

**Where do the visually impaired in Oregon go to retrieve health
information?**

Comparison of the experiences/opinions of visually impaired Internet and
non-Internet users within rural and suburban/urban Oregon

by

Julian Lipscombe, MSc, BSc (Hons), BS

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CERTIFICATE OF APPROVAL

This is to certify that the Master's Thesis of

Julian Lipscombe

has been approved

Mentor/Advisor

Member

Member

School of Medicine
Oregon Health & Science University

Certificate of Approval

This is to certify that the Master's Thesis of

Julian Lipscombe

“Where Do The Visually Impaired in Oregon Go To Receive Health Information? Comparison of the Experiences/Opinions of Visually Impaired Internet and Non-Internet Users Within Rural and Suburban/Urban Oregon”

Has been approved

[Redacted Signature]

Holly Jimison, PhD

[Redacted Signature]

Thesis Member – Richard Appleyard, PhD

[Redacted Signature]

Thesis Member – Winslow Parker

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The inspiration for this project came from a chance observation in the center of Portland with an unknown pedestrian who was out with his guide dog. As she prepared to cross SW 4th Street, I wondered how the guide dog knew when there was no traffic coming and it was safe for them to both cross the road. Thinking about this observation later, I quickly came to the shocking realization (to me anyway) that I was completely ignorant of the experiences of people with forms of visual impairment and how they lived their lives in relation to my normal sighted existence. Therefore, armed to overcome my lack of knowledge in this area, I endeavored to try to perform a study for my Thesis that provided some answers to fill these glaring gaps in my knowledge. Following much iteration and changes throughout the process of the Thesis, I am happy to present my findings within this document and to claim that I am not completely ignorant of the experiences of people with visual impairment now, just mostly ignorant.

There are many people that I would like to thank regarding the completion of this study and can state that it definitely would not have been completed without their input and support. Firstly, I would like to thank the members of my Thesis Committee: Richard Appleyard, my thesis advisor and general bandit around the golfing greens, who was invaluable in pushing me in the right direction during the embryonic stages of the study – may you never lose that English part of your accent; Holly Jimison, who plowed many hours into the production of the study as it wended its way through the potential minefields of ethics committee, I not only enjoyed talking and conferring with you about this and other subjects, but thoroughly enjoyed all of the modules that I took with you; and, Winslow Parker, who through his employment at the Oregon Commission for the Blind was invaluable with his input into the structure of the study and locating volunteers for the suburban/urban side of the project.

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ABSTRACT

As the amount of health information on the Internet and its increased availability grows at a rapid rate, it is important to ensure that all groups within society have access to and make use of this growing resource. This increase in health information online has been mirrored by the increasing use of this resource in addition to more traditional methods of retrieving health information. This phenomenon has been noted by many reported studies and reports. However, how frequently this resource has been used by people with visual impairment and their experiences when using the Internet and when searching for health information online has not been previously reported. This research sought to remedy this gap in knowledge and detail the experiences of searching for health information by people with the visual impairment within the state of Oregon.

Twenty-eight semi-structured interviews were performed with individuals with some form of visual impairment between May and August 2006. Fourteen of the interviews were performed on individuals living in areas classified as suburban/urban areas and the other fourteen on individuals living in rural areas. The interviews were performed with the intention of determining how people with visual impairment currently obtain their health information, whether they feel their health education needs are being met by the information on the Internet, what type of information they seek on the Internet and what websites they access, whether they feel this information is accessible to them and what barriers and obstacles they encounter, and identifying any variations between the Internet health information use and characteristics of rural participants compared to suburban/urban participants.

The results from the study showed that the respondents within the study were using the Internet as a resource for health information at a rate that is comparable with previous research on the general population. This result underlines how valuable and empowering a resource the Internet can be for people with visual impairment. This was demonstrated within the study as the respondents reported on the amount of printed health information they had been previously given and how frustrating it had been for the participants. The Internet, while certainly not perfect, was shown to potentially provide the freedom for people with visual impairment to access identical health resources to the rest of the population which should be the aim of any country.

The main barrier noted by the respondents was that of inaccessible websites. This is a major problem as certain types of websites and formats used within websites make navigation and use of a screen reader, at best frustrating and time-consuming, and at worst impossible. There is governance currently within the United States concerned with the accessibility of websites for people with disabilities, but unfortunately this is only currently enforced on companies with government contracts. The solution to the problem would be to enforce this governance on all health websites which purport to give out health information, although this solution is unlikely to happen in the near future.

INTRODUCTION

From the initial stages of discussion regarding the possible aims of a project examining the health information needs and experiences of people with visual impairment, there were a number of areas and previous research into health information seeking practices on the Internet, but none of these studies had looked specifically at only a sample of people with visual impairment. Therefore, this study looked to examine the health information practices of people with visual impairment, and to identify their experiences and any barriers or obstacles they had had when searching for health information online or when using computers within the state of Oregon. The study was then solidified into attempting to address the following three main aims –

1. Determine where and how people with visual impairment in Oregon currently retrieve and receive their health information.
2. What are the experiences of people with visual impairment when they search for health information on the Internet?
3. What barriers/obstacles are people with visual impairment experiencing when accessing the Internet or using computers?

BACKGROUND

As the Internet becomes more widespread and accessible, the number of people searching online for health information has increased exponentially. A recent report of the Pew Internet & American Life Project reported that seventy-nine percent of Internet users had searched for information on at least one major health topic (the report stated that 59% of American adults reported that they had Internet access). This percentage equates to around 95 million American adults (those aged 18 years and older) who have used the Internet to find health information¹. The report outlines that certain groups are more likely to have sought health information online: women, Internet users younger than 65, college graduates, those with more online experience, and those with broadband access.

Previous research performed by the same author had suggested that online health seekers were mainly motivated to search for information that relates to actions they might need to take to address specific health concerns and issues in their lives, irrespective of whether these health concerns are problems they or a close relative/friend are experiencing². The study carried out in November 2004 reported that the most common health topics that online searches were performed on were –

- Information about a specific disease or medical problem (66% of Internet users)
- Information about a certain medical treatment or procedure (51%)
- Research diet and nutrition (51%)
- Information about exercise and fitness (42%)

¹ Fox S. Pew Internet & American Life Project: Health Information Online. Report released on May 17, 2005. Available at www.pew.internet.org. 1

² Fox S & Fellows D. Pew Internet & American Life Project: Internet Health Resources. Report released on July 16, 2003. Available at: http://www.pewinternet.org/PDF/r/95/report_display.asp

- Information about prescription or over-the-counter drugs (40%)³.

However, this most recent report did not specify whether the Internet users sampled included people who were suffering from disabilities, especially those with visual impairment.

To determine the use of the Internet in locating health information by people with visual impairment, the number of people suffering from this condition needs to be calculated and reported. The Census performed in the United States in 2000 reported that there were 49.7 million people with some type of long lasting condition or disability⁴. This represented 19.3% of the total population of the United States who were aged 5 and older in the non-institutionalized population. Within this group of people with disabilities, 9.3 million people (3.6% of the total population) were reported as having a sensory disability which involved either sight or hearing⁴.

In addition, a report commissioned by the National Eye Institute (NEI), a component of the National Institutes of Health produced in 2002, documented the prevalence of vision impairment and blindness within the United States for those aged 40 and older by state, race and sex based on the United States Census of 2000⁵. This report stated that there was 3,406,280 people suffering from vision impairment (including blindness) aged 40 and

³ Fox, S. Pew Internet & American Life Project: Health Information Online. Report released on May, 17 2005. Available at www.pew.internet.org. 3-6

⁴ U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau. United States Census 2000: Disability Status: 2000 – Census 2000 Brief. Issued March 2003. Available at: <http://www.census.gov/prod/2003pubs/c2kbr-17.pdf>

⁵ National Eye Institute. Vision Problems in the U.S.: Prevalence of Adult Vision Impairment and Age-Related Eye Disease in America. Report produced in 2002. Available at: <http://www.nei.nih.gov/eyedata/pdf/VPUS.pdf>

above within the United States based on the 2000 Census. This figure equated to an overall national average of 2.85%. The State of Oregon was reported to have 44,704 people aged 40 and above with some form of visual impairment (28,907 females and 15,796 males) which equated to 2.94% of the population. The authors speculated that variations in percentages were most likely caused by demographic differences in age, race and/or sex distribution, although it is just as likely that the figures are equally affected by social and economical state characteristics.

The number of disabled people that access the Internet has been examined by the Pew Internet & American Life Project within an examination of the Internet population. People with disabilities face different challenges when using the Internet, but it potentially allows them greater connection to others, greater access to information (including health information), and better accessibility through the computer. However, the report outlined that people with disabilities were less connected to the Internet than most other groups of Americans. In the survey, 38% of people with disabilities reported using the Internet compared to 58% of all Americans sampled – about a fifth of them stated that their disability made use of the Internet difficult⁶. Of the people with disabilities who do not use the Internet, 28% said their disability impaired or made impossible the use of the Internet.

⁶ Lenhart A, Horrigan J, Rainie L, Allen K, Boyce A, Madden M, O'Grady E. Pew Internet & American Life Project: The Ever-Shifting Internet Population: A new look at Internet access and the digital divide. Report released April 16, 2003. Available at: http://www.pewinternet.org/pdfs/PIP_Shifting_Net_Pop_Report.pdf

A report by the National Telecommunication and Information Administration (NTIA) produced in September 2001 included data on computer and Internet use of people with disabilities based on questions within the Current Population Survey (CPS), a survey performed by the NTIA⁷. The people with disabilities were split into various types of disabilities, including a category entitled “Blindness or a severe vision impairment even with glasses or contact lenses” and asked about their computer and Internet use. This data was then compared to the population within broad age groups (individuals under 25, 25 to 60 year olds, and those over 60) who reported having no disabilities.

The data showed that within the lowest age group, aged under 25, Internet use between the blind or severe vision impairment was comparable to those who had no disability (56.3% compared to 56.9%). However, the two older age groups showed a growing disparity in Internet use between visually impaired people and those with no disabilities (51.5% compared to 63.1% in those aged 25 to 60, and 9.6% compared to 25.4% in those aged over 60). One of the interesting findings of the study was that they found variation in the Internet activities of people with disabilities, as people with disabilities were more likely than the population in general to use the Internet to play games and search for health information. This trend, however, was not seen in the patients with visual impairment who searched the Internet for health information at a similar rate to those with no disabilities (38.7% compared to 39.1%)⁶.

⁷ The National Telecommunication & Information Administration & The U.S. Department of Commerce. “A Nation Online: How Americans are Expanding Their Use of the Internet” Chapter 7: Computer and Internet Use Among People with Disabilities. 2002. Available at: <http://www.ntia.doc.gov/ntiahome/dn/html/Chapter7.htm>

The American Foundation for the Blind (AFB) estimated that the number of visually impaired people who were using computers numbered 1.5 million in 1999, including those who are blind. The AFB also reported that the number of people aged 15 and older who had access to the Internet was just over 1.5 million (1,549,000) while the number of the same group who regularly used a computer was just under 1 million (979,000)⁸.

Internet regulations and methods to allow websites greater accessibility for people with visual impairment

As noted above, people who suffer from disabilities generally tend to use computers and the Internet less than the rest of the population. This trend is repeated in those who suffer from visual impairment and the American Foundation for the Blind reported that the more severe the visual impairment, the lower the rate of both access to the Internet and regular computer use⁹.

One of the main reasons that undermine people who have visually impairment from accessing many Internet sites is that many do not follow published guidelines for accessibility. One of the main organizations that publish guidelines on accessibility is the Web Accessibility Initiative of the World Wide Web Consortium (W3C)¹⁰. Unfortunately, these guidelines are not well known and therefore not conformed to. In addition, within the United States, only companies which have government contracts are

⁸ American Foundation for the Blind. Internet and Computer Usage. Available at: <http://www.afb.org/section.asp?SectionID=43&TopicID=224&DocumentID=2313>

⁹ American Foundation for the Blind. The Challenges of Web Accessibility. Available at: <http://www.afb.org/Section.asp?SectionID=4&TopicID=167&DocumentID=2512>

¹⁰ World Wide Web Consortium. Web Accessibility Initiative. Available at: <http://www.w3.org/WAI/intro/wcag.php#for>

subject to Section 508 of the Rehabilitation Act which forces them to make their web sites accessible to people with disabilities. This leaves the emphasis to make web sites accessible on the heads of the web site developers, who may have a lack of training in developing accessible sites, have problems with the rapid pace and turnover of computer technology, or may simply be ignorant of the guidelines and requirements of visually impaired and disabled patients.

However, the AFB reports that the future looks bright for web accessibility as more and more organizations are asking designers to make their web sites more accessible. Reasons for this include purely financial concerns as online stores may have a great deal to gain from making their sites accessible to visually impaired people who may find it easier to shop via the Internet rather than to a store in person, and creating a more positive reputation by being socially responsible and concerned⁸.

There are a number of browser technologies that can be used to help web site developers develop their sites to allow them to become more accessible and available to visually impaired people. These include –

- **Speech and Braille output software:** this software works with the platform on a standard monitor to produce either a screen reader and/or a refreshable Braille display. Screen readers output, orally, what you would ordinarily see including start up screens, desktop and tool bars, and all software packages and browsers. A screen reader will read the outputted page from top to bottom, left to right. To use the Braille output, Braille keypad hardware is attached to the length of a keyboard

and small pins are pushed up to output the content of the web page in Braille. This software relies solely on the keyboard to navigate around a page, as it is a non-visual medium so the mouse cannot be used.

- Screen magnification software: this software works together with the operating system and web browser to enlarge the contents. This enlargement usually far exceeds the largest settings that a standard operating system has in its settings. The software simply magnifies the screen and can vary depending on the preferences of the person using it. Most people who use screen magnification also change the contrast and color settings to make it easier to read, although images generally do not scale well and become blurred when magnified.
- Text-based browsers: these browsers display the contents of the page as text. They do not support images, JavaScript, Java, plug-ins or dynamic HTML. As with screen readers and refreshable Braille displays, text-based browsers render content in a linear fashion. Pages are navigated using a series of keyboard commands and cannot be used with a mouse and is accessible in a similar way to screen readers where correct and intuitive text must be provided within a logical order of content to enable the text to be read in a linear way¹¹.

