

## The Accessibility of Computer-based Health Information for Patients: Kiosks and the Web

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### Abstract

*The Internet is a rich source of health information but it is not as accessible as many claim. This paper brings together three projects to illustrate technical and cost barriers and some options to overcome them. (1) A survey amongst a representative sample of 180 patients in rural Spain showed a marked age gradient in computer access. None over the age of 50 had, and less than 10% planned, access to the Internet whereas a quarter were prepared to use health centre based touchscreen kiosks. (2) Half the commonly used search engines did not include the two most relevant websites for Glasgow colorectal cancer patients in the first ten documents listed, showing the difficulty facing patients in finding relevant information. Selection of information would help patients avoid being overwhelmed with information. (3) One method to improve accessibility is to download websites to kiosks but two projects showed that considerable work is required to reformat the information. Public access computing, such as kiosks, could help make the Internet more accessible. We discuss whether Web sites which structure their information according to method of access, place and person provide a way forward.*

### Keywords:

Consumer health informatics; World Wide Web; Health information kiosks; Access.

### Introduction

The Internet is emerging as a rich source of health information for patients but the accessibility to non-American populations is often overstated. We need to take positive steps to ensure that under-served populations, with limited access to technology and limited computing skills, do not become "information have-nots"<sup>1</sup>. One method which attempts to give wider access is the use of health information kiosks<sup>2-11</sup>. Three Glasgow medical student studies are presented here which illustrate (a) whether this is likely to provide greater access, (b) the work involved in

converting web pages for touchscreen use, and (c) the issues which need to be addressed in further development of health information on the Internet.

### Study 1. Attitudes to patients' use of computers for health information in rural Spain.

The aim of this study by Fay Balfour (FB), was to examine the levels of use, and attitudes to further use, of computers by patients to obtain health information. Interviews with patients and clinicians were conducted in a General Hospital and a primary care health centre both in the City of Segovia, and in a village health centre in Carbonero El Mayor in central rural Spain. Interviews were then conducted with Primary Care Health Service managers.

### Methods

A quota sample of 180 patients was recruited from waiting areas. Patients comprised 10 from each of 18 groups: 3 age groups (<30, 30-50, >50), 2 genders (M,F), 3 locations. The face to face interview was supplemented with text and photographs to inform the subject about a touchscreen kiosk, Infosalud<sup>11</sup>, and the possibilities of using it and other computers to acquire health information. Throughout the 'mini-presentation' the subject was asked to comment and give opinions, mainly using closed questions.

Fifteen doctors and nurses comprised an opportunistic sample of clinicians from each of the three locations. They were presented with similar information to the patients but asked open-ended questions about this approach to providing information. After all the interviews had been conducted, the results were summarised to the Primary Care Health Service Managers for Segovia Province. After a short presentation, the results were discussed and managers' views noted.

## Results

### *Sources of health information.*

The most frequent source of health information in the past three weeks was family and friends followed by a doctor or nurse (Table 1). However, this overall result hides age-gender differences: only 5 out of 30 males under 30 had consulted family or friends compared to 23 out of 30 women aged over 50, and 18 out of 30 males under 30 had obtained information from newspapers or magazines but only 10 women over 50 had done so. Patients in the two town locations had obtained more health information from all sources compared to those in the village.

### *Current use of technology*

Nearly one in five had a computer at home or at work and for 12% the computer was connected to the Internet (Table 2). However, although there was no difference between males and females, there was a big 'age-gradient' in computer use. Only two people over the age of 50 had a computer at home or at work and neither had access to the Internet while 42% of the under 30s had Internet access. The age-gradient was also seen with the more common technology of ATM ('Cash-machine'). There was also a difference between both current and future intentions to use computers between town and village with nearly half those in the town hoping to have Internet access compared to only 16% in the village.

