In the original project general promotional materials have been produced for the health care profession (see http://www.healthinfo4u.org.uk/html/bid_text.html, WP4). However research has indicated that in order to promote the quality-assured element of Healthinfo4u, additional materials need to be developed for general practitioners and consultants.

Resources required: publicity materials; project worker; administrative support time.

D4 Promotional materials

WP5 Dissemination

The original bid outlined a number of proposed dissemination opportunities (see http://www.healthinfo4u.org.uk/html/bid_text.html, section 3.6) within the health care sector. In addition it is proposed to contribute to any CPP dissemination events to share lessons learnt with a wider audience, and to pursue the possibilities of publishing a monograph centred on Healthinfo4u.

Resources required: project leader; project worker; administrative support; clerical time.

D5 Conference contributions and papers, and other publications as appropriate

8. Timetable

Month 15 Aug 2002	16	17	18	19	20	21	22 March 2003
WP1.1	WP1.1 WP1.2	WP1.1 WP1.2	WP1.1 WP1.2	WP1.1 WP1.2	WP1.2 D1.1	WP1.2	D1.2
	WP2.1	WP2.1 D2.1.1	WP2.2 D2.1.2	WP2.2	WP2.2 D2.2.1	WP2.2 D2.2.2	
		WP3 D3	WP3 D3	WP3 D3	WP3	D3	
		WP4	WP4	WP4 D4			
	WP5 D5	WP5	WP5	WP5	WP5 D5	WP5	WP5 D5

WP = Work Package D=Deliverable

The original project would end at Month 19. Additional funding will extend the duration of the project by three months. Some additional work will be undertaken in preceding months.

9. Committed and potential funding

The change in circumstances relating to the availability of full text access has resulted in a need to research complex economic models to secure sustainability as a combined electronic and document supply service that will respond to user needs in a variety of settings. Funding is required to develop economic models to prepare for medium and long-term sustainability.

Details of funding committed by the partners are given in §12 below.

In order to create the option to extend to national delivery an application will be submitted to the BUPA foundation this year. The national use of the site is envisaged to occur in various locations including: doctors' surgeries; health information points in the community; health information kiosks in supermarkets and chemists; community and day care centres. This wider use will enable further research into complex economic models for medium term sustainability as an electronic service.

10. Publicity and dissemination

10.1 Reports

There will be a report documenting the deliverables outlined in this bid.

10.2 Conferences

Suitable conferences will be sought to publicise the pilot project. In addition to conferences in both the library and health sectors outlined in the original bid, other opportunities will be targeted in partnership with the British Library.

10.3 National seminar

As outlined in the original bid, the NHS Library Advisor will host a national seminar at the Department of Health's London office to promote the potential of the service and the lessons learned.

10.4 Web site

The project will maintain the website <http://www.healthinfo4u.org.uk> where details of the project will be made available. In addition <http://www.healthinfo4u.org> will provide access to the demonstrator product.

10.5 E-mail lists and articles

Full reports will also be publicised through e-mail lists and articles will be submitted to relevant professional journals.

10.6 Final report

The final report will be published, presented to the British Library, and disseminated as outlined above. Consideration will be given to publishing a monograph centred on Healthinfo4u.

10.7 Publicity materials

Publicity materials will be designed to promote Healthinfo4u as a sustainable product.

11. Costs and contributions

As detailed in §7 above, there is a need for increased funding for: research worker time, administrative support, software development, indexing, document supply, document acquisition, travel and subsistence.

		Bournemouth University	British Library
Staff	Project Worker (3 month extension)		7,000
	Administrative support (inc. on-costs)	6,000	
	Document access software development	8,000	3,000
	Time of Project Leader	1,000	
Non-recurrent costs	Document supply to extend demonstrator phase		4,000
	Clerical assistance	500	
	Publicity materials		2,000
Recurrent costs	Contribution to postage/consumables	250	
	Library facilities and office space	500	
	Services and time from partners	750	
Travel and subsistence	Additional costs using standard BU rates: e.g. travel associated with additional access sites.		1,000
TOTALS		£17,000	£17,000

David Ball
28th June 2002

Appendix B Project Dissemination

Ball, D., Beard, J. 2002. *Healthinfo4u: repurposing quality-assured health information for the lay public*. A paper presented at Working successfully across sectors, NHS South West Workforce Development Confederations Knowledge Resources Development Unit, Bristol. 13 November, 2002.