An interesting varying direction on the improved accessibility of Internet websites for visually impaired people is discussed by Goble et al¹². Within this article, the authors suggest a variation exists between the methods and directions employed by sighted and

¹¹ Royal National Institute for the Blind. Web Access Centre. Available at:

http://www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public_disabilityandtheweb.hcsp

¹² Goble C, Harper S, Stevens R. The Travails of Visually Impaired Web Travellers. Available at:
<http://towel.man.ac.uk/hypertext2000.pdf>

visually impaired people to navigate themselves around websites and that these methods are ignored by traditional software devices employed by the visually impaired, such as those used by screen readers. These variations include the sighted web searcher being able to easily identify and ignore “obstacles” such as advertising banners and sponsors links to easily navigate to the parts of the website useful to them. The visually impaired web searcher using a screen engine which outputs all of the information from top to bottom, left to right traditionally has no option to ignore the “obstacles” and inhibits the usefulness of the search. The article suggests an algorithm that can be introduced into the software used by the visually impaired to circumnavigate this problem by allowing the software to identify and ignore any potential “obstacles”.

Previous research into the health information needs and Internet use of people with visual impairment

There have been a number of published articles that have outlined the needs and accessibility of health information and e-health for people who are visually impaired. A study that examined the use and effect of the Internet by visually impaired and blind people was performed by Jonathan Berry in the United Kingdom¹³. This study consisted of qualitative interviews with a number of partially sighted or blind participants regarding their experiences of using the Internet. Some of the main findings of the research included that the blind respondents felt empowered as they could now obtain access to information in a format that they could access and use reasonably well; that both groups viewed equity of access as an important issue; the partially sighted people did not feel

¹³ Berry, J. Apart or A Part? Access to the Internet by Visually Impaired and Blind People, With Particular Emphasis on Assistive Enabling Technology And User Perceptions. Available at: <http://www.rit.edu/~easi/itd/itdv06n3/article2.htm>

excluded from any function or part of the Internet, while some of the blind people felt excluded as access and use was more difficult and took longer; and, the overriding perception, particularly of the blind respondents, was that the advantages of using the Internet considerably outweighed the disadvantages.

Davis in 2002¹⁴ reported that out of 500 health information Web sites that provided information on 50 common illnesses and conditions, only 19% of these Web sites were accessible to visually impaired individuals who relied on use of automated screen readers.

A recent article by Chiang et al in 2005¹⁵ reported on the specific barriers to the use of computers and associated websites faced by patients with visual disabilities. The conclusions to this study found that while some patients with visual disabilities were using some assistive devices successfully, there were still some important gaps in knowledge. In addition, the authors recognized that the cognitive strategies used by patients who were blind or partially sighted in organizing and processing information during computer and Web navigation was not well understood. The same researcher also presented a paper at MEDINFO 2004¹⁶ which evaluated a number of consumer health Web sites for their accessibility for users with sensory and physical disabilities. Within this study, the author found that of 30 popular consumer health websites, 22 made it

¹⁴ Davis JJ. Disenfranchising the disabled: the inaccessibility of Internet-based health information. *J Health Commun.* 2002 Jul-Sep; 7(4): 355-67.

¹⁵ Chiang MF, Cole RG, Gupta S, Kaiser GE, Starren JB. Computer and World Wide Web Accessibility by Visually Disabled Patients: Problems and Solutions. *Survey of Ophthalmology.* 2005 Jul-Aug; 50(4): 394-405.

¹⁶ Chiang MF, Starren J. Evaluation of consumer health website accessibility by users with sensory and physical disabilities. Paper presented at MEDINFO 2004, San Francisco, CA.

impossible for some groups of disabled users to access information from them, while all 30 of them made it difficult for some groups of people with disabilities to access information. The conclusion reached suggested that accessibility to many consumer health websites was limited to many people with disabilities.

A more wide reaching article by Zeng and Parmanto¹⁷ in 2004 examined whether the accessibility to online health information was equally available to those people who relied on special devices or technologies to overcome their visual, hearing, mobility, or cognitive limitations. The researchers found that within 108 consumer health information Web sites, none of them were completely accessible to people with disabilities, even those that were mandated under relevant laws and regulations.

The American Foundation for the Blind funded a study in 2005 to examine people with visual impairment and document their experiences with using the Medicare website including general satisfaction, impressions of accessibility, and utility for obtaining specific information¹⁸. The main findings of the study found that the Medicare website was very troublesome in locating specific required information and in accessing the information that was available; it took longer to gather information from the web than it would have done over the telephone; the frustration of having to use repetitive links; having difficulty in finding how to download documents; and the search function and

¹⁷ Zeng X, Parmanto B. Web Content Accessibility of Consumer Health Information Web Sites for People with Disabilities: A Cross Sectional Evaluation. *Journal of Medical Internet Research*. 2004; 6(2): article e19.

¹⁸ American Foundation for the Blind. Social Research on Use of, and Preferences for, [WWW.Medicare.Gov](http://www.Medicare.Gov) by People Who are Blind or Visually Impaired. Available at: <http://www.afb.org/section.asp?SectionID=43&TopicID=224&DocumentID=2316>

interactivity of the databases was cumbersome which caused users to encounter problems in retrieving the information they wanted. Despite these negative issues, the study reported that most of the users would return to the website as they appreciated that the site allowed them direct access to information.

A systematic review of the existing medical literature concerning the health information needs of visually impaired people by Beverley et al¹⁹ in 2004. The authors found that there were very few studies that actually examined the unique health information needs of the visually impaired. These studies generally looked at information which contributed to establishing a healthy lifestyle, mainly to do with health promotion. However, the majority of studies examined by the authors were concerned with more specific health information issues to the exclusion of identifying the needs of the visually impaired people themselves. Some of these health issues were information about visual impairment itself or co-morbidities, coping with visual impairment, and about accessing health services such as medication labels and test results.

The review by Beverley et al raised a number of important and relevant issues when examining the existing literature regarding the health information needs of the visually impaired. One of these issues was concerned with the theoretical basis for the research examining the health needs of this group. The authors argued that there were three general hypotheses that were acting as a basis for the existing literature and research:

¹⁹ Beverley CA, Bath PA, Booth A. Health information needs of visually impaired people: a systematic review of the literature. *Health and Social Care in the Community*. 2004; 12(1): 1-24.

- Visually impaired people have the same wide range of health information needs as the general population
- Visually impaired people are disadvantaged
- Visually impaired people simply require the same health information, but in alternate formats.

These three models, however, all fail to appreciate that people suffer from visual impairment may have a specific set of requirements and require health information that varies from the needs of the general population. Therefore, the authors argue, a fourth model needs to be created which assumes that visually impaired people have unique health information needs and requirements that are worthy of research in their own right without the restrictions and burdens imposed on them by previous research into the health information needs of other populations.

Examining the results and conclusions of the previous published research into the accessibility of health Web sites for people with visual impairment, it becomes obvious of the current less than satisfactory state of affairs. It appears clear that these Web sites are not keeping pace with the requirements needed for accessibility by people with disabilities in general, and the visually impaired specifically. However, the report by the American Foundation for the Blind indicated that they believe that improvements may be forthcoming, although this may have more to do with potential financial benefits garnered by the organizations involved than any improved appreciation of the needs of the visually impaired.

The review of the existing literature produced by Beverley et al indicates that there currently is a gap in the literature concerning the actual health information needs of the visually impaired. These health information needs are likely to be a unique mix of a number of specific health requirements including those of the general population, to particular requirements of the levels of visual impairment, and to the complex interaction of visual impairment with all the other factors of health information requirement. It is within this apparent gap in the existing literature that this thesis project will attempt to provide some answers as to the specific and unique health information needs of the visually impaired.

Rural and Suburban/Urban Internet Use in the United States

There have been few reports of potential variations between the Internet use and habits of rural Americans compared to those who live in suburban or urban areas, especially when the health information requirements of the visually impaired residing in these areas is considered. It is hoped by some rural officials that technology in general and the Internet specifically will bring powerful benefits to rural areas, many of which have suffered economic problems as residents have migrated to suburban or urban areas. This hope is based on the fact that the Internet allows people to communicate easily and cheaply with any other person connected to the Internet and be able to gather comparable information quickly and efficiently irrespective of physical location, thus making rural life more desirable.

One of the main problems when determining variations between rural, suburban, and urban areas is defining what constitutes these areas. For the purposes of this project, the definitions of rural, suburban, and urban areas will be consistent with those used within the Pew Internet & American Life Project report on rural Internet use²⁰. This study uses the United States Department of Agriculture Economic Research Service definitions to differentiate rural areas. These definitions are as follows –

- Respondents are “rural” if they reside in a non-metropolitan statistical area (MSA) county.
- Respondents are “suburban” if they reside in any portion of an MSA county that is not in a central city.
- Respondents are “urban” if they reside within a central city of an MSA.

The Department of Agriculture classifies metropolitan and nonmetropolitan areas as being defined on the basis of counties which have active political jurisdictions, having programmatic importance at the Federal and State level, and estimates of population, employment, and income are available for them annually²¹. Metropolitan counties are defined as either central counties which have one or more urbanized areas, or outlying counties that are economically tied to the core counties as measured by work commuting (measured as either 25% of workers living in the county commuting to the central county, or if 25% of the employment in the county consists of workers coming out of the central county).

²⁰ Bell P, Reddy P, Rainie L. Pew Internet & American Life Project: Rural Areas and the Internet. Released on February 17, 2004. Accessible at: <http://www.pewinternet.org>

²¹ United States Department of Agriculture, Economic Research Service: Measuring rurality: what is rural?. Available at: <http://www.ers.usda.gov/Briefing/Rurality/WhatisRural/>

Using these descriptions and definitions of rural (nonmetropolitan counties) and suburban/urban areas (metropolitan counties) to differentiate residents within the counties of Oregon State the project can identify those people with visual impairment living in those areas. The results can then be compared to previous studies using the same criteria. Using the Department of Agriculture classification of Oregon counties, the state is subdivided as follows –

Rural counties: Baker; Clatsop; Coos; Crook; Curry; Douglas; Gilliam; Grant; Harney; Hood River; Jefferson; Josephine; Klamath; Lake; Lincoln; Linn; Malheur; Morrow; Sherman; Tillamook; Umatilla; Union; Wallowa; Wasco; Wheeler.

Suburban/Urban counties: Benton; Clackamas; Columbia; Deschutes; Jackson; Lane; Marion; Multnomah; Polk; Washington; Yamhill.

As mentioned above, one of the published studies that have compared rural, suburban, and urban patterns of Internet use was the Pew Internet & American Life Project report on Rural Areas and the Internet²⁰. This survey, based on data collected in 2003, reported that rural residents were less likely to use the Internet than those residents who lived in urban or suburban areas (52% of rural residents compared to 66% of suburban residents and 67% of urban residents). The variation demonstrated was consistent with similar data trends found by the same researchers in 2000.

The authors speculated that these differences were primarily driven by patterns amongst low-income rural individuals who were much less likely to be online than similar low-

income individuals in suburban or urban areas. The report found that there was little variation between the Internet usages of middle or upper income people irrespective of the area they lived in. Other potential reasons for the gap of Internet use between rural and suburban/urban areas were speculated as being that rural residents as a group were older, less wealthy, and have lower levels of educational attainment.

One of the most interesting and relevant findings of the survey showed that there was very little variation between those Internet users who searched for health information dependent on the area that they lived with those living in rural areas being slightly more likely to have searched for health information than those who were living in suburban or urban areas (69% for rural Internet users compared to 66% for suburban users and 65% for urban users). When the sample was altered to include only those users who had been online for three years or greater, the variation between rural users and suburban/urban users was even greater with 73% of rural users accessing health information compared to 68% of suburban users and 64% of urban users.

RESEARCH QUESTIONS

After examining the evidence of previous research undertaken on the subject of health information retrieval and the use of the Internet and computers to retrieve and receive this information, a qualitative study was thought to be the best method to examine the health information needs for people with visual impairments within the state of Oregon. The study also sought to examine these patient's offline and online needs for health information and whether their current needs were being met.

Once the project had been finally agreed and its objectives clarified, a number of main research questions that hoped would be answered from the results of the project were calculated. These questions were:

- 1) Where do people with visual impairment in Oregon go to satisfy their health information needs and requirements?
- 2) What barriers or obstacles exist that prohibits or stops those people with visual impairments from using online health information resources?
- 3) Are there variations in the health information seeking patterns of people with visual impairment in rural areas compared to suburban/urban areas in Oregon?
- 4) What suggestions or improvements would people with visual impairments like to see with relation to health information resources?

METHODS

Following Institutional Board Review approval for the study from the Oregon Health and Science University, twenty-eight interviews were performed by the lead researcher with individuals with some form of visual impairment between May and August 2006 within suburban/urban and rural Oregon. Fourteen of the interviews were performed on individuals living in areas classified as suburban/urban areas and the other fourteen on individuals living in rural classification areas.

The interviews were performed with the intention of determining how people with visual impairment currently obtain their health information, whether they feel their health education needs are being met by the information on the Internet that is currently accessible to them, what type of information they seek on the Internet and what websites they access, whether they feel this information is accessible to them and what barriers and obstacles they encounter, and any variation between the Internet health information use and characteristics of rural users compared to suburban/urban users.

The interviews were performed on suitable volunteers suggested by a number of individuals working within the Oregon Commission for the Blind. The transcripts were recorded on audio cassette, in addition, to the researcher taking simultaneous notes during the interviews to ensure the consistency and correctness of the information captured during the interview process. The participants were read the contents of the Consent Form (attached in Appendix C), which was authorized by the Ethics Committee of the Oregon Health and Science University, by the researcher and were required to have

understood the contents of the Consent Form and were given time to ask questions of the researcher before signing the form. It was only after the participant had agreed to the contents of the form and signed it, that the interview was allowed to take place.