### *Use of a touchscreen kiosk*

When shown a picture of a touchscreen kiosk and asked if they would be willing to use it on site (i.e. health centre or

hospital) or elsewhere (e.g. pharmacy or public library), age and gender differences were smaller (Table 2). For example, although only 7% (95%CI: 1-13%) over the age of 50 thought they may have home access to the Internet, 38% (95%CI: 26-50%) would be willing to use a touchscreen kiosk. Patients in the village remained more reluctant to use such technology compared to those in the town.

### *Clinicians' views*

Ten out of 15 thought that less than half their patients would be capable of using a touchscreen kiosk and all thought that older patients would be less interested and less capable of using it compared to younger patients. All thought that touchscreen kiosks had potential for patient education but expressed concerns that complicated information might confuse older and less-educated patients leading to problems such as wrong self-diagnosis and self-medication.

### *Health Service Managers*

Health service managers were sceptical that kiosks could be useful in improving the level of patient education amongst the population of Segovia, particularly in the villages. They highlighted the ageing population, noted that formal teaching of information technology in schools had only been implemented within the last 5 years, and that, consumer health information was not advanced with few facilities such as telephone help-lines or self-help groups. Support for patients normally came from the family and support networks for patients and families were not run by the public or health services, but by the church. The health service had not become integrated with this service.

*Table 1 - Current sources of health information for patients in Segovia showing differences by age and gender and by location*

Source	M <30	M 30-50	M >50	F <30	F 30-50	F >50		City	Village	ALL
Doctor or nurse	9	10	18	16	20	22		68 (57%)	27 (45%)	95 (53%)
Family or friends	5	14	19	23	22	23		74 (62%)	32 (53%)	106 (59%)
TV or radio	13	11	14	14	21	17		61 (51%)	29 (48%)	90 (50%)
Newspapers or magazines	18	21	11	17	14	10		66 (55%)	24 (40%)	91 (51%)
Books or leaflets	16	9	9	8	9	10		44 (37%)	17 (28%)	61 (34%)
Number of respondents	30	30	30	30	30	30		120	60	180

*Table 2. Current and future technology use amongst patients in Segovia by age and location*

Current use	<30	30-50	>50		City	Village	ALL
Computer use	33	22	2		46 (38%)	11 (18%)	57 (32%)
ATM use	49	37	16		78 (65%)	24 (40%)	102 (57%)
Internet use	25	11	0		29 (24%)	7 (12%)	36 (20%)
Future use							
Internet at home in future	38	23	4		55 (46%)	10 (16%)	65 (36%)
Willing to use kiosk on site	37	39	23		77 (64%)	22 (37%)	99 (55%)
Willing to use kiosk elsewhere	32	22	15		57 (48%)	12 (20%)	69 (38%)
Number of respondents	60	60	60		120	60	180

## Study 2. Information for colorectal cancer patients

This study aimed to identify suitable sites for patients with colorectal cancer and to convert one for use on a touch screen computer.

### Identification of suitable sites

Michelle Gillies (MG) searched the Web using the term “colorectal cancer” between November 1998 and January 1999 and identified 49,707 indexed web pages of which 292 were recorded and reviewed. After duplicates were removed there were 126 independent sites of which 10 (8%) were categorised as patient information resources. Two local community general health resources were excluded, leaving a total of eight oncology specific patient information sites (Table 3), of which 3 were produced and maintained in Britain, and 5 in USA.

### Evaluation Tools

A search of the Web in early 1999 identified 48 documents with criteria for evaluating web sites. Based on these a 16-item evaluation instrument was developed for use in this study<sup>10</sup>. Using this tool a value of between 1 (poor) to 5 (excellent) was assigned to each site. An early version (not specifically Internet version) of DISCERN<sup>11</sup> was also used. The DISCERN score and the Internet specific evaluation were in agreement for five of the eight sites (Table 3).

Table 3. Eight sites suitable for patients with colon cancer showing local and DISCERN rating.