Beard, J. 2001. *Quality Health Information for the lay public*. Proceedings of the Capital Planning Information Healthy Living seminar held at Stamford, Lincolnshire on 31st October 2001. Instant Library Limited.

Beard, J., de Vekey, J. 2002. *Healthinfo4u*. A report presented at the West Midlands and British Library Co-operation and Partnership Programme Showcase, Coventry. 24 October, 2002.

Beard, J., de Vekey, J. 2002. *Healthinfo4u: developing a clear path to quality health information*. The Beacon. Issue Two. October 2002. (Online) URL: <http://www.bournemouth.ac.uk/ihs/PDF/beacon2.pdf>. (Accessed 12 February 2003).

Beard, J., de Vekey, J. 2002. *The quality assurance of Healthinfo4u: a web-based Internet resource for the lay public*. A paper to be delivered at the 5th Northumbria International Conference on Performance Measurement in Libraries and Information Services, Durham. July 28th – 31st 2003.

Beard J. Lamki, J. 2001. *Together We Stand: a UK Library Partnership Experience*. A conference paper presented at the 9th Special Health & Law Libraries Conference, Melbourne Australia. August 28th 2001.

Beard, J., Madge, B. 2002. *Working with public libraries to enhance access to quality-assured health information for the lay public: a case study*. A paper presented at the HLG conference, Edinburgh. 15 July, 2002

Beard, J., Madge, B. 2002. *Working with public libraries to enhance access to quality-assured health information for the lay public: the interim report*. A paper presented at the EAHIL conference, Cologne. 16-20 September 2002.

Beard, J., Mclean, F. 2002. Offering access to professional health information via public libraries. *Health Information on the Internet*. April (26). (Online) URL: <http://mustafa.ingentaselect.com/vl=2623242/cl=45/nw=1/rpsv/cgibin/linker?ini=rsm&reqidx=/cw/rsm/14604140/v26n1/s7/p10>. (Accessed 12 February 2003).

The project had an exhibition stand at the Bournemouth Health Network Heart Health Network Day in Bournemouth in December 2002 and March 2003.

The project exhibited at the Centre for Health Information Quality (CHIQ) National Conference in London in January 2003 to promote improving the quality of patient information.

The project will present a paper entitled “The quality assurance of Healthinfo4u: a web-based Internet resource for the lay public” (Beard, J., and de Vekey, J., 2003) at *Library measures to fill the void:*

Appendix B

assessing outcomes, the 5th Northumbria International Conference. on Performance Measurement in Libraries and Information Centres, Durham, England, on 28-31 July 2003.

Appendix C Steering Group membership

Peter Baker (until April 2002)
Director
Men's Health Forum

David Ball – Project Leader; chair of Steering Group.
University Librarian
Bournemouth University
e-mail: dball@bournemouth.ac.uk

Jill Beard – Project Manager. Also represented the *British Nursing Index*.
Deputy University Librarian
Bournemouth University
e-mail: jbeard@bournemouth.ac.uk

Frank Black – represented the project demonstrator sites
District Information Services Manager
Chelmsford Library

Beverley Bowyer-Davies (replaced by Jane de Vekey in March 2002) – Project Researcher
Research Associate
Bournemouth University

Jackie Cahoon – represented the project Technical Group and Lippincott, Williams and Wilkins.
NHS Partnership Development Manager
Ovid Technologies

Ann Darnbrough (also represented by Derek Kinrade)
Director
National Information Forum

Katherine Darton
Information Officer
Information Unit
Mind

Brian Dolan
Emergency Care Nurse Consultant
Dolan & Hunt Consultancy Limited

Dr. Keith Donaldson – represented the Royal College of General Practitioners
General Practitioner

Veronica Fraser
NHS Library Advisor
NHS Information Policy unit

Nancy Gerry
International Journal Sales Manager
Blackwell Publishing

Shane Godbolt – attended via e-mail
Head of London Library & Information Development Unit
London Department of Postgraduate Medical and Dental Education

Sally Grant – Project Administrator
Academic Services Administrator
Bournemouth University
e-mail: sgrant@bournemouth.ac.uk

Vivienne Grier – represented NHS Direct
Librarian
Healthpoint
Poole Central Library

Tom Hain (also represented by Bronwyn Ward and Glenda Trevorrow)
Manager
Centre for Health Information Quality
The Help for Health Trust