There were two variations of interview questions and structure which depended on the level of computer literacy and experience of the participant and are included in Appendices A and B. These levels of computer literacy were determined based on the definitions obtained from an article by Childers available at the American Library Association website²². These descriptions are mainly derived using the Basic Computer Equipment Competencies List created by the Library Network Technology Committee²³ and split levels of computer literacy into three groups based on users' abilities to perform general computing actions involving areas such as the setting up of computers, printers, operating systems, computer security, and use of web browsers and the Internet. Considering the design of the project, the levels of computer literacy will be based solely on the definitions concerning the use of web browsers and the Internet. The required knowledge of computer actions each level is as follows –

- **Level 0: No computer usage**
 - No knowledge of basic computer functions such as turning on computer
 - Does not know how to open web browsers
 - Does not know how to use e-mail
 - Does not know how to navigate around websites

²² Childers C. Computer Literacy: Necessity or Buzzword? Available at: <http://www.ala.org/ala/lita/litapublications/ital/2203childers.htm>

²³ The Library Network Technology Committee. Basic Computer Equipment Competencies. Available at: <http://tech.tln.lib.mi.us/finalbasic.htm>

- **Level 1: Baseline**
 - Know how to open and close web browser
 - Know how to use the menu and toolbar buttons
 - Able to change options and preferences
 - Able to add, use, and edit bookmarks
 - Know how to open a URL
 - Know how to use a variety of search engines and subject directories

- **Level 2: Advanced**
 - Know the differences between various Internet browsers and their different versions
 - Have a basic understanding of different terms such as chat rooms
 - Know how to deal with frames when printing e-mails or information from websites
 - Awareness of the potential security and privacy threats when using the Internet, including unsecured communication of private information and viruses.

For the purposes of which set of interview questions and structure were to be used for each individual, the researcher asked the participant prior to the interview of their previous and current computer usage. The participants were then split into those with no computer literacy/usage (Level 0) and those with some or advanced computer literacy/usage (Level 1 and Level 2) with the appropriate interview structure and questions. Both groups of participants answered the questions relating to some basic

demographic information (Section A), the questions relating to their visual acuity background (Section B), and questions relating to their current health information seeking practices (Section C). The variations within the interview structure occurred in the remaining questions and sections asked with the non computer literate group answering a series of questions on their computer and technological usage (Section D of the non computer literate group), while the computer literate group answered questions in two further sections – questions on their Internet, computer and other technology use (Section D for the computer literate group), and questions relating to health information retrieval using the Internet (Section E for the computer literate group). The participant’s location and the visual impairment that they suffer from did not have an effect on which grouping they were placed in and which questions that they were asked.

The differentiation between the volunteers in relation to their computer literacy levels and geographical location is shown in Table 1. Out of the twenty-eight participants, twenty-four (85.7%, 92.9% of urban participants, 78.6% of rural) felt that they were computer literate, with only four (14.3%, 7.1% of urban, 21.4% of rural) regarding themselves as computer illiterate.

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Computer literacy			
Not computer literate	4 (14.3%)	1 (7.1%)	3 (21.4%)
Computer literate	24 (85.7%)	13 (92.9%)	11 (78.6%)

Table 1. Computer literacy levels and geographical location of volunteers

The interviews consisted of a semi-structured qualitative format with a number of open ended questions. The protocol and questions contained within the interview were agreed with review and input by the Thesis Committee. These questions were based on a number of previous studies which examined health information patterns and requirements of Internet users, and studies that examined the general health information retrieval trends of people who are visually impaired and what health information they seek, especially the Pew Internet & American Life Project reports.

RESULTS

The responses obtained from the interviews were placed into a Microsoft Access database and were then analyzed using the statistical package SPSS for Windows 14.0 using chi-square and t-test analysis where the questions were appropriate to being analyzed in this manner. Throughout the course of the results, only those variables that were found to have statistically significant results have been reported on and shown within the tables, although other variables were also analyzed and found to have non-statistically significant results.

During the course of the results section, some grouping of individual responses has been performed by the main researcher and author of this Thesis in order to show consistency and trends within responses that would have otherwise would have been needed to be performed by the reader. However, all quotes included in the report are actual word-for-word representations of the responses of the participants of the study. As most of the questions encouraged the respondents to produce open-ended answers, the responses given often were often multiple and therefore the percentages given in some of the frequency tables indicates percentage of respondents (out of the twenty-eight participants), whereas the number of actual answers within the tables are often greater than twenty-eight.

Section A. Demographic Information

Table 2 shows the basic demographic characteristics of the sample and these questions were common to both interview structures irrespective of the participant's computer

literacy level. The average age of the participants was 49.7 years, with the suburban/urban sample being slightly younger on average at 48.6 years compared to 50.7 years among the rural participants. The participants who were not computer literate were on average older than those who were computer literate (57.5 years against 48.4 years).

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Average age	49.7 (n=28)	48.6 (n=14)	50.7 (n=14)
Not computer literate	57.5 (n=4)	60.0 (n=1)	56.7 (n=3)
Computer literate	48.4 (n=24)	47.8 (n=13)	49.1 (n=11)
Gender			
Female	14 (50.0%)	8 (57.1%)	6 (42.9%)
Male	14 (50.0%)	6 (42.9%)	8 (57.1%)
Marital status			
Married	17 (60.7%)	8 (57.1%)	9 (64.3%)
Single	9 (32.1%)	4 (28.6%)	5 (35.7%)
Divorced	2 (7.1%)	2 (14.3%)	0
Employment Status			
Full-time worker	9 (32.1%)	7 (50.0%)	2 (14.3%)
Part-time worker	4 (14.3%)	2 (14.3%)	2 (14.3%)
Retired	5 (17.9%)	3 (21.4%)	2 (14.3%)
Disabled	4 (14.3%)	0	4 (28.6%)
Unemployed/ volunteering	6 (21.4%)	2 (14.3%)	4 (28.6%)

Table 2. Demographic details of the study participants

The study had an equal number of female and male participants although there were slightly more female participants in the suburban/urban sample than males with an equal inverse proportion in the rural sample. Over half of the participants were married (60.7%), while the remainder were either single (32.1%) or divorced (7.1%). The most common employment status was full-time worker with nine respondents (32.1%), with six people being currently unemployed or volunteering (21.4%), five who had retired (17.9%) and four people each who were either a part-time worker or were disabled (14.3%). There was again a disparity between geographical areas as the majority of urban respondents (9/14 – 64.3%) were currently employed in some capacity as either a full- or part-time worker whereas the majority of rural participants were either disabled or unemployed/volunteering (8/14 – 57.1%).

The respondents were asked about their highest level of education and the results are shown in Table 3. Five participants (17.9%) stated they had not completed high school, twelve (42.9%) reported that they had completed high school, one (3.7%) individual had completed trade school, four (14.3%) had completed an undergraduate degree, while six (21.4%) had completed a masters degree. However, there was a large disparity between the two geographical areas with the majority of the urban participants having completed at least an undergraduate degree (9/14 – 64.3%) compared to just one individual in the rural sample having achieved a similar level (7.1%). These responses were then grouped into the categories of whether they had either completed a college degree (undergraduate or masters) or not with the individual who stated that they had completed trade school excluded from this grouping as it was difficult to evaluate the comparable level of

education. A chi-square statistical analysis was performed to identify whether this was a statistically significant variation between geographical areas and it was found to be significant at a $p < .01$ level.

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Highest level of education			
Completed college degree	10 (37.0%)	9 (64.3%)	1 (7.7%) ***
Did not complete college degree	17 (63.0%)	5 (35.7%)	12 (92.3%)
Did not complete high school	5 (17.9%)	2 (14.3%)	3 (21.4%)
High school	12 (42.9%)	3 (21.4%)	9 (64.3%)
Trade school	1 (3.6%)	0	1 (7.1%)
Undergraduate degree	4 (14.3%)	3 (21.4%)	1 (7.1%)
Masters degree	6 (21.4%)	6 (42.9%)	0

*** $p < .01$

Table 3. Highest level of education of the study participants

Section B. Visual Acuity background

Table 4 outlines the visual acuity characteristics of the sample. Once again these set of questions were asked of all participants in the study, irrespective of their level of computer literacy. Nearly half of the sample were totally blind (42.9%, 57.1% of the urban participants, 28.6% of the rural participants), while four participants (14.3%) had light perception only (could only see between night and day), three respondents were

legally blind, but had some vision in at least one eye, two were blind in one eye, but had limited vision in their other eye, two had peripheral vision only and two had tunnel or central vision only with no peripheral vision, while the remaining three participants had other visual problems (“almost totally blind”, “20/200”, and “2800 with contacts; 2-1 feet fingers of vision”).

The participants were asked when they first developed their visual impairment, five (17.9%) reported that they were born with the visual impairment, another five (17.9%) stated that they developed the visual impairment within their 1st year, six respondents (21.4%) replied that it was in their youth, aged between 1 and 16, that they developed their visual impairment, while twelve (42.9%) stated that the problems developed after they were aged 16 or that they experienced a gradual visual impairment during their lives. The majority of participants (twenty-one or 75%) reported that they had learnt to read print before they developed their visual impairment and this trend was even more clearly marked in the rural respondents (92.9%) compared to the urban respondents (57.1%). There was also a high proportion amongst the sample who stated that their vision was currently stable (twenty-four participants or 85.7%) and this finding was consistent across geographical area. The participants whose vision was not stable were all suffering from degenerative conditions that could continue to detrimentally affect their vision in later life.

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Level of visual impairment			
Total blindness	12 (42.9%)	8 (57.1%)	4 (28.6%)
Light perception only	4 (14.3%)	1 (7.1%)	3 (21.4%)
Legally blind	3 (10.7%)	1 (7.1%)	2 (14.3%)
Blind in one eye, poor vision in other	2 (7.1%)	0	2 (14.3%)
Peripheral vision only	2 (7.1%)	2 (14.3%)	0
Tunnel vision only	2 (7.1%)	1 (7.1%)	1 (7.1%)
Other poor eyesight levels	3 (10.7%)	1 (7.1%)	2 (14.3%)
When had vision problems			
When born	5 (17.9%)	2 (14.3%)	3 (21.4%)
Lost within 1 st year	5 (17.9%)	4 (28.6%)	1 (7.1%)
Between 1 and 16	6 (21.4%)	3 (21.4%)	3 (21.4%)
Aged over 16 and gradual loss	12 (42.9%)	5 (35.7%)	7 (50.0%)
Learnt to read print before lost sight?			
Yes	21 (75.0%)	8 (57.1%)	13 (92.9%)
No	7 (25.0%)	6 (42.9%)	1 (7.1%)
Is your vision stable?			
Yes	24 (85.7%)	12 (85.7%)	12 (85.7%)
No	4 (14.3%)	2 (14.3%)	2 (14.3%)

Table 4. Visual acuity characteristics of the study participants

Section C. Current Health Information Seeking Practices

This was the final section of the interviews where the questions contained within the section were asked of all of the respondents, irrespective of whether they were classified as being either computer literate or non-computer literate. Tables 5 and 6 show the responses to the first three questions within this section:

1. If you wanted to find out some information on a medical or health related issue, what methods do you use to retrieve that information?
2. Who would you ask questions regarding health information?
3. Who are the people you would trust to ask specific health questions or to retrieve health information for you?

The most frequent responses to the question about the methods that respondents would use to retrieve information on a medical or health related issue was talking to a doctor or other health professional (responses included oncologist, pharmacist, eye surgeon, and chiropractor), or they would use the Internet or a computer to access health or medical related information with eighteen responses each. The next most frequent response with nine participants was that they would talk to friends, family or a person they knew who may have knowledge in the area of interest. Other responses to this question included finding information off the television or radio (three respondents), from magazines or reference books (two respondents), while one participant each stated going to a hospital's ER, working in a health clinic, and from individuals working in health food stores.

It is interesting to note the disparity between the two geographical areas with regards the two most common responses to this question, nearly all of the suburban/urban participants stated that they would use the Internet or computers (13/14) whereas this option was not as common amongst the rural participants (5/14). This trend was inversely seen when the response to the question was talking to a doctor or health professional where eleven rural participants stated this response compared to seven of the suburban/urban participants. To determine whether this variance between geographical areas was statistically significant, a chi-square analysis was run on the major responses to this question and while the frequency of using the Internet of computers was found to be statistically significant to a $p < .01$ level between geographical areas, talking to a doctor or health professional was found to be not statistically significant.

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Methods used to retrieve information?			
Use Internet/computer	18	13	5 ***
Talk to doctor/health professional	18	7	11
Talk to friends/family/ person with knowledge	9	6	3
TV & radio	3	2	1
Magazines/books	2	1	1
Hospitals ER	1	1	0
Work in health clinic	1	1	0
Health food stores	1	0	1

*** $p < .01$

Table 5. Question 1 of Section C

The respondents were asked who they asked questions of when seeking health information. Three quarters of the participants (21/28) replied that they would ask a doctor or physician and this answer was the most popular irrespective of geographical location. The next most common answer was that they would ask family or friends with six respondents, whereas five participants stated that they would ask a different health professional (ENT specialist, EMT, pharmacist, neurosurgeon, or acupuncturist), or would ask someone who had experience or knowledge of the condition they were asking about. The next common response was asking a nurse (four respondents), while other responses including books/public library, using an Internet site (both two participants), listening to the radio, people who know natural products, and the Oregon State Department of Human Services (all one respondent).

The most common response to the question regarding who the people they trusted to ask specific health questions or to retrieve health information for them was friends or family with twenty-one respondents. This was followed by nineteen participants who stated that they would trust their doctor/physician, six respondents who trusted a different type of health professional (pharmacist, diabetic educator, vision and mobility specialist, or acupuncturist), four people who would go to the library to seek health information or ask an librarian, and three respondents who stated they would trust the information they sought via the Internet. In addition, single individuals reported that they trusted nurses, someone with a similar condition, people who know natural products, radio shows that

describe health conditions and remedies, health insurance agents, and the Oregon State Department of Human Services.

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Who would you ask health questions?			
Doctor/physician	21	9	12
Friends/family	6	3	3
Other health professional	5	3	2
Someone who knows condition	5	4	1
Nurses	4	2	2
Books/public library	2	2	0
Internet	2	2	0
Radio	1	1	0
Knows natural products	1	0	1
Dept. of Human services	1	0	1
Who do you trust to ask health questions?			
Friends/family	21	12	9
Doctor/physician	19	10	9
Other health professional	6	3	3
Library/librarians	4	3	1
Internet	3	3	0
Nurse	1	1	0
Someone with similar condition	1	1	0

Knows natural products	1	0	1
Radio	1	0	1
Dept. of Human services	1	0	1
Health insurance agents	1	0	1

Table 6. Questions 2 and 3 of Section C

Table 7 reports on the responses of the participants for the following questions within Section C of the interview schedule:

4. What type of health information did you most recently seek?
5. What methods did you use to retrieve this information?
6. Were you satisfied with the information that you received?

If NO, why was this?