Website	origin	Local rating	DISCERN
American Cancer Soc.	US	3	3
CancerBACUP	UK	5	5
Cancerguide	US	5	3
CancerHelp UK	UK	5	5
CancerNet	US	4	5
Cancerweb	UK	3	3
Colorectal Cancer	US	1	1
Oncolink	US	4	5

Only two sites CancerHelpUK and CancerBACUP were ‘shortlisted’ as being of good quality (DISCERN) and suitable for use by a Glasgow population (local rating). These were not identified in the first five sites retrieved by four of the eight commonly used search engines. CancerBACUP site was reported in the first ten document retrieved by just one of the eight search engines. These results highlight the challenge faced by patients in identifying relevant information sites, given the enormous volume of information available online. The site owners for CancerHelp UK were approached and permission sought, and granted, to redevelop for use in this study.

### System Development

Part of the Cancerhelp UK site was redeveloped for use on a touchscreen using Microsoft FrontPage 98. Information specific to colorectal cancer was supplemented with general

cancer information from the website. In some places this required a restructuring of the information provided. All scroll bars were removed and the information divided into smaller manageable sections, which would fit onto one screen. This was achieved by cutting and pasting sections of the imported web pages onto new screens. Considerable editing was required to remove external and redundant internal hyperlinks, and to add new hyperlinks to facilitate the restructuring described. Hypertext links with annotations to explain difficult concepts were included. The content of the information was in no way altered or edited. The system ran on Netscape Navigator 32 in kiosk mode in which all browser navigation bars and buttons are concealed. The main menu had seven options and the completed system consisted of around 800 screens. The system took approximately one month to develop for local use. Much of this time was spent identifying which information from the web site was to be included in the system. Since redevelopment, the information contained on the web site has been updated and changes would need to be made to the touchscreen version. The process will become simpler as more advanced editing packages become available but still requires a commitment to make those changes. Since completing this small study, CancerBACUP have produced a CD-ROM version of their web site and this is one way of providing greater access to the WWW.

## Study 3. Redevelopment of HEBSWEB for a touchscreen kiosk

This project aimed to make available part of the Health Education Board for Scotland’s website (HEBSWEB<sup>14</sup>) on a touchscreen kiosk in a community setting. The idea came from a community group (Clydebank Health Issues Group) who provided the kiosk. Work started in August 1999.

The system was developed on a standard multimedia Windows 98 machine with a 17" touchscreen monitor. Pages were constructed in HTML and included sound and video. They were displayed using Internet Explorer 5.0 running in kiosk mode. The topics covered included heart disease, cancer, stroke, mental health, HIV and sexual health, oral health, accidents and safety, smoking, diet, physical activity, alcohol and drug misuse. Each topic was composed of a sequence of between one and thirty pages. Users navigated through the pages via simple buttons along the bottom of the screen. The system was designed to return to the introductory screen automatically after three minutes of inactivity. This cycled through a series of pages containing videos from some HEBS advertisements.

The format in which the information was presented on the HEBSWEB site did not lend itself to easy conversion into the single pages required for the kiosk. The whole site was downloaded to hard disk and the text from individual pages copied and pasted into the HTML editor being used to construct the kiosk pages. A variety of editors was used – Microsoft FrontPage Express, Microsoft Word and Adobe PageMill. Around 50 hours were spent constructing the topic pages and an additional 5 in developing and testing the menu shell and video carousel. The first version of the

system was installed at the end of September 1999. A substantial update was produced in September 2000 to improve access for people with poor vision.

## Discussion

FB's study in rural Spain showed that public touchscreen kiosks might reach over a third of the over 50s whereas less than 10% were likely to have home Internet access. Family and friends are always likely to remain the most common form of health information. The impact of the Internet on the provision of health information needs to be kept in this perspective and informaticians need to consider equity of access. Other studies show the gradients in computer use that you would expect from USA to Europe, from young to old, and increasing use over time. A recent large US telephone survey<sup>1</sup> (although it could be criticised for its low response rate (51%)) found 92% of those under 60 had used a computer compared to 46% over 60. This contrasts with 32% of gastroenterology outpatients in 1996<sup>13</sup>, 32% of cancer patients in 1997<sup>14</sup>, and 59% of patients treated for anxiety in 1999<sup>15</sup> in Glasgow. Outwith Western countries, Internet access is further reduced. South Asia with 23% of the world's people has less than 1% of the Internet users.<sup>17</sup> Many media claims of Internet access use incorrect arithmetic and unreliable indicators such as web-counts and crude population figures. The only true estimates of Internet access come from surveys in well-defined populations.