Bruce Madge (also represented by Fiona McLean and replaced by Richard Wakeford in October 2002) – represented the British Library and the British Library *Allied and Complementary Medicine Database (AMED)*.
Head of Health Care Information Services
British Library

Katherine Murphy
Deputy Director of Press and Public Awareness
Patients Association

Margot Pinder
Development Manager, Information & Delivery Foundation for Integrated Medicine
Foundation for Integrated Medicine

Nick Rosen – represented the National Electronic Library for Health (NeLH)
Physiotherapist and NeLH Portal Developer

Linda Thomas (also represented by Phil Whomes)
Editor in Chief
RCN Publishing

Gordon Watson
Health Promotion Specialist (Communications)
Health Promotion Information & Resource Library
Durham Health Authority

Ruth Windsor (until March 2002)
Chief Executive
Caring Matters

Lucy Wood
Social Worker
Kings Park Community Hospital

Appendix D Project Board membership

All the following were members of the Project Board and individual sub-groups as indicated.

David Ball – Project Leader. Publishers Group.
University Librarian
Bournemouth University
e-mail: dball@bournemouth.ac.uk

Jill Beard – Project Manager. Chair of all project board groups.
Deputy University Librarian
Bournemouth University
e-mail: jbeard@bournemouth.ac.uk

Frank Black (also represented by Hilary Hames) – Demonstrator Site Planning Group.
District Information Services Manager
Chelmsford Library

Beverley Bowyer-Davies (replaced by Jane de Vekey in March 2002) – Project Researcher.
Attended all project board groups.
Research Associate
Bournemouth University

Jackie Cahoon (from January 2002) – Publishers Group; Technical Group.
NHS Partnership Development Manager
Ovid Technologies

Nancy Gerry – Publishers Group.
International Journal Sales Manager
Blackwell Publishing

John Gill – Demonstrator Site Planning Group; Technical Group.
Head of Library Services; *British Nursing Index* Executive.
Poole Hospital (NHS Trust)

Vivienne Grier – Demonstrator Site Planning Group.
Librarian
Healthpoint
Poole Central Library

Sally Grant – Project Administrator. Attended all project board meetings.
Academic Services Administrator
Bournemouth University
e-mail: sgrant@bournemouth.ac.uk

Allison Hartman (until January 2002) – Technical Group
Managing Director
Health Communications Network.

Sally Hernando – Demonstrator Site Planning Group; Partnership Group.
Knowledge Resource Development Unit
NHS South West Work Force Development Confederation

Jenny Lang – Partnership Group; Producers Group.
Head of Library Services; *British Nursing Index* Executive.
Salisbury Health Care NHS Trust.

Shelagh Levett (represented by Medi Bernard and Shirley Kersey) – Demonstrator Site Planning Group.
Head of Arts, Libraries and Museums Services
Bournemouth Borough Council

Jackie Lord (also represented by Kate Clark) – Producers Group; Publishers Group; Technical Group.
Head of Library and Information
Royal College of Nursing

Bruce Madge (replaced by Richard Wakeford in October 2002) - Producers Group; Technical Group.
Head of Health Care Information Services.
British Library

Pauline Dyer (represented by Linda Matthews) – Demonstrator Site Planning Group; Partnership Group.
Head of Libraries & Museums and Archives
Wiltshire Education and Libraries.

Linda Thomas – Publishers Group.
Editor in Chief
RCN Publishing

Appendix E First Cycle Evaluation Questionnaire

Demonstrator Site Evaluation of Prototype *Healthinfo4u*

Unique Trial identifier: _____ Interview Number: _____

Date: _____

Start time of interview: _____ End time of interview: _____

INTERVIEWEE RESPONSE

AGE GROUP:	MALE / FEMALE
Under 20 <input type="checkbox"/> 20 – 35 <input type="checkbox"/> 35 – 50 <input type="checkbox"/> 50 – 65 <input type="checkbox"/> 65+ <input type="checkbox"/>	
On first viewing the website what is your initial impression: Easy to Read: Y / N Easy to Use: Y / N Overall impression: Good / Fair / Poor	

Do you think the categories cover most popular subjects?	Top 12 Y / N Top 100+ Y / N
Which other category(ies) would you like to see included? _____	