The participants were asked the type of health information that they most recently sought. Over half of the respondents (16/28) looked for general information on a specific illness/disease or ailment such as conditions for a stroke, information of high blood pressure, Hodgkin's disease, toxoplasmosis, or asthma. The next most common responses were that they searched for dietary information (such as the glycaemic intake of food and blood sugar lowering for diabetics) or for information on health insurance (such as medication coverage) with three respondents each. Two participants each were seeking information of specific drug information (e.g. looking for drugs regarding arthritis), specific treatment options (e.g. information on Insulin pumps), information on types of surgical procedures (e.g. foot surgery to remove a bunion), and the use of natural

or homeopathic treatments and products (e.g. herbal remedies for arthritis and osteoarthritis). In addition, single participants was seeking information on the health and medical effects of living close to a Meth laboratory (classified as public health information), and on a device that would enhance the user to better retrieve print (classified as Aids).

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Type of information of recent search?			
Illness/disease/ailment	16	9	7
Dietary information	3	2	1
Health insurance	3	2	1
Drug information	2	2	0
Specific treatment	2	1	1
Surgical procedures	2	1	1
Natural products/treatment	2	0	2
Public health information	1	1	0
Aids	1	0	1
No recent search	1	0	1
Methods used to retrieve information?			
Internet	14	9	5
Doctor/physician	9	3	6
Other health professionals	6	3	3
Friends/family	4	3	1
Someone with similar condition	3	2	1
Books	2	0	2

ER	1	1	0
Hospital classes	1	0	1
Nurse	1	0	1
Prescription company	1	0	1
Satisfied with the information?			
Yes	24 (85.7%)	12 (85.7%)	12 (85.7%)
Mostly/Quite/Reasonably	3 (10.7%)	2 (14.3%)	1 (7.1%)
Yes & No	1 (3.6%)	0	1 (7.1%)
If no, why not?			
Not getting information due to data protection	1	1	0
Dissatisfied with having to use the Internet	1	1	0
Not consistent	1	1	0
Vast amount of information to go through	1	0	1

Table 7. Questions 4, 5, and 6 of Section C

When the participants were asked the methods that they employed during their most recent search for health information, the most common response was that they used the Internet or computers as part of their information retrieval method with exactly half the respondents (14/28) reporting this. However, there appeared to be a discrepancy between geographical areas as nine of the fourteen respondents in the suburban/urban areas reported using the Internet compared to only five of the fourteen rural participants although there was no statistically significant variation using a chi-square analysis. The next most popular method was to ask a doctor or physician with nine respondents,

although six of the nine respondents who reported this method were from rural areas. Six participants reported that they asked another type of health professional (pharmacist, disease specialist, eye surgeon, or acupuncturist), four respondents stated that talking to family or friends was part of their health information retrieval methodology, and three people reported that they talked with someone who was suffering from the same illness or condition. Other methods stated were using books (two respondents), called the Emergency Room (ER), attending local hospital classes, talking to a nurse, and telephoning a prescription company (all one participant each).

The participants were then asked if they were satisfied with the health information that they retrieved and twenty-four (85.7%) of the participants stated that they were happy with the information they retrieved, three other participants (10.7%) said that they were either quite, reasonably, or mostly satisfied with the information that they retrieved. The other participant (3.6%) stated that they were both satisfied and not satisfied with the information they received due to the poor prognosis provided by the website accessed. However, the participants also added some comments following their answer of yes or no, which allowed them to further elaborate their thoughts in relation to this question. Some of these comments included that the information was “detailed, allayed fears”, “wanted information on spike foods – no list of spike foods”, “confirmed diagnosis and prompted to get better products”, and “was frustrated as looking for information for someone else and could not specific information”.

The four respondents who were not completely satisfied with the information that they received or retrieved had the opportunity to elaborate on their dissatisfaction. These respondents provided comments such as “could not/would not give information due to not knowing who patient/caller was, they would only give information in patient was in the OR”, “dissatisfied with having to get it that way (by the Internet)”, “not consistent, could be something being hidden or incomplete”, and “vast amounts of information from the Internet is hard to sift through” as the reasons behind their dissatisfaction.

Table 8 contains the responses to the final two questions contained within Section C:

7. What barriers/obstacles have you encountered when retrieving health information?
8. Do you feel that your visual impairment hampers you in getting adequate health information?

When the respondents were asked what barriers or obstacles they had encountered when retrieving health information, the most common response was that the brochures and information that they were being given was always in printed form that made no allowance for the fact that they could either not read them or would require someone to read it to them and were inaccessible to them. This barrier was reported by ten respondents and examples of their comments included: “brochures in print, nothing in Braille”, “going to a Doctor’s office – prescription never accessible as always in print form”, and “medical people handing written sources as a resource – which are useless as I need someone to read them to me”. A further four respondents also stated that the inaccessibility of certain websites was also a problem as highlighted by these comments:

“not all websites are accessible due to screen reader problems”, and “occasionally websites primarily graphically orientated without text boxes so difficult to navigate”. In addition, five respondents specified other related Internet issues as barriers they had encountered. These included, “(not) knowing what words to put in computer searches”, and “not being able to access Internet except at library”.

However, the inaccessibility of health information to the participants and other Internet issues appeared to be a more common occurrence within the suburban/urban respondents than the rural respondents, although due to the format of the information within this question, it was not suitable to perform a quantitative test such as a chi-square analysis on this data to determine whether this variation between geographical areas is statistically significant or not. Within the rural participants the major barrier appeared to be various problems with dealing with health professionals (half of the rural participants, and nine respondents overall). Some of the issues raised within this category appeared to be unavoidable such as the comments as “not always having the doctor available when having a query as he is familiar with condition”, and “doctor’s vacation held him up”, but there were also some more worrying comments regarding the attitudes of some health professionals when dealing with people with visual impairment as reported. This was demonstrated by comments such as “eye doctor gave no information on how to adapt to deteriorating eyesight – had to do my own research”, “not being taken seriously all the time”, and “health professionals are condescending”. These sort of comments are disturbing when you consider that people with visual impairment sometimes require their information in a different format to normally sighted patients (in a non-written format)

which may require slightly more effort on behalf of the health professionals, effort that does not appear to be being given to some patients at this current time.

Other barriers reported by the respondents included issues to do with cost (e.g. “cost (Medicare doesn’t cover)”), transportation or location (e.g. “transportation to Roseburg; have to coordinate with wife & kids to get a lift”), problems with interpretations of data protection laws (e.g. “reluctance of medical personnel to give information due to laws/restrictions”), and personal attitudes providing barriers and problems (e.g. “am afraid to ask questions”, and “lack of patience”) which all had two respondents reporting these issues. Four participants stated that they had encountered no problems or barriers when accessing the health information they sought.

Variable	Total Sample (n=28)	Suburban/urban participants (n=14)	Rural participants (n=14)
Barriers when retrieving information			
Use of printed material	10	7	3
Problems with health professionals	9	2	7
Other Internet issues	5	4	1
Accessibility of Internet websites	4	3	1
Cost	2	0	2
Transportation/location	2	0	2
Personal issues	2	1	1
Data protection laws	2	1	1
None/no problems	4	2	2

Visual impairment hinders you in getting health information?			
Yes	8 (28.6%)	5 (35.7%)	3 (21.4%)
Sometimes	6 (21.4%)	4 (28.6%)	2 (14.3%)
No	14 (50.0%)	5 (35.7%)	9 (64.3%)
Ways being hindered			
Communication/respect with health professionals	5	1	4
Information only accessible by Internet	3	3	0
Takes longer	3	1	2
Given information in inaccessible form	2	2	0
Accessibility of some websites	1	1	0

Table 8. Questions 7 and 8 of Section C

The final question within Section C asked the participants if they thought their visual impairment hindered them when attempting to retrieve health information. Half of the respondents (14/28) stated that they did not think that their visual impairment hindered them. The other participants reported either that it sometimes hindered them (6/28 or 21.4%), or that they thought it did actively hinder them (eight respondents or 28.6%). The participants who felt that their visual impairment hindered them (either answered yes or sometimes to the original question), were then asked to elaborate on the specific problems they encountered. The main issue raised, with five respondents reporting this,

was a lack of communication or respect with health professionals. Comments reporting this problem included: “people do not communicate with me, they communicate through other people rather than through me”, “when call a company and say you’re blind – seems they don’t know how to help you”, and “took a while to find doctor who respected me; frustrated with OR people who do not treat me as a parent”.

The next most common barriers that were hindering the respondents were that some information was only accessible via the Internet, and it was taking them longer to retrieve health information than normal sighted people with three participants each reporting these issues. An example of a comment regarding information being only accessible via the Internet was, “general information can only be accessed via the Internet, whereas the comment that finding health information “takes longer, but same information” was typical of the statements containing within that grouping. The other problems that were mentioned as providing obstacles were to do with accessibility issues, two respondents commented that the health information they were receiving was in an inaccessible format (e.g. “most information is in print and some information is not in accessible form”), and one person reported that their visual impairment, “hampers looking at graphs/pictures with some websites better than others”.

Section D (for non computer literate respondents). Computer and Technological Usage

This section was the final section for those respondents who were classified as non computer literate during the initial stage of the interview and sought to identify the causes

of their non usage of computers and the Internet, to examine their current use of other modern technological machines (to identify whether the respondents reluctance to use computers or the Internet extended to other modern technology as well), to attempt to identify the circumstances in which they would use computers or the Internet (not solely in an attempt to retrieve health information), and their opinions and thoughts of asking other people to access health information from the Internet for them and whether they felt that they would trust the accuracy and correctness of the health information that was currently available from the Internet.

When the study was initially conceived it was thought that the number of respondents between the non computer literate and the computer literate categories could potentially be similar. However, this theory was shown to be false as within the study sample, only four out of the twenty-eight respondents (14.3%) were classified as being non computer literate and answered the questions within this section. Only one of the respondents from the suburban/urban area (7.1%) was considered non computer literate compared to three (21.4%) respondents from the rural areas. Despite the small numbers answering the questions within this section, these respondents provide invaluable insights into problems that certain individuals face within the 21st Century when access to common information available to the majority of the population is not available to them due to extenuating circumstances.

The responses to the first three questions of Section D (for the non computer literate respondents) are contained within Table 9. These questions are as follows:

1. What are the main reason(s) you do not use the Internet or computers?
 2. What problems/obstacles have you encountered when attempting to the use the Internet or computers?
 3. Do you use any other modern technological machines such as a television, video recorder, or cell phone?
- If YES, do you require any devices that help you to use these modern technological machines?

The first question within this section asked the main reasons why the respondents did not currently use computers or the Internet. Two respondents gave the answer that they did not have the knowledge or experience to use computers as outlined by the comment that they did not have the, “knowledge of using them; does not know ‘how’ to”. A further two respondents listed security issues as being an issue with one stating that a reason they did not use the Internet was due to “privacy issues”, while the other was worried about “problems with viruses”. Two participants also preferred to use other methods to retrieve information as one found that they could “communicate easier himself by Braille”. Other reasons given included cost (e.g. “cannot afford the adaptive tools”), using family members to retrieve the information (e.g. “can use family members to access Internet), and the inaccessibility of some websites (e.g. “frustrated by lack of text only”).

The next question asked the respondents what barriers or obstacles they had encountered when attempting to use the Internet specifically or computers in general (if they had indeed attempted to use computers). The most common problem reported was one of

frustration with two participants reporting this. Their comments were that “computer programs that use the Internet are frustrating so old ways are better”, and that they had “no patience with learning”. Other barriers that the participants stated were that they “had not used computers before so was a novice”, or “can’t read the screen”, and that they would not use a computer due to an absence of “not learning the keyboard”.

Variable	Total Sample (n=4)	Suburban/urban participants (n=1)	Rural participants (n=3)
Main reason not to use computers?			
Knowledge/experience	2	1	1
Security issues	2	0	2
Prefer other methods	2	0	2
Cost	1	0	1
Uses family	1	0	1
Website accessibility	1	0	1
Problems using the Internet?			
Frustration	2	0	2
Novice user	1	1	0
Can’t read the screen	1	0	1
Not learning keyboard	1	0	1
Use other technological devices?			
Yes	4 (100.0%)	1 (100.0%)	3 (100.0%)
No	0	0	0
Types of machine?			
Cell phone	3	1	2
Television	2	1	1

VCR	2	0	2
Stereo	1	0	1
DirectTV	1	0	1
Any devices to help use these machines?			
Braille on devices	1	0	1
Talking clocks and watches	1	0	1
Raised numbers on cell phone	1	0	1

Table 9. Questions 1, 2, and 3 of Section D for non computer literate respondents

The next question in this section sought to identify whether the individuals who were non computer literate used other modern technological machines with the exception of computers and the Internet, or whether they did completely without those type of new technology. The answer was that all the respondents stated that they did use other modern technological machines regularly, just not computers. Three of the four respondents used cell phones, two of the respondents used either a television or a video recorder, while one respondent each used and owned a surround sound stereo, or had access to and used the cable technology DirectTV. The question was then asked as to whether the participants required any special devices in order to use these machines. The responses to this question were that one individual stated that they had Braille on the devices to make it easier to use, one respondent reported that they had talking clocks and watches, while one of the participants had a cell phone which had raised numbers to aid them in using it.

The next three questions contained within Section D (for the non computer literate respondents) were as follows with the responses to these questions reported within Table 10:

4. What problems/obstacles have you encountered using any of these modern technological machines?

5. Do you feel there are any potential benefits for you in accessing the Internet?

If YES, what are the benefits?

6. What motivation/requirements (if any) would be required for you to use the Internet or computers?

When these individuals were asked about the problems and obstacles that they had encountered when using these modern technological machines, half of the respondents (2/4) replied that they had had no encountered no problems, although one of the respondents stated that they had experienced “None that have been not able to overcome”. The two respondents who did report on encountering problems listed a number of problems that they had experienced. These included that “Cell phones are so small, can’t see and use buttons” and, that cell phones have “many features on them that are being installed are not useful”. In addition some modern technological machines had “Too many buttons, remotes to remember” and that the respondent had a problem due to having “no talking machines”.