MG's cancer study illustrates how difficult it can be to find relevant information about a particular topic. It is not enough for information to be rated highly by independent assessors, or even by 'objective' evaluation tools (HON<sup>18</sup>, DISCERN<sup>11</sup> etc). (In this paper we have not touched on the difficulties and limitations of such tools<sup>19-20</sup>). Patients need more than true, well presented evidence-based information. They need information appropriate for their cultural, geographical and personal situation. For example, in another recent study<sup>14</sup> we found that patients given information specific to their individual situation were more likely to say they had learned something, to think the information relevant, to use the computer again, to show the computer print-out to others. They also showed more improvement in anxiety than those with access just to general information.

Most 'English' language health web sites originate in the USA and carry cultural, economic and geographic assumptions which may not hold elsewhere. For example, the Medical Library Association (of USA) lists various sites as 'particularly useful'.<sup>21</sup> However, most have 'embedded' assumptions about a US population. For example, we asked a nutritionist and dietician to review two of these sites AMA Health Website and NOAH for their suitability for a Glasgow population. They commented

*'[AMA].... had plenty of nutrition information. Much of this was a little too complicated and 'high-brow' for your average Glaswegian. Perhaps this reflects the greater interest that middle-class America may take in its health*

*generally and the higher level of base-line knowledge. Some translation might be necessary for use here. Good use was made nevertheless of simpler tools and explanations such as the 'food pyramid' which gets its message across immediately. [NOAH]... much would mean little to many folk over here and would require further explanation.....Both sites lack immediate relevance to Glaswegians. This may be largely due to the cultural differences between the US and here. Health and nutritional recommendations and guidelines differ in America, so for example recommended daily intakes of vitamins and minerals as well as main dietary constituents have less relevance outwith the US. We had not heard of some of the foodstuffs that were mentioned on both websites.'*

There is a conflict between the need to involve the users in designing systems (ensuring that the information provided is appropriate<sup>22-23</sup>), and the need to be more efficient in the development of sites (if possible re-using information rather than re-inventing it). Patient information will be of limited use if aimed at a particular audience or a particular mode of delivery such as by desktop PC to website. We need information sources that are accurate and evidence based, but which can be adapted to different contexts. MG's and DS's conversion of web sites for use on touch screens showed that even the simplest kind of adaptation (for touch screen kiosks) currently requires a fair bit of work making web sites 'paginated' removing the need for scroll bars, having suitable sized text and buttons, and removing links which could not be reproduced on a stand-alone machine. Adapting to geographical or cultural context requires more.

We would recommend that web site developers at least think of possible users on other devices, in particular touch screen kiosks. But for the future we need patient information to be represented in such a way that information can be presented differently according to: (a) what device is being used (desktop, touchscreen, WAP, TV, etc); (b) which country/language is required; (c) which part of the country; (d) the personal characteristics of the user. The web site will then tailor the information to that user. The technology to enable this is now becoming available. In other applications, web site providers are motivated by the increased use of small mobile devices (e.g., WAP phones) to set up their systems in such a way that the information is presented differently according to the device being used. Experimental travel information systems have been developed that also adapt information according to the user's location, and even the current weather<sup>24</sup>. Use of XML (and also database) technology allows information to be represented independent of presentation, with different presentation styles and content selection rules available.

For healthcare information the challenge now is how to exploit these technologies while retaining assurance of quality of the resulting information. A database (or XML file) may contain accurate and complete information, but once information is selected from that source, and presented in a particular way, the result may be misleading. There are

no simple solutions, and the problem of equity of access, and providing information relevant and accessible to all populations will remain a major challenge for some years.

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