Would you like to be able to search sub-categories?	Y / N

How many Search Results would you like to see?	1 only / 1-5 / 5-10 / more than 10
Would you like to see, say: 1, 5 or 10 Search Results with an option to see more?	Y / N
Would you like to be able to mark specific articles for looking at later?	Y / N

Would you prefer a combined search (rather than nurses/therapists)?	Y / N
Where the article is available online, would you: PRINT IT? / DOWNLOAD IT?	
Where the article is not available online, would you want a print copy?	Y / N
Would you be interested in receiving a copy of the full article?	Y / N

Following completion of the session, did you find the website:	
Easy to Read: Y / N Easy to Use: Y / N Overall impression: Good / Fair / Poor	

As part of this product, would you find access to an online Dictionary useful?	Y / N
Do you think you would use this product in the future?	Y / N
If so, would you be searching mostly for yourself / a relative / a friend / other ?	

Do you think you would search for specific, chronic conditions , or for general background information ?	

FIRST SEARCH

Question asked:	_____
Top 12 Category:	_____
Top 100+ Category:	_____
	[Researcher]
Free Text Search String:	_____
Comments:	_____
	[Search Expert]

SECOND SEARCH

Question asked:	_____
Top 12 Category:	_____
Top 100+ Category:	_____
	[Researcher]
Free Text Search String:	_____
Comments:	_____
	[Search Expert]

THIRD SEARCH

Question asked:	_____
Top 12 Category:	_____
Top 100+ Category:	_____
	[Researcher]
Free Text Search String:	_____
Comments:	_____
	[Search Expert]

Appendix F Second and third cycle self-administered and mediated evaluation questionnaire: completed after using the website.

WHAT DO YOU THINK OF *HEALTHINFO4U*?

What do we want to find out from you?

Your opinions so that we can develop our product HealthInfo4U to meet your needs. In order to understand your needs there are some questions about you, how you look for health information and what you think about the product.

Who are we?

Eleven organisations brought together into a partnership to research public access to quality assured health information. We have developed a pilot website called HealthInfo4U which provides access to articles from health care journals (magazines). Pilot trials are taking place in libraries from the partnership in Dorset, Essex and Wiltshire. Fifty percent of the funding has come from our national library, The British Library, and fifty percent from the partners, who include the [British Nursing Index \(BNI\)](#), the [Allied and Contemporary Medicine Database \(AMED\)](#), the database company Ovid Technologies Ltd, and publishers Blackwells and Royal College of Nursing Publications. For more information see the project website:

www.healthinfo4u.org.uk

How long will it take?

The questionnaire is in 3 parts and should take approximately 25 minutes.

*You are free to use HealthInfo4U for as long as you like and to come back again. All we ask is that on the first occasion you complete all the questions, and if you come back again please just complete questions **C2 to 4**.*

HealthInfo4U Questionnaire

A: General information about you

1. How did you find out about the *HealthInfo4U* demonstration study? *(Please tick all that apply)*

- e-mail bulletin
- local library
- project website
- took part in earlier trials
- word of mouth
- other
-

2. Where do you go for health information? *(Please tick all that apply)*

- chemist
- doctors surgery
- family or friends
- support groups or societies
- hospital
- library
- local council offices

- NHS Direct (24hr telephone service 0845 4647)
- websites
- other (please give details):

3. Age Group (Please tick the age group that applies to you)

- Under 15 15 - 20 21 – 35 36 – 50 51 – 65
 66 - 75 76 +

4. Gender : male female

5. Is English your first language: yes no

6. What was the highest level of education or training you have taken part in? (Please tick)

- secondary schooling
- further education (not degree level)
- higher education (degree, higher diploma)
- apprenticeships or trade qualification
- other

7. Ethnic Origin (Please tick)

Note: This question is **optional** for monitoring use only. The information is anonymous. Any reports using this information will give statistics in which individuals will not be identifiable.

- Asian- other
- Bangladeshi
- Black-African
- Black-Caribbean
- Black- other
- Chinese
- Indian
- Pakistani
- White British
- White Irish
- any other White European background
- any other ethnic group: please specify:

.....

8. Are you registered disabled or disabled under the terms of the 1995 Disability Discrimination Act?

- yes no

9. If **yes**, what type of disability do or did you have (please tick all that apply)

- Asthma
- Blind/partially sighted
- Deaf/hard of hearing
- Diabetes
- Dyslexia
- Epilepsy
- Mental health difficulties
- wheelchair user
- other mobility problem
- other disability. Please specify

.....