Variable	Total Sample (n=4)	Suburban/urban participants (n=1)	Rural participants (n=3)
Problems/obstacles with these machines?			
Cell phones too small	1	1	0
Features on phones not useful	1	1	0
Too many buttons/ remotes to remember	1	0	1
No talking machines	1	0	1
None	2	0	2
Potential benefits of Internet?			
Yes	2 (50.0%)	1 (100.0%)	1 (33.3%)
No	2 (50.0%)	0	2 (66.7%)
What benefits?			
Broaden knowledge	2	1	1
Like reading a newspaper	1	1	0
Communication	1	0	1
Motivation to use the Internet?			
Work	1	1	0
Apparatus	1	0	1
Cost	1	0	1
Financial gain	1	0	1

Table 10. Questions 4, 5, and 6 of Section D for non computer literate respondents

The respondents were then asked to outline what motivation or requirements would be necessary in order for them to begin to use computers and the Internet more regularly (or at all). The participants gave a varied response to this question which detailed their personal motivations for learning to use computers. One interviewee outlined their motivation to be connected with their employment when stating that “Main motivation is work as job requires use of computers and some information would be on the Internet”, while another said it was dependent on work but would be looking for “Some real financial gain” for their business. Other motivational factors reported were the actual computer itself by one respondent who stated that they were missing “Just the apparatus”, and cost considerations as one person stated that the requirement they need is “Money for JAWS”, where JAWS is one of the most popular pieces of screen reader software available and is frequently used by people with visual impairment.

The responses to the remaining questions within Section D (for the non computer literate respondents) are contained within Table 11. The questions within this part of the section are as follows:

7. Would you ever consider asking someone else to retrieve health information for you from the Internet?

If YES, who would you ask and what type of health information would you ask them to seek?

If NO, why is this?

8. How trustworthy and accurate do you consider health information on the Internet to be?

9. Are there any other comments you would like to make regarding your experiences of retrieving and accessing health information?

Variable	Total Sample (n=4)	Suburban/urban participants (n=1)	Rural participants (n=3)
Consider asking someone else to retrieve health info?			
Yes	4 (100.0%)	1 (100.0%)	3 (100.0%)
No	0	0	0
Who would you ask?			
Family	2	1	1
Professionals/nurses	1	0	1
Natural health store	1	0	1
Working colleagues	1	1	0
Type of health information?			
Medication information	2	1	1
Symptoms of disease/ailment	1	1	0
General medical questions	1	0	1
Information that was workable/usable	1	0	1
Internet trustworthy and accurate?			
Accurate	3 (75.0%)	1 (100.0%)	2 (66.7%)
Don't know	1 (25.0%)	0	1 (33.3%)

Other comments on retrieving health info?			
Determination	2	0	2
Satisfaction with experiences	1	1	0
Health insurance problems	1	0	1
Active encouragement	1	0	1

Table 11. Questions 7, 8, and 9 of Section D for non computer literate respondents

The non computer literate respondents were then asked if they had ever considered asking someone else to retrieve health or medical information from the Internet for them and then reporting back to them. If they had, they were then asked to name those people they trusted to retrieve the health information for them and what type of health information they would be asked to seek for them. All four of the respondents reported that they would consider asking someone to retrieve health information for them, and had already done so on multiple occasions. When asked the identity of the people they would ask to retrieve this information, half of the respondents (2/4) stated that they would ask members of their family to search the Internet for them. Other people who they would ask as reported on by one individual each were professionals and nurses, other employees at the respondent's place of employment, and people at a natural health store. The most common answer to the type of health information they would ask someone to seek for them from the Internet was medication information with two respondents, although one stated that they would like to find information on natural products that would help with high blood pressure. The other types of health information that they would seek from the

Internet were symptoms of a disease/ailment, general medical questions such as on WebMD, and one individual who stated they would get someone to access health information from the Internet for them, “if I thought it was workable and usable”.

The perception as to whether the Internet was a trustworthy and accurate purveyor of information, especially concerning health and medical questions, was the underlying interest behind the next question which asked how trustworthy and accurate the respondents considered the health information on the Internet to be. This question was especially interesting within this group of non computer literate respondents as it would give an idea of the perception of health information on the Internet by those people who may not have actually used it as a resource. The impression given by this group of respondents was that they did actually consider the health information contained on the Internet to be accurate as three out of the four respondents (75.0%) stated that they thought the information to be accurate with comments such as “from experience, has been accurate”, “use Internet before Braille pamphlet as is more convenient”, and “consider it to be just as accurate as other media, especially WebMD”. The other respondent was not sure as to the answer of this question and commented that they “don’t know – would always seek 2nd opinion”. This generally positive response, despite the small numbers involved, to this question seems to show a generally positive picture of the perception of trustworthiness and accuracy of health information contained within the Internet by those individuals who are not experienced users of computers or the Internet.

The final question of this section, and final question of the interview for this group of respondents, asked them whether they had any other comments to make regarding their experiences of retrieving and accessing health information. Two of the respondents outlined the importance of determination when seeking out health information when one stated that as they were an “assertive person so would definitely call someone to answer questions until satisfactory answer is found”, while the other claimed that a “number of people get turned down because they don’t have the patience/determination to go through the hoops”. This individual also added that they “would like to see people being taught to get through the hoops”. The other comments stated by some of the respondents were that one had “been satisfied with experiences so far”, while the other was having problems with health insurance as “health insurance cannot be paid for son, the Oregon Health Plan does not cover”.

Section D (for computer literate respondents). Internet, computer and other technology use.

This section was the first of two additional sections for those individuals who were classified as being computer literate after the initial discussion between the participant and the researcher. Out of the initial study sample of twenty-eight respondents, twenty-four (85.7%) were classified as being computer literate and answered the questions within this section and the subsequent section. When looking at geographical area, thirteen out of the fourteen respondents (92.9%) recruited from suburban/urban areas were classified as computer literate, while eleven out of fourteen respondents (78.6%) from rural areas were similarly classified. The questions within this section were

designed to seek the computing and Internet habits of those computer literate respondents, the devices that they used to help them to use computers and the Internet, and questions regarding their use of other technological machines, what (if any) devices they needed to enable them to use them, and the obstacles and problems that they may have encountered when using these machines.

The participant's responses to the questions within this section that related to the respondents use of computers and the Internet are listed in Table 12. They include the first four questions within the section and are as follows:

1. Do you have a personal computer (PC) at home?

If NO, where do you usually access a computer from?

2. Do you use the Internet at home?

If NO, what location do you usually access the Internet from?

3. Do you know what type of Internet connection you have at home?

4. Do you require any devices that help you to use computers or the Internet such as screen readers?

The first question within this section asked the respondents whether they had a computer at their home. Out of the twenty-four participants who answered this question, twenty-three (95.8%) of them stated that they did have a computer they could use at home, while only one respondent (4.2%) reported that they did not have a computer at home. The next part of the question asked the participant who did not have a computer at home where

they usually accessed a computer from and they replied that they used the machines at their local public library.

The participants were then asked whether they had access to actually use the Internet at home and if they didn't use it at home, the location where they accessed the Internet from. Twenty-one of the twenty-four respondents (87.5%) stated that they used the Internet at their home, whereas the remaining three (12.5%) participants reported that they did use the Internet, but using computers based at a different location. These three respondents were asked where they accessed the Internet if not at their home, one respondent gave the answer that they did so at their place of work, another stated that they accessed the Internet at their local library, and the remaining participant stated that they used a computer at their daughter's home.

Variable	Total Sample (n=24)	Suburban/urban participants (n=13)	Rural participants (n=11)
Do you have a computer at home?			
Yes	23 (95.8%)	12 (92.3%)	11 (100.0%)
No	1 (4.2%)	1 (7.7%)	0
If NO, where do you access computer?			
Library	1	1	0
Do use the Internet at home?			
Yes	21 (87.5%)	11 (84.6%)	10 (90.9%)
No	3 (12.5%)	2 (15.2%)	1 (9.1%)

If NO, where do you access Internet?			
Employment	1	1	0
Library	1	1	0
At daughter's	1	0	1
Type of Internet connection at home?			
Broadband	11 (45.8%)	7 (53.8%)	4 (36.4%)
Cable	3 (12.5%)	3 (23.1%)	0
DSL	3 (12.5%)	2 (15.2%)	1 (9.1%)
Dial-up	2 (8.3%)	0	2 (18.2%)
Charter – Highspeed	2 (8.3%)	0	2 (18.2%)
Satellite	1 (4.2%)	0	1 (9.1%)
Not applicable	2 (8.3%)	1 (7.7%)	1 (9.1%)
Use devices to help with computers?			
Yes	22 (91.7%)	11 (84.6%)	11 (100.0%)
No	2 (9.3%)	2 (15.4%)	0
What devices?			
JAWS for Windows	15	8	6
WindowEyes	5	3	2
Screen magnification software	3	0	3
Zoomtext	2	0	2
Freedombox	1	0	1
Jordy	1	0	1
19 inch LCD	1	0	1

Table 12. Questions 1, 2, 3, and 4 of Section D for computer literate respondents

The next question that was asked was whether the respondents knew what sort of Internet connection they had at home and to tell the researcher what it was. Nearly half of the participants (11/24 or 45.8%) stated that they had a broadband connection of some sort at home, either Cable broadband, DSL broadband, cable DSL broadband, DSL broadband high speed or wireless broadband. The next most common response given was either Cable or DSL with three respondents (12.5%) each. These answers indicated that the respondents did not know specifically what type of Internet connection they had, but they knew from which company they had purchased the connection from, therefore it was impossible to determine whether they had a broadband, high speed, or dial-up connection. Two respondents (8.3%) reported having a dial-up connection, and both were from the rural geographical area. A further two rural participants stated they had a high speed connection via the Charter company, which is likely to be a broadband connection, but the participants did not specifically state this. There were two respondents (12.5%) who did not answer this question as they stated in the previous question that they did not currently have an Internet connection at home.

The respondents were then asked whether they required and used any devices that enabled them or assisted them to use computers and the Internet. Nearly all of the respondents (twenty-two out of the twenty-four respondents or 91.7%) stated that they did use some form of device which enabled or assisted them in using computers or when accessing the Internet. The respondents were then asked to list the devices that they used in this manner. Over half of the respondents (fifteen out of twenty-four respondents) reported that they used the screen reader, JAWS for Windows when using their

computers and accessing the Internet. The next most common response was another type of screen reader, this time called WindowEyes which was used by five respondents. Three participants stated that they used some sort of screen magnification software on their computers, but did not name the specific names of the software, whereas two more respondents stated that they used the Zoomtext screen magnification software in order to assist them using their computers. Other devices reported by single respondents each were Freedombox (another type of screen reader software), Jordy (a machine that is put around the head surrounding the eyes that allows the recipient more peripheral vision – named after a character from the Star Trek Next Generation television series), a magnification screen text and screen reader called Lunar (although the participant reported that the “speech is not great”), and a 19 inch LCD screen that allowed the respondent to use their computer.

There were two further questions asked within Section D for the computer literate respondents and the responses to these questions are listed within Table 13. These final questions of the section are as follows and are questions that were also asked of the non computer literate respondents during Section D of their interview:

5. Do you use any other modern technological machines such as a television, video recorder or cell phone?

If YES, do you require any devices that help you to use these modern technological machines?

6. What problems/obstacles have you encountered using any of these modern technological machines?

The participants were then asked about their experiences and use of other modern technological machines besides computers and the Internet. The initial question asked whether they use any other modern technological machines with the examples being given as a television, video recorder or cell phone besides computers. Twenty-three of the twenty-four respondents (95.8%) replied that they did use one or more of these sort of modern machines with the respondent who stated that they did not, did state that they used other technology, just not those types of machines. The respondents were then asked to list the modern technological machines that they currently used. The most common response was that of a television with seventeen out of the twenty-four participants stating they used this. The next two most common responses were using a video recorder with fifteen respondents and a cell phone with fourteen participants.

All of the top three most frequently used machines were commonly used across both geographical areas. However, the next most frequent responses, DVD players (with seven respondents) and Braille note takers/PDA (with five respondents) seemed to be more geographical biased with the majority of the DVD player users (six out of the seven respondents) coming from the rural areas, while all of the Braille note takers/PDA came from the suburban/urban respondent group. Other responses to this question were two respondents who used a landline phone, and single respondents whose answers were grouped into the categories of musical machines (MP3 player, CD player, radio, stereos, and tape recorder), and other machines (microwave, CCTV, DirectTV, video games, scanner, and a machine that checks blood sugar levels).

The respondents were then asked whether they required or needed any special devices or aids that allowed them to use these types of modern technological machines and if so, what devices they were commonly using. The majority of the respondents stated that they did require a type of device to enable them to use these machines with fifteen of the twenty-four respondents (62.5%) stating this, with the remaining nine participants (32.5%) stating they did not require any special devices or aids. The most frequent device used by those individuals who did require an aid was using speech output options on their cell phones (six respondents), although one participant did state that not all the options on their cell phone were available to them using the speech output options. This option appeared to be more frequently used by the suburban/urban participants as five of the six people who reported this came from this geographical area. The device reported most commonly among rural participants (three respondents) was some form of magnifier for their TV or DVD players which allowed them to initially learn the options available within the machine. Devices that were listed only by suburban/urban participants with two responses each were Braille enhanced machines, specifically within the Braille Notes PDA system, and more generally using Braille marked machines and keyboards. Types of tape recording systems were also reported by two participants where they could record information on digital recordings which could then be transferred to a computer. Other single responses which were grouped into other devices within Table 13 were larger print on their cell phone, white push ons on the television so that they could see the variations in light, talking books, and the Jordy device mentioned previously.

Variable	Total Sample (n=24)	Suburban/urban participants (n=13)	Rural participants (n=11)
Use other technological devices?			
Yes	23 (95.8%)	12 (92.3%)	11 (100.0%)
No	1 (4.2%)	1 (7.7%)	0
Types of machine?			
Television	17	7	10
VCR	15	6	9
Cell phone	14	7	7
DVD player	7	1	6
Braille Notes/PDA	5	5	0
Landline phone	2	0	2
Musical machines	5	4	1
Other machines	6	1	5
Any devices to help use these machines?			
Yes	15 (62.5%)	8 (61.5%)	7 (63.6%)
No	9 (37.5%)	5 (38.5%)	4 (36.4%)
Types of device used to help			
Cell phone speech output options	6	5	1
Magnifier for machines	3	0	3
Braille on devices	2	2	0
Braille Notes/PDA	2	2	0
Tape recording machines	2	1	1
Other devices	4	1	3

Problems/obstacles with these machines?			
Experiencing problems	21 (87.5%)	13 (100.0%)	8 (72.7%)
Non experiencing problems	3 (12.5%)	0	3 (27.3%)
Type of problem			
Inaccessibility of some cell phone options	5	3	2
Takes longer	3	1	2
Inaccessibility of DVD players	3	3	0
Need people to come over and help them	3	1	2
Overlay's on machines	2	2	0
Cannot see menus	2	2	0
Inaccessibility of TV options	2	2	0
JAWS problems with Internet	2	2	0
Not enough light	1	1	0
Cost	1	0	1
Print on guides	1	0	1
Learning new software	1	0	1
Inaccessibility of other machines	2	2	0

Table 13. Questions 5 and 6 of Section D for computer literate respondents

The final question in this section asked the respondents what problems and obstacles they had encountered, if any, when using some of the modern technological machines as

outlined during question 5. There was a large proportion of the respondents (twenty one respondents or 87.5%) who stated that they had encountered various problems or obstacles when using these types of machines. All of the suburban/urban respondents reported this, whereas there were three rural respondents who stated they had had no problems with using these machines.