10. If you have a visual impairment

(Please tick the word that best describes how readable overall the site is for you)

excellent very good good fair inadequate poor

11. Do you ever have anyone dependent on you for his or her care? **yes**

no

12. If **yes** please tick all that apply.

pre-school child

school age child

adult

elderly person

B: Background Knowledge

1. What level do you consider your health knowledge to be? *(Please tick the word that applies the most)*
 excellent very good good fair inadequate poor

2. Which of these reasons might lead you to seek health information? *(please tick all that apply)*
 after a diagnosis I never seek health information prevent illness
 broaden knowledge manage an illness professional development
 find out information for someone prepare for an appointment studying health
 other (please give details):

3. Do you study or do paid or voluntary work in the health sector? *(If yes, please tick closest job or main activity you do)*
 doctor chiropractor
 nurse osteopath
 midwife other complementary medicine professional
 other health care professional other job in complementary medicine sector
 other job in the health care sector student in complementary medicine
 student in conventional health care

4. Do you study or do paid or voluntary work in the information industry? *(If yes, please tick closest job or main activity you do)*
 information science student software engineer
 IT student web design
 librarian or information scientist other job in information industry

5. How do you rate your web searching skills? *(Please tick)*
 excellent very good good fair inadequate poor

6. Do you use the Internet for any of the following *(Please tick all that apply)*
 looking up information
 shopping, banking or booking holidays
 TV websites e.g. BBC

7. Do you use e-mail? yes no

8. Have you used any of the following websites on health? *(Please tick all those you have used)*
 BBC Health (www.bbc.co.uk/health)
 BUPA (www.bupa.co.uk)
 Local Health Authority Website (which include these sites) →
 National Electronic Library for Health (NeLH) (www.nelh.nhs.uk/)
 NHS Direct Online (www.nhsdirect.nhs.uk)
 PPP Healthcare (www.ppphealthcare.co.uk)
 Tesco's healthy living ([www.tesco.com/healthy living](http://www.tesco.com/healthy_living))
 Wellbeing.com (part of Boots Plc)
 have never used websites for health information
 other websites for health information but not on this list

DORSET = HealthinfoDorset
www.dorset.swest.nhs.uk/healthinfo/index.htm
WILTSHIRE = healthyWiltshire
www.healthywiltshire.org.uk
ESSEX = North or South Essex Health Authority www.southessex.nhs.uk
or http://www.ne-ha.nthames.nhs.uk/asp/neh_home.asp
or SEAMLESS (www.seamless.org.uk)

C: What do you think about *HealthInfo4u*? (www.healthinfo4u.org)

1. On first viewing the website rate your impression (
- Please tick the word that most applies*
-)

	excellent	very good	good	fair	inadequate	poor
Product name						
Product logo						
Easy to read						
Easy to use						
Overall impression						

2. Please think of a health topic you want to look up and write it down

If you wish to search more than once, please pick up another questionnaire and complete section C2 to 4

3. Can you find the topic on the website? yes no
If **yes**, select the item and a range of articles on that topic should appear (the search results), go to **question 5**.
4. If **no**, can you find any useful information on your topic using another word? yes no
If still **no** go to **question 12**, if **yes** go to **question 5**.
5. If there are a lot of results, how many would you like displayed on the page before an option to see more?
 up to 5 up to 10 up to 20 up to 30 up to 40
 up to 50 over 50
6. Out of the search results, how many articles do you think you would like to read?
 0 1 - 5 6 - 10 10 - 20 20 - 50
 50+
7. The most recent articles are shown first. Do you think this a good way to show results? yes no
8. If **no**, how would you like to see results shown? (*Please tick your first choice*)
 in order by author
 by magazine title (source)
 by difficulty of the article
 other (please specify):
.....

9. Did you like the feature of being able to mark articles you want to obtain?
-
- yes
-
- no

Click on "VIEW" or "ORDER" boxes

10. Where the article is available for you to see on screen, would you prefer to:-
 Print it
 Read it on the screen
 Save it to disk

11. If the article is not available on screen but a printed copy can be sent to you, would you consider this?

yes no

If **yes**, please click on "ORDER" and complete form at bottom of list of articles.

12. Instead of searching by choosing a topic, would you prefer to type yourself and press a search key?

yes no

13. Did you think the "hot topics" – MMR and ACUPUNTURE - are a good idea? yes no

14. Would you like the site to have an online encyclopaedia or medical dictionary? yes no

15. If English is not your first language, would it help if the website were in different languages, even though the final articles will always be in English? yes no

16. Please rate the site now you have browsed it (*tick the word that most applies to each feature*)

	excellent	very good	good	fair	inadequate	poor
product name						
product logo						
ease to read						
ease to use						
overall impression						

17. What words best describe *HealthInfo4u* for you (*Please tick all that apply*)

<input type="checkbox"/> a good idea	<input type="checkbox"/> looks exciting but you can't take the information away
<input type="checkbox"/> a mine of information	<input type="checkbox"/> needs a bit of work but a good idea
<input type="checkbox"/> a place for diet and exercise advice	<input type="checkbox"/> needs a lot of work, but a good idea
<input type="checkbox"/> a promising product	<input type="checkbox"/> somewhere to get the latest research
<input type="checkbox"/> a way to get information I couldn't get elsewhere	<input type="checkbox"/> somewhere to look for information about syndromes
<input type="checkbox"/> confusing	<input type="checkbox"/> too detailed information for me
<input type="checkbox"/> difficult to find out what I want	<input type="checkbox"/> too difficult to use
<input type="checkbox"/> educational	<input type="checkbox"/> useful for anyone interested in health
<input type="checkbox"/> gives specific health information	<input type="checkbox"/> useful for anyone studying health care or medicine
<input type="checkbox"/> good for general health knowledge	<input type="checkbox"/> useful for school projects
<input type="checkbox"/> I don't like it	<input type="checkbox"/> useful information about disorders
<input type="checkbox"/> I was surprised by what I could find	<input type="checkbox"/> useless

18. Please give **any other comments** about *HealthInfo4u*:

19. Would you use the product in the future? *(Please tick)* yes no not sure

20. If you were to use the product again, where might you be likely to go? *(Please tick all that apply)*

- cyber café
- doctor's surgery
- high street chemist
- home
- hospital
- public library
- school or college
- supermarket
- work
- other (please list):

.....

Thank you for taking part. Please fill in the next page to **enter our book token prize draw**.

Please hand your completed questionnaire in at the library desk.

<u>FOR OFFICE USE ONLY</u>	British Library Co-operation and Partnership Programme Evaluation Stage II & III
Location:	Interview Number:
Date Returned:	Independent/ Mediated <input type="checkbox"/> C2 - 4 only

Please enter my name in the Prize Draw:

Name:

Tel. No:

E-mail address:

We will be holding local FOCUS GROUPS towards the end of April and beginning of May to look further the usefulness of HealthInfo4U. If you would like to take part in one of these, please indicate your preferred time by circling the box below.

I would prefer to come to a FOCUS GROUP in the :

- Morning**
- Afternoon**
- Evening**

You will receive an invitation to a FOCUS GROUP in your area approximately one week before it is held.

Thank you for completing the questionnaire. Please hand this sheet in separately to the library desk.

Appendix G Second and third cycle self-administered follow-up evaluation questionnaire: completed after receipt of articles.

What do you think of *HealthInfo4U*: The Information Found

Thank you for taking part in the second stage of our survey. Now you have read your article(s) please complete the questions below. Please return the completed questionnaire(s) in the Stamped Addressed Envelope provided.

1. What was the topic you researched?

.....

2. What was the name of the article obtained?

Author:

Title:

Magazine:

3. How did you obtain the information? (*Please tick all that apply*)

- printed it from the *HealthInfo4U* website read it on the screen post

4. How long would you be prepared to wait for similar information in the future? (*Please tick all that apply*)

- prefer to read on screen not prepared to wait prepared to wait for postal delivery of 0 - 7 days
 7 - 14 days
 14 - 21 days

5. Please rank how useful the article has been to you? (*Please tick the word that most applies*)

- indispensable valuable significant
 helpful of some use of no use

6. What did you use the information for? (*Please tick all that apply*)

- after a diagnosis manage an illness professional development
 broaden knowledge prepare for an appointment studying health
 find out information for someone else prevent illness other (please give details):
.....