The respondents were then asked to state the problems they had faced and a number of them stated that one of the most common problems they were having was that some of the options within these machines were not accessible to them. The most frequent of all problems reported was with the inaccessibility of some of the options within cell phones with five respondents stating this problem. Other devices which were providing problems due to certain options (or the device as a whole) being inaccessible were DVD players (with 3 respondents, who all came from suburban/urban participants who mainly stated that DVD players were completely inaccessible), televisions (with two respondents), an home entertainment centre, and an IPOD (both with one respondent, grouped together in Table 13 as the category of 'Inaccessibility of other machines').

Apart from the inaccessibility of some options within machines, some of the other problems and obstacles that were reported by the respondents included how it was taking them longer to use the machines with three participants stating this including the example that it "takes twice as long to learn", while another three respondents reporting that they often needed people to come over to help set up machines or to help if they encountered any problems with the machines. Problems that two respondents each stated included

issues with some overlays they had on machines which didn't allow them to see what is underneath them, not being able to see and access some menus on the machines (although the machines were not stated), and the screen reader, JAWS for Windows, having problems accessing and being able to read some websites. Other obstacles listed by single individuals were that the writing on some guides for the machines was too small to read, the cost of some types of visual equipment, the difficulty in adapting from one version of Zoomtext to another, while one respondent stated that they "can't use ff/rewind as not enough light/contrast".

Section E (for computer literate respondents). Health Information retrieval using the Internet

This section was the final section for the twenty-four computer literate respondents and contained questions asking the participants of their experiences and recollections of using computers and the Internet when searching for health information and of the websites that they had accessed. In addition, the respondents were also asked about their experiences and perceptions of the Internet in general and also how they felt about the accuracy and trustworthiness of the information that was being stored there, and the potential benefits of being able to access health information via computers and the Internet that people with visual impairment might enjoy.

The section begins by asking the participants if they had ever used the Internet to search for health information. If the respondents answered yes to this question, then they were asked to answer the majority of the questions within the section which outlined their

experiences during these searches for health information. If the respondents had not previously used the Internet to search for health information, they were asked a smaller subset of questions within the section which attempted to identify what requirements would be needed to persuade them to begin using the Internet to retrieve this information or what obstacles they had encountered which had stopped them using the Internet. These questions were also asked on the non computer literate participants except these pertaining only to accessing health information on the Internet only.

The responses to the first questions within Section E are contained within Table 14 and include all the initial questions asked of those respondents who had not previously used the Internet to search for health information (questions 1.a. to 1.c). The questions which were asked within Table 14 are as follows:

1. Have you ever used the Internet to search for health information?
 - a. If NO, what are the main reason(s) you do not use the Internet to search for health information?
 - b. What motivation/requirements (if any) would be required for you to use the Internet to search for health information?
 - c. Would you ever consider asking someone else to retrieve health information for you from the Internet?
 - i. If NO, why is this?

The first question asked to the participants within this section was whether they had ever used the Internet to search for health information. Seventeen of the twenty-four computer

literate respondents (70.8%) stated that they had searched for health information on the Internet, five respondents (20.8%) stated that they had not used the Internet for this type of information search, while the remaining two participants (8.3%) reported that they either had only ever searched once on the Internet for health information, or that they had not used the Internet recently for this purpose. After discussion with the respondents concerned, the researcher decided to include these two individuals in the group answering the questions relating to those who had not used the Internet to search for health information, but that the respondent who had searched for health information although not recently would also answer the questions relating to their experiences when they had used the Internet. However, for further statistical analysis using the chi-square statistic to determine whether there was variation between the geographical areas, the respondents were divided into those who had searched for health information on the Internet at least once (even the individual who had not searched recently) which translated into nineteen respondents (79.2%) compared to the five respondents who had never used the Internet for this purpose. There was a large disparity in geographical areas in the answers to this question as all of the suburban/urban respondents reported that they had all used the Internet at least once to search for health information, whereas it was only just over half of the rural respondents (54.5%) who stated this and using the chi-square statistic, this disparity was found to be statistically significant to the level of $p < .01$.

The seven respondents (two suburban/urban respondents and five rural respondents) who either reported that they had not searched for health information on the Internet or had used it once or not recently were then asked to answer some additional questions specific

to this grouping. The first of these was to try to establish the reasons behind these individual's reluctance to use the Internet to retrieve health information while using computers for other reasons. In answer to this question, four of the seven respondents stated that they had either not considered using the Internet for this task or had not got round to using it for this purpose. Two respondents stated that they would still ask their doctor for any health information as this had been a tried and tested resource previously. The other responses given by a single individual each were due to the unwieldiness of the Internet, the inconsistency of the screen reader that they were using, and that the participant felt they were "pretty healthy".

Variable	Total Sample (n=24)	Suburban/urban participants (n=13)	Rural participants (n=11)
Used Internet to search for health information?			
Yes	17 (70.8%)	11 (84.6%)	6 (54.5%)
No	5 (20.8%)	0	5 (45.5%)
Once/not recently	2 (8.3%)	2 (15.4%)	0
Used Internet – Yes/No			
Yes at least once	19 (79.2%)	13 (100.0%)	6 (54.5%) ***
No	5 (20.8%)	0	5 (45.5%)
Reasons do not use Internet for health info?			
Haven't considered it/got round to it	4	1	3
Use doctors	2	0	2
Inconsistency of screen reader	1	1	0

Unwieldiness	1	1	0
Am healthy	1	0	1
Motivation to use Internet for health info?			
More training/learning to use it	2	1	1
Wanted instant information	2	0	2
Only way to access information	1	1	0
Wanted different info than provided by doctor	1	0	1
Wouldn't use it	1	0	1
Ask someone else to retrieve health info?			
Yes	7 (100.0%)	2 (100.0%)	5 (100.0%)
No	0	0	0
Who would you ask?			
Family	4	0	4
Friend	2	1	1
Colleague	1	1	0

*** p<.01

Table 14. Questions 1 and 1a, 1b, and 1c of Section E for computer literate respondents

The respondents were then asked to state what motivation or requirements would be required for them to use the Internet to search for health information. Two of the seven participants stated that they would use the Internet if they wanted to locate instant information with one individual stating that if they “wanted to find out instant

information at strange times”. Another two participants reported that they would use the Internet if they had more training and experience with using it including one participant saying that the requirement would be to “basically just learning how to use it”. The other responses to this question suggested by one individual each included comments such as “if heard about medical information and the only way to access that information is by the Internet”, if they were “wanting more or less detailed information than get from doctor”, and one individual who stated that they “don’t think would use the Internet” to ever retrieve health information.

Although they had not personally used the Internet to access health information, the next question asked the respondents whether they would consider asking someone else to retrieve health information for them from the Internet, and if so, who they would ask to get the information. All seven of the respondents stated that they would consider asking somebody else to get this information for them with the majority (four out of the seven participants) stating that they would ask a member of their family to do the search, including an individual who stated that they would their daughter who was a nurse. Two participants reported that they would ask a friend, with one stating they would get them to find information on health insurance for them, while the other individual stated that they would get a work colleague to use the Internet for them.

The rest of question 1 within Section E and the appropriate sub-questions were then asked of those participants who stated that they had searched for health information using the Internet (including the respondent who specified that they had not searched recently)

which meant that twelve suburban/urban respondents and six rural respondents (eighteen participants in all) answered these questions. Table 15 demonstrates the responses to the first three questions asked of these respondents regarding their experiences of searching for health information on the Internet and were in connection with the sort of health information they have sought using the Internet and the frequency of their searches. The questions asked are as follows:

1. d. If YES, what type of health information have you searched for on the Internet?
- e. What type of health information do you most frequently search for on the Internet?
- f. How frequently do you search for health information on the Internet?

In order to determine the sorts of health information that the respondents had sought on the Internet, the initial question asked the types of health information that they had searched for on the Internet at any time. All but two of the respondents (sixteen out of eighteen participants) stated that they had looked for information regarding an ailment or disease. Examples of the types of ailments or diseases searched for included asthma, autism, Crohn's disease, multiple sclerosis (MS), Addison's disease, and osteonecrosis. A third of the respondents (six out of eighteen) stated that they had used the Internet to look for information on drugs or medications including drug interactions, while four respondents each reported searching for dietary and vitamin information, and to seek information on specific health professionals, including pharmacists and foot doctors. Other common responses to this question included seeking any new information with regards to eye problems in general, and specifically the visual problems that they were

suffering from, and looking at health insurance information with three respondents each, and information on specialized equipment or aids which was stated by two participants. The remaining types of information that were mentioned by one participant each were work-related queries, new studies or research that was being undertaken, surgical procedures, herbal remedies, and information on the services that are provided for people with visual impairment.

There appeared to be a disparity in the type of health information sought on the Internet between geographical areas with the suburban/urban respondents being more likely to seek information on dietary and vitamins, research into eye problems, and health insurance information. All of the rural respondents specified that they had sought information on a disease or an ailment using the Internet, although due to the nature of the responses and the question itself, this apparent disparity cannot be examined statistically using quantitative statistical methods so can only be reported as a potential trend between the geographical areas.

The next question sought to identify the types of health information that they most frequently sought when using the Internet for this purpose by asking them to be more specific than the previous question. A third of the respondents (six out of eighteen) stated that they most frequently searched for general health information when and if the need arose, whereas information on new cutting-edge research, dietary and nutritional information, health insurance, and seeking information on specific ailments was reported by three participants each. The other categories of type of health information stated by

one respondent each were diagnostic information, drug information, treatment into multiple sclerosis, surgical procedures, exercise, and natural remedies. One other respondent stated that they most frequently searched for health information “as needed”.

Variable	Total Sample (n=18)	Suburban/urban participants (n=12)	Rural participants (n=6)
Type of health information sought?			
Information on a disease/ailment	16	10	6
Drug information	6	4	2
Dietary/vitamins	4	4	0
Health professionals	4	3	1
Research into eye problems	3	3	0
Health insurance	3	3	0
Equipment/aids	2	1	1
Work-related	1	1	0
Studies being undertaken	1	1	0
Procedures	1	1	0
Herbal remedies	1	0	1
Services	1	0	1
Type of health information most frequently sought?			
General health	6	4	2
Research	3	3	0
Dietary	3	2	1

Insurance	3	2	1
Specific ailments	3	1	2
Diagnostic	1	1	0
Drug	1	1	0
Treatment	1	1	0
Surgical procedures	1	1	0
Exercise	1	0	1
Natural remedies	1	0	1
As needed	1	1	0
Frequency of health information searches?			
Fortnightly	5 (27.8%)	4 (33.3%)	1 (16.7%)
Monthly	8 (44.4%)	6 (50.0%)	2 (33.3%)
2 monthly	1 (5.6%)	0	1 (16.7%)
6 monthly	3 (16.7%)	1 (8.3%)	2 (33.3%)
As needed	1 (5.6%)	1 (8.3%)	0

Table 15. Questions 1d, 1e, and 1f of Section E for computer literate respondents

The respondents were then asked to describe how frequently they used the Internet to search for health information. The most common response with eight out of the eighteen respondents (44.4%) was that they used the Internet to search for health information once a month. Five participants (27.8%) stated that they searched even more frequently than that by reporting that they searched on the Internet twice a month or fortnightly. The remaining respondents reported searching for health information either once every two months (one respondent, 5.6%), once every six months or twice a year (three respondents, 16.7%), or as needed (one respondent, 5.6%). These figures were tested for

statistical significance using a t-test analysis to determine if the variance between geographical areas was significant or not and it was found to be not significant.

Now that the types of health information that were being sought by using the Internet and also the frequency of these searches had been established, the next set of questions attempted to establish whether the respondents had encountered any problems or had to overcome any obstacles when retrieving this information, how they had overcome these problems and obstacles, and whether they only searched for themselves or for other people as well and who these people were. The questions asked within this set are as follows:

1. g. Have you encountered any problems/obstacles while retrieving health information on the Internet?
 - h. How did you overcome these problems?
 - i. Do you search for health information only for yourself or have you performed searches for other people as well?

The responses to these questions are shown in Table 16 and the questions asked in a way as to encourage a similar type response to the questions relating to any problems the participants may have had technological machines as asked in the previous section.

The respondents were asked if they had experiencing any problems and obstacles when retrieving health information from the Internet. The majority of respondents (fourteen out of eighteen respondents or 77.8%) stated that had encountered problems during these

type of retrievals, while four respondents (22.2%) stated that they had experienced no problems or obstacles during their searches for health information on the Internet.

The respondents then specified a large number of different barriers and obstacles that they had encountered when retrieving health information from the Internet. The most common response with four respondents was problems with inaccessible websites. An example comment of this problem was that “some sites (off Google) for topics – just not accessible”. Other obstacles that were mentioned by three respondents each were with the prevalence and readability of graphics on websites (e.g. “websites using too many graphics without text”), and navigational problems caused by the screen readers they use (e.g. “screen readers don’t read everything on screen and skip stuff”, while problems mentioned by two respondents respectively were in relation to pdf (files created in Adobe Acrobat) files being unreadable, having trouble retrieving the specific information desired, and the problems of locating the information required within the information available on the Internet (e.g. “hard to locate what I want due to the vast amount of information on the Internet”). Some of the other problems and obstacles mentioned by one participant were problems with data entry, the transferring and formatting of files into a readable format, websites that have advertisements that are not readable, that it takes longer for them to access the information they require, and the unwieldiness of the Internet.