7. To what extent has the information received from *HealthInfo4U* satisfied your expectations? *(Please tick)*

- exceeded completely mainly fairly partly not at all

8. How would you rate the article in terms of difficulty to read (medical jargon)? *(Please tick the most appropriate phrase)*

- Advanced- for professionals only**
 difficult- but good for someone who knows a lot about the subject
 moderate- some medical terms but understandable
 easy - for anyone

9. What words best describe *HealthInfo4U* for you? *(Please tick all that apply)*

- | | |
|--|---|
| <input type="checkbox"/> a good idea | <input type="checkbox"/> looks exciting but you can't take the information away |
| <input type="checkbox"/> a mine of information | <input type="checkbox"/> needs a bit of work but a good idea |
| <input type="checkbox"/> a place for diet and exercise advice | <input type="checkbox"/> needs a lot of work, but a good idea |
| <input type="checkbox"/> a promising product | <input type="checkbox"/> somewhere to get the latest research |
| <input type="checkbox"/> a way to get information I couldn't get elsewhere | <input type="checkbox"/> somewhere to look for information about syndromes |
| <input type="checkbox"/> confusing | <input type="checkbox"/> too detailed information for me |
| <input type="checkbox"/> difficult to find out what I want | <input type="checkbox"/> too difficult to use |
| <input type="checkbox"/> educational | <input type="checkbox"/> useful for anyone interested in health |
| <input type="checkbox"/> gives specific health information | <input type="checkbox"/> useful for anyone studying health care or medicine |
| <input type="checkbox"/> good for general health knowledge | <input type="checkbox"/> useful for school projects |
| <input type="checkbox"/> I don't like it | <input type="checkbox"/> useful information about disorders |
| <input type="checkbox"/> I was surprised by what I could find | <input type="checkbox"/> useless |

10. Would you use the product in the future? *(Please tick)* yes no not sure

11. Please add any other comments you have about the information you have read overleaf .

FOR OFFICE USE ONLY

Date Returned:

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WEB RESOURCES

BBC Health website <http://www.bbc.co.uk/health/>

British Heart Foundation website <http://www.bhf.org.uk/>

Budapest Open Access Initiative website <http://www.osi.hu>

CancerBACUP website <http://www.cancerbacup.org.uk/info/index.htm>

CHIQ website <http://www.hfht.org/chiq/index.htm>

Health Canada website <http://www.hc-sc.gc.ca/english/index.html>

HiQuality website http://www.hiquality.org.uk/producers_guidelines.htm

NeLH website <http://www.nelh.nhs.uk/>

NHS Direct Online website <http://www.nhsdirect.nhs.uk/index.asp>

Open Society Institute website <http://www.soros.org/index.html>

Glossary

AMED	<i>Allied and Complementary Medicine Database</i>
BL	British Library
BLDSC	British Library Document Supply Centre
BNI	<i>British Nursing Index</i>
BOAI	Budapest Open Access Initiative
CEC	Commission of the European Communities
CHIQ	Centre for Health Information Quality
CICAC	Congressional Internet Caucus Advisory Committee
CSU	California State Universities
DOH	Department of Health
HCN	Health Communication Network
HE	Higher Education
IPR	Intellectual Property Rights
LA	Local Authority
MA	Managing Agent
NeLH	National Electronic Library for Health
NESLI	National Electronic Site Licence Initiative
NHS	National Health Service
NSFs	National Service Frameworks
ONS	Office for National Statistics
OSI	Open Society Institute
PALS	Patient Advice and Liaison Service
PDF	Portable Document Format
PEAK	Pricing Electronic Access to Knowledge
RCN	Royal College of Nursing
Action research	A collection of participative and qualitative and/or quantitative research methodologies to simultaneously pursue action (change) and research (understanding) in order to achieve practical change. The process is emergent and iterative, involving cycles of action and critical reflection.
ARTWeb	Document supply service provided by the British Library where customers complete article orders online and receive the documents by post.
Expert Patients Programme	An initiative developed by the DOH to help people living with long-term health conditions to maintain their health and improve their quality of life through self-management courses led by lay people.
HTML	Hypertext Markup Language, the scripting language used to define the content and appearance of a web page.

Glossary

IP address	Unique numerical identifier given to each Internet connection that enables data from a web site to be displayed on a personal computer.
Perl script	A script programming language.
SPSS	Computer software package that analyses data and produces statistics, presenting them in a variety of outputs.
Triangulation	The employment of more than one research and/or data collection method to investigate the research question(s). Triangulation is used to balance the relative strengths and weaknesses of each research and data collection method in order to generate increased confidence in the meaningfulness of the research results.