Variable	Total Sample (n=18)	Suburban/urban participants (n=12)	Rural participants (n=6)
Problems retrieving info. from the Internet?			
Experienced problems	14 (77.8%)	10 (83.3%)	4 (66.7%)
Experienced no problems	4 (22.2%)	2 (16.7%)	2 (33.3%)
Type of problems			
Inaccessible websites	4	3	1
Graphics not labeled	3	3	0
Navigation for screen reader	3	2	1
Pdf files not readable	2	2	0
Trouble retrieving specific information	2	1	1
Too much information	2	1	1
Entering information	1	1	0
Transferring/formatting files to readable format	1	1	0
Advertisements	1	1	0
Takes longer	1	1	0
Unwieldiness	1	1	0
How did you overcome problems?			
Go to more accessible website	5	4	1
Call somebody for help	5	4	1
Convert file to accessible format	2	2	0
Bookmark links	1	1	0

Write letters of complaint	1	1	0
Persistence	1	0	1
Scream a little	1	0	1
Haven't overcome them	1	0	1
No problems	5	3	2
Search for health information only for self or other people?			
Self only	7	5	2
Self, family	7	2	5
Self, friends	5	2	3
Self, other people too	4	4	0
Self, work colleagues	2	2	0
Self, students	1	1	0
Self, people with development disabilities	1	1	0
Self, client	1	1	0

Table 16. Questions 1g, 1h, and 1i of Section E for computer literate respondents

Now that the respondents had been asked what problems and obstacles they had encountered when searching for health information on the Internet, they were then asked to identify how they had overcome these problems. The two most frequent responses (with five respondents each) were that they either went to websites that were more accessible than the ones they originally accessed (e.g. “not designed for me will go to a website more accessible”), or that they called somebody over to help them access the information that they desired (e.g. “call somebody to ask for help” and “get a sighted person to navigate themselves”). Other methods to overcome the problems reported in the

previous question were to convert inaccessible files into more accessible formats (two respondents), book marking and remembering links, writing letters to complain about inaccessible websites, and persistence (one respondent each). In addition, two respondents had not overcome their problems with one suggesting that they “scream a little”, while the other stated that they hadn’t overcome their problems. Once again, a sizeable number of respondents (in this case, five out of eighteen respondents) stated that they had no problems with accessing health information via the Internet.

The respondents were next asked whether when they searched for health information on the Internet, they did it only for themselves or whether they also performed searches for other people as well, and if so, who these people were. The most frequent responses with seven participants each were that they only searched for health information for themselves, and that they searched for other family members in addition to themselves. There was some variation between geographical areas as the suburban/urban respondents were more likely to search only for themselves (5/12 suburban/urban respondents), whereas five out of the six rural respondents also searched for family members as well. Some of the other common responses were that the participants also performed searches for friends (five respondents) or for unspecified other people (four respondents) as well as for themselves. The remaining responses offered to this question included performing searches for work colleagues (two participants), students of theirs, people with developmental disabilities, and looking up related information for a client (one respondent each).

The next set of questions within this section sought to identify the methods that the respondents used when searching for health information using the Internet, and to examine their impression of some of the websites they had visited during these searches while listing the sites that they had encountered. The responses to these questions are reported within Table 17 and the specific questions asked are as follows:

1. j. What method do you use when searching for health information on the Internet?
- k. What are some of the websites that you have visited recently?
- l. What was your impression of these sites?

When the respondents were asked about the methods that they employed when searching for health information on the Internet, the most common response was something that indicated that people with visual impairment using the Internet were employing the same methods for accessing information as the rest of the population as the vast majority of the respondents (fifteen out of eighteen respondents) by using the search engine Google (www.google.com) as their initial point of access to enter a search term and then using the links specified to look for more specific information. The next most common response was to enter their search terms using a different search engine (usually MSN search) with five participants with the majority of these respondents coming from the rural geographical areas, while four respondents stated that they used the health information website WebMD (www.webmd.com). Two respondents each reported using information held within medical libraries and from websites connected with health insurance agencies to search for health information, while one individual each specified using websites that were dedicated for people with visual impairment, other health

browsers (unspecified by the respondent), Medline, the Mayo Clinic website (www.mayoclinic.com), the Kelly Blue Book, and alternative newsletters as the methods employed.

The next question asked the respondents to list which health information websites that they had visited recently. There were many varied responses to this question and so the websites reported have been grouped into categories when the underlying functions of the websites were predominantly similar. The most frequent response given by the participants was that they had visited websites that gave specific medical information that they required with six respondents stating this. Examples of these websites were a Cincinnati podiatrist, the National MS Society (www.nmss.org), www.carcinomacarcoid.org, www.maxiatas.com, and a website run by a Dr. Harkola for tropical conditions. The next most frequent answers with three participants each were using the links specified following the entering of search terms within Google, health insurance websites (e.g. UnitedHealth and CaseWesternReserve), and using WebMD (www.webmd.com), whereas two participants each reported accessing Medline, the Mayo Clinic website (www.mayoclinic.com), drug information websites (e.g. Rxlist – www.rxlist.com), and health and nutrition websites (e.g. www.DrWeal.com and www.foodnetwork.com). Other websites visited by one individual were the Vision Northwest website, the National Health Service (NHS) site, sites linked to Universities (OHSU and West Washington State), a newspaper site (SF Tribune), Wikipedia, and a herbal website for cures and remedies. In addition, three respondents could not remember the specific health information websites that they had recently visited.

Variable	Total Sample (n=18)	Suburban/urban participants (n=12)	Rural participants (n=6)
Method of searching for health information?			
Google	15	10	5
Other search engine	5	1	4
WebMD	4	2	2
Medical libraries	2	2	0
Insurance agencies	2	2	0
Websites for visually impaired	1	1	0
Health browsers	1	1	0
Medline	1	1	0
Mayo Clinic site	1	1	0
Newsletters	1	1	0
Kelly Blue Book	1	0	1
Websites visited when searching?			
Specific medical sites	6	5	1
Links off Google	3	2	1
Health insurance sites	3	2	1
WebMD	3	1	2
Medline	2	2	0
Mayo Clinic site	2	2	0
Drug information	2	2	0
Health & Nutrition	2	1	1
Vision NW	1	1	0
University site	1	1	0
Newspaper site	1	1	0

Wikipedia	1	0	1
Herbal site	1	0	1
Can't remember	3	2	1
Impression of websites visited?			
Positive impression	11 (68.7%)	7 (70.0%)	4 (66.7%)
Negative impression	5 (31.3%)	3 (30.0%)	2 (33.3%)
Specific impression reported			
Accessible to use	5	3	2
Easy to navigate	4	3	1
Good/satisfactory	3	2	1
Not able to find specific information	2	1	1
Informative	2	1	1
Problems with links	1	1	0
Professional and authoritative	1	1	0
Relieved to be done	1	1	0
Not easy to navigate	1	0	1
N/A	1	1	0

Table 17. Questions 1j, 1k, and 1l of Section E for computer literate respondents

The respondents were then asked to give their impressions of the websites that they had visited to retrieve health information via the Internet. The responses were generally positive with the most common response being that the websites they had visited were accessible to use with five participants reporting this response with an example of the type of comment reported being that the websites visited were “accessible and able to get

your information”. Four participants stated that the websites they had visited were easy to navigate (e.g. “columns separated easily so could easily navigate well and easily”), while three respondents simply stated that the sites they had visited were good or satisfactory for their purposes. However, not all the responses reported were positive with two respondents stating that they had had problems retrieving the information they desired (e.g. “frustrated because it said it would give information and didn’t find it”, and “pain to find specific information”), one individual had problems with navigating around the websites they visited (“not easy to navigate; can’t get into some places on the site”) and one specifying that the links they were accessing were not totally accessible. Other impressions of health information websites included two respondents reporting that the websites visited were informative, while one participant thought that the site they visited was “very professional and authoritative”, one was just “relieved to be done”, while the final participant did not give an opinion. These responses were then grouped into positive and negative impressions given by the individuals on the health websites visited to examine if there was any variation between geographical areas with two individuals being excluded from this further analysis as the responses they gave could not be designated as either positive or negative. However, a t-test analysis on this grouping showed that there was no statistically significant variation seen between the geographical areas.

The next set of questions sought to identify how satisfactory the respondents were with the information that they managed to retrieve when using the Internet to search for health information, the length of time they usually spent when performing these types of

searches, and how they described their experiences of searching for health information on the Internet. The specific wording of these questions is as follows:

1. m. How satisfied have you been with the health information that you have retrieved?

n. How long does it normally take you to perform these searches?

o. What has been your experience when searching for health information online?

The respondent's responses to these questions are shown in Table 18.

When asked about how satisfied the participants were with the health information that they had retrieved via the Internet, the majority of the respondents were happy with the results they managed, seven of the respondents (38.9%) specified that they were either pretty satisfied or quite satisfied with the information that they retrieved while another seven respondents (38.9%) stated that they were very satisfied with the results of their searches. There was an apparent disparity between geographical areas as the majority of respondents who were pretty or quite satisfied came from the suburban/urban respondents, while nearly all the rural participants (5/6 or 83.3%) stated they were very satisfied. Other single individual responses (5.6%) were that one participant was minimally satisfied, another individual found no reason for dissatisfaction, while the final respondent found the experience to be "so-so". To examine the significance of this apparent disparity within the geographical areas, the responses were then further grouped into the three categories of 'Very', 'Quite' which included the pretty satisfied, quite satisfied, so-so, and no reason for dissatisfaction comments, and 'Minimally' for a t-test

analysis to be performed on these categories. This further analysis showed a statistically significant variation to the level of $p < .01$.

However, just reporting on the satisfaction level of the respondents tells only half the story of their responses to this question as nearly all of the answers contained information detailing why their satisfaction levels were as they were so it is important to list some of the comments to put their levels of satisfaction into context. Some of the comments that accompanied the pretty of quite satisfied responses included “pretty satisfied, more information that could have gotten any other way”, “quite satisfied, more confident about the surgical procedure”, and “quite satisfied, managed to find the information was searching for”. Comments for the very satisfied group included “very satisfied, double check with health professionals if unsure”, “been very satisfied, would have found diagnosis much quicker if just used Internet”, and “very satisfied with all sites, easily navigatable”. The individuals who were not quite as satisfied with the results of their searches included comments such as “no reason for dissatisfaction, but more information needed on areas of interest”, “minimally, so much verbage – give me the facts!”, and “so-so, not specific enough, want you to pay for services for information”.

Variable	Total Sample (n=18)	Suburban/urban participants (n=12)	Rural participants (n=6)
Satisfaction with health information?			
Very satisfied	7 (38.9%)	2 (16.7%)	5 (83.3%)
Pretty/quite satisfied	7 (38.9%)	7 (58.3%)	0
Minimally satisfied	1 (5.6%)	1 (8.3%)	0

No reason for dissatisfaction	1 (5.6%)	1 (8.3%)	0
So-so	1 (5.6%)	0	1 (16.7%)
No answer	1 (5.6%)	1 (8.3%)	0
Secondary grouping of satisfaction			
Very	7 (38.9%)	2 (18.2%)	5 (83.3%) ***
Quite	9 (52.9%)	8 (72.7%)	1 (16.7%)
Minimal	1 (5.6%)	1 (9.1%)	0
Length of time taken to perform search?			
Less than 15 minutes	4 (22.2%)	3 (25.0%)	1 (16.7%)
15-29 minutes	4 (22.2%)	3 (25.0%)	1 (16.7%)
30-59 minutes	5 (27.8%)	2 (16.7%)	3 (50.0%)
1 hour or more	3 (16.7%)	2 (16.7%)	1 (16.7%)
Other time periods	2 (11.1%)	2 (16.7%)	0
Experience of searching for health information online?			
Positive experience	11 (64.7%)	9 (81.8%)	2 (33.3%) **
Negative experience	6 (35.3%)	2 (18.2%)	4 (66.7%)
Specific comments of experience			
Positive	8	7	1
Information is there if you take time	4	2	2
Too much effort to browse	3	3	0
Frustrating	3	1	2
Problems with screen reader	3	1	2

Always specific	1	1	0
Get information quickly	1	1	0
Enables informed decisions	1	0	1
Inconsistency	1	0	1
Takes time to learn	1	0	1

*** p<.01, ** p<.05

Table 18. Questions 1m, 1n, and 1o of Section E for computer literate respondents

The next question asked the respondents the length of time that they normally took to perform searches for health information using the Internet. As the responses to this question often took the form of ranges of time, the answers were grouped into time periods for reporting purposes. The most common length of time taken for searches was between 30 and 59 minutes (answers of 30 minutes, 45-60 minutes, and 30-45 minutes) with five respondents (27.8%) reporting this length of time. Four respondents each (22.2%) stated that their searches took less than 15 minutes to take (5 minutes, 10 minutes, and 10-15 minutes) or between 15 and 29 minutes (15 minutes, 20 minutes, and 15-20 minutes) to perform, while three respondents (16.7%) stated that their searches took an hour or more (1 hour or 2 hours) to retrieve the information they wanted. The remaining two respondents (11.1%) gave lengths of time that traversed more than one of time groupings with one individual giving their searching time as between 15 minutes and an hour, while the other stated theirs as being between 5 minutes and 30-45 minutes to perform their health information searches. These groupings, with the exception of the two respondents who specified time periods that traversed more than one time grouping,

were then statistically tested using t-test analysis and were found to be not statistically significant.

The respondents were then asked to describe their experiences of searching for health information online and whether it was positive or not, or if they had encountered any problems or obstacles when using the Internet in this manner. The majority of respondents (eight out of eighteen respondents) stated that their experience's was generally positive, with often the participants stating that they generally found the specific health information that they were seeking. The next most common response with four respondents was that the participants stated that the information they were seeking was always available on the Internet as long as you had the patience and time to locate it. An example of this type of comment was "information is out there – just have to dig through sites to find information looking for". However, some respondents reported less positive experiences when performing their searches with three respondents each stating that using the Internet was taking to much effort or time to browse for information (e.g. "too much effort to browse"), that they found their experiences frustrating for them (e.g. "frustrating, due to length of time searching on Internet"), or that they were experiencing problems with using their screen readers when using the Internet (e.g. "sites are so cluttered, screen reader doesn't know where to go"). Other responses recorded when answering this question by one respondent each were that one individual always searched for something specific on the Internet, one stated that they could always get to accurate information very quickly, one stated that the Internet allowed them to make informed decisions regarding medical matters, one reported that they were having problems due to

the inconsistency caused by not being able to follow links, while the final respondent stated that it took a long time to generate the correct searches for the information they were looking for.

The responses to this question tended to be consistently negative or positive, even if the respondents specified a number of different comments relating to their experiences. The responses were then compressed into individuals who stated they had a positive experience (i.e. they had stated positive comments when answering this question) against those who had a negative experience (stated negative comments about their experience), with only one individual not being able to be grouped in this way as their response was ambiguous about whether their experience was positive or not. When the responses were grouped in this manner, there appeared to be a disparity between geographical areas with the suburban/urban respondents being apparently more likely to have a positive experience (nine out of eleven respondents or 81.8%) compared to the rural respondents (two out of six respondents or 33.3%). When this disparity was tested using the chi-square analysis, this disparity was found to be statistically significant to a level of $p < .05$.

The final two questions within this section that were solely asked of those participants who had reported using the Internet to search for health information, sought to ask the respondents whether they thought that their visual impairment hindered them when accessing health information online and if it did, in what ways, and whether they could come up with any recommendations or improvements that they could identify from their experiences on the Internet which would allow them to better access health information

online. The responses to these questions are found in Table 19 and the full questions are as follows:

1. p. Do you think your visual impairment hinders you when accessing health information online?
 - i. If YES, in what ways?
- q. What recommendations/improvements would you like to see to enable you to better access health information online?

The respondents were asked whether they thought that their visual impairment had hindered them when they attempted to retrieve health information from the Internet. As well as answering the main question, the respondents also often qualified their responses with additional comments which can also be reported. The participants were evenly split in response to this question with seven respondents each (38.9%) reporting that they thought that their visual impairment did hinder them when using the Internet, while an equivalent number stating that their visual impairment did not hinder them. The remaining four respondents (22.2%) stated that their visual impairment did hinder them at times, but not all the time. There appeared to be an apparent disparity between geographical areas with relation to this question as half of suburban/urban respondents stated they did feel that their visual impairment hindered them compared to just one of the six rural respondents who stated this, whereas two-thirds of the rural respondents reported that they did not feel their visual impairment hindered them at all. This variation was tested using a t-test statistical analysis and was found to be statistically significant at a level of $p < .05$.

As mentioned previously, the respondents often qualified their answers to this question with an additional comment. For those participants who stated that their visual impairment did not hinder them, example of why it did not included “with adaptive stuff can do same things”, “slower, but that means that you can remember a lot more about the information”, and “at work or at home as have tools with a smaller monitor”. These types of comments are important to note as it gives some insight into the lives of people with visual impairment and how they adapt to their impairment with respect to accessing and using computers and the Internet and how they see themselves using these machines to access health information which they might otherwise have problems accessing. These results can also be compared and contrasted with the opinions and comments of other computer and Internet users to determine any consistency or variation between groupings. There was only one individual who gave a comment as to why they thought their visual impairment hindered them when accessing health information online and they stated that “Yes, but not having enough education or experience of using computers”, which implied that the problems encountered were maybe less to do with their visual impairment and more to do with a basic lack of knowledge concerning the use and accessing of computers and the Internet.

For those people who stated that they thought that their visual impairment hindered them when searching for health information on the Internet, they were asked the circumstances that saw them being hindered (twelve respondents answered this question, ten suburban/urban participants, including an individual who previously stated that their

visual impairment did not hinder them, and two rural participants) in this manner. The most common complain was due to the inaccessibility of certain websites with the screen readers that the participants used which was reported by half the respondents (six out of 12). An example of a comment outlining this problem was in answer to the question, “accessibility issues – if the screen readers cannot read the page, not a whole lot you can do”. The other major hindrance that was reported by the participants that their visual impairment caused them was the additional length of time it took to perform their computer searches which was stated by four respondents. A telling comment was “takes longer; wife takes half the time for similar searches”. Other reported ways that single respondents mentioned as ways they thought their visual impairment hindered them were that they just could not scan a page within a website, they had a fear of computers, having problems with accessing photographs and videos on the websites, making it difficult to find the information that the participant was looking for, and having a monitor that was too small, making it “impossible or difficult”.

The participants were then asked what recommendations or improvements they would like to see which would better enable them to access health information on the Internet. The respondents gave a wide range of suggestions in answer to this question, with the most common response, with five participants each were making all websites accessible to all people, including those suffering from disabilities, and the related issue of websites containing too many photographs which could not be interpreted by screen readers with the photographs being replaced by text based information. Examples of replies for these groupings were “make sure people who create sites follows guidelines from W3C”, and “more people who learn to make their sites accessible” for the first grouping, while the

comments “little less photos, more text captions, voiceovers for photos and videos”, and “less pictures – should be option” were typical of the second grouping.

Variable	Total Sample (n=18)	Suburban/urban participants (n=12)	Rural participants (n=6)
Visual Impairment hinders you when using Internet?			
Yes	7 (38.9%)	6 (50.0%)	1 (16.7%) **
Sometimes/not always	4 (22.2%)	3 (25.0%)	1 (16.7%)
No	7 (38.9%)	3 (25.0%)	4 (66.7%)
Ways in which visual impairment hinders?			
Inaccessible sites with screen reader	6	6	0
Takes longer	3	3	1
Can't scan website	1	1	0
Fear of computers	1	1	0
Problems with videos/photos	1	1	0
Not easy to find information	1	0	1
Too small to read	1	0	1
Recommendations for making websites more accessible?			
Make websites more accessible	5	5	0
Less photographs/ more texts	5	3	0

Increasing webtags/PDF files	3	3	0
Label all graphs	2	2	0
Specific health browser	2	1	1
No ads/pop-ups	2	1	1
Sites specially for visually impaired	2	0	2
Websites screen reader friendly	1	1	0
Better access to research	1	1	0
Spelling issues	1	1	0
Increased use of HTML	1	1	0
Better organization	1	0	1
Information that's site specific	1	0	1
Consistency	1	0	1
Too much music/entertainment	1	0	1

** p<.05

Table 19. Questions 1p, and 1q of Section E for computer literate respondents

Other recommendations suggested by multiple respondents were the increase of webtags, especially within PDF files (e.g. “webmasters who don’t use webtags should be educated”) with three respondents, and, ensuring that all graphs within websites are properly labeled (e.g. “labeled graphs make it so you can tab through stuff”), the creation of a specific health browser (e.g. “health browser – make it similar to main browser or Google”), the removal of advertisements and pop-ups from websites (e.g. “nice to skip banners and advertisements”), and the creation of websites that are created specifically

for people with visual impairment (e.g. “Sites that specializes for people with visual impairment”) that were all stated by two participants each. Recommendations and improvements suggested by one individual each were making websites more screen reader friendly, allowing easier access to cutting-edge research and development, ensuring all spelling problems are sorted out, the increased use of HTML in website creation, better organization of websites, websites containing information that is state specific, ensuring consistency between websites which makes it easier to navigate, and reducing the amount of music and entertainment on certain websites.

The remaining questions within this section were answered by all the participants in the study who were considered computer literate again, including those who had not used the Internet to search for health information previously (thirteen suburban/urban respondents and eleven rural participants) and therefore answered some different questions previously in the section. The next couple of questions sought to question the respondents about how much benefit the Internet could be in providing health information for people with visual impairment, and also to attempt to identify how trusting and truthful they thought that the health information that they could retrieve from the information actually was. This second question was also asked of the non computer literate group also. These questions are as follows:

2. Do you think that being able to access health information online provides potentially greater benefit for people with visual impairment?
3. How trustworthy and accurate do you consider health information on the Internet to be?

The participant's responses to these questions are recorded in Table 20.

In response to the questions asking the respondents whether they thought that being able to access health information online provided greater benefit to people with visual impairment, the majority of participants suggested it would with twenty-one out of twenty-four respondents reporting this answer (87.5%). Out of the three remaining respondents who did not answer yes to this question, one participant each (4.2%) thought it didn't provide any greater benefit, one stated that they didn't know one way or the other, and the final participant suggested that it depended on the person as they suggested that "some people might be scared".

The participants were then asked to elaborate on their reasons given for their answer to the previous question. The most frequent answer (ten respondents) reported was that they thought the Internet would provide benefit by allowing instant access to health information. Examples given by the respondents included "[provide information] for people who can't get information any other way", and "instant accessibility to information rather than relying on doctors". Other common themes included allowing easy access to non-printed material which was reported by five respondents as typified by the comment, "lots of information available, people not restricted to Brailled information", the ability to have some freedom and independence which was stated by four participants (e.g. "privacy to find information on your own, some independence"), whereas three participants stated that it allowed them to access information at their homes

such as the comment that the Internet was a “resource that can be accessed at home with large amount of information”.

Other themes raised by the respondents in answer to this question were that being able to access health information online would allow better informed decisions to be made (e.g. “access to information that allows patients to make better informed decisions”), and that it was easier to retrieve information than going to a library with two respondents reporting this each. Responses stated by single individuals were that it needed to provide benefits for people with visual impairment, it would allow hospitals to provide information before visits, it depended on the person, and that benefits would only occur if the person had either the skills to navigate online, or only if they had the right equipment to use.

Variable	Total Sample (n=24)	Suburban/urban participants (n=13)	Rural participants (n=11)
Do you think the Internet provides greater benefit?			
Yes	21 (87.5%)	12 (92.3%)	9 (81.8%)
No	1 (4.2%)	1 (7.7%)	0
Don't know	1 (4.2%)	0	1 (9.1%)
Depends on the person	1 (4.2%)	0	1 (9.1%)
Will benefit in what ways?			
Instant access to information	10	5	5

Access to non-printed material	5	4	1
Have freedom/independence	4	2	2
Accessibility at home	3	0	3
Allow more informed decisions	2	2	0
Easier than library	2	2	0
Provide benefits for visually impaired	1	1	0
Provide information before visits	1	1	0
Depends on the person	1	0	1
Only if you have the skills to navigate	1	0	1
If you have the right equipment	1	0	1
Is health information on the Internet accurate & trustworthy?			
Depends on the site/source	11	8	3 (27.3%)
Associated with university/hospital/ailment	8	5	3 (27.3%)
If it's a reputable/credible source	3	3	0
Research multiple sites and compare	3	1	2 (18.2%)
Think it is accurate and trustworthy	2	1	1 (9.1%)
Negative responses	5	4	1 (9.1%)
Questioning responses	4	2	2 (18.2%)

“Comparable” responses	4	2	2 (18.2%)
Accuracy rating responses	3	0	3 (27.3%)
Solely positive or negative response?			
Positive response	6 (60.0%)	4 (100.0%)	2 (33.3%) **
Negative response	4 (40.0%)	0	4 (66.7%)

** p<.05

Table 20. Questions 2 and 3 of Section E for computer literate respondents

The respondents were then asked to give their opinion on how trustworthy and accurate they thought the health information on the Internet to be. As the responses given were very wide ranging and in many occasions the respondents offered more than one comment, there has been a need to group some of the less frequent responses into themes identified by the respondents, these are shown within Table 20 as negative responses, questioning responses, comparable responses, and accuracy rating responses. The most frequent individual response given to this question with eleven respondents was that the accuracy and trustworthiness was dependent on the site or source information, whereas eight respondents suggested that they would be more confident of the websites content if it was associated with or obtained its information from a university, a hospital, a website that was associated with trusted medical professionals, or a website that was solely associated with a specific ailment or disease. Other responses reported by multiple respondents were that the respondents would be happy to trust a website where the information came from a reputable or credible source, that the respondents would look at the information reported on multiple websites and compare the results (three respondents

each), and two individuals who simply stated that they thought that the health information stored on the Internet was accurate and trustworthy.

As mentioned previously, some of the respondent's responses to this question were grouped into themes. The negative responses (five participants) provided responses that doubted the accuracy and trustworthiness on the Internet of some health information and consisted of comments such as "pharmaceutical site not trustworthy", and "some websites are not trustworthy as per TV". Four respondents gave answers that implied that they would themselves question the accuracy of the information they had accessed including the statements that they "would question website if just came across it", and "seeing where the site is getting its information from". Another four participants reported answers where they compared the health information that can be retrieved from the Internet with other sources such as "comparable to stuff read in the newspaper", and "if doctor recommends website would be more trusting". A further three respondents stated a percentage for how accurate and trustworthy they considered the information to be with one individual stating it was "80-90% accurate", another reporting they thought it to be "75% trustworthy", while the final respondent was less convinced and only thought it to have "50%/50% accuracy".

The responses were then grouped into individuals who commented solely in a positive or negative manner to the accuracy and trustworthiness of health information on the Internet. This reduced the number of individuals to six individuals who gave solely positive comments and four respondents who stated solely negative comments. However,

it was interesting to note that all of the suburban/urban respondents classified in this manner gave positive comments compared to two-thirds of the rural population who gave negative comments and when this disparity was statistically analyzed using a chi-square analysis, this variation was found to be statistically significant at a level of $p < .05$, although this result needs to be quantified as only using a subset of the respondents where a clear pattern of positive or negative comments was observed.

The final two questions of the section and interview for the computer literate respondents sought to identify whether the participants thought that they were being able to retrieve and receive comparable health information to those people who do not have visual impairment, irrespective of the means they employed to get that information, and whether they wished to share any other details of their experiences of searching for health information which had not been previously recorded. The final question was also the final question asked of the non computer literate respondents as well. The responses to these questions are shown in Table 21 and the full explanation of the questions asked is as follows:

4. Do you feel you are getting comparable health information to those people who do not have visual impairment?
5. Are there any other comments you would like to make regarding your experiences of retrieving and accessing health information?

The respondents were then asked whether they believed that they were getting comparable health information to those people who did not have visual impairment. This

question was not solely asked with the Internet as the source of health information, but of all methods of retrieving this information. The majority of respondents thought that they were receiving comparable information with seventeen out of the participants reporting this (70.8%). However, five respondents (20.8%) stated that they did not think they were getting equivalent information, while the remaining two respondents reported that they thought they were getting fairly comparable information, or that they couldn't judge so far (one individual or 4.2% each). These results (with the exception of the individual who couldn't judge so far who was excluded from this analysis) were then statistically tested using the t-test statistic and were found to be not statistically significant.

The respondents were then asked to expand on their answers to give an explanation of why they thought they were or were not getting comparable information and their comment were very varied and difficult to group into themes. The most common response was that the Internet allowed them to access information that they could not otherwise access as they could not browse the information at a library or using books. This response was stated by five respondents. The next common response was that four participants who reported that their searches took them longer regardless of whether they thought they could get comparable information, whereas three respondents stated that they thought they could get all the information they wanted for the most part using the Internet as a resource. Themes raised by two individuals each were that two people who thought they were not getting comparable information due to visually impaired people having to rely on other people to read information to them, that they were frustrated when doctors continually gave them written pamphlets and booklets, that people with visual

impairment were more focused during their searches, and that they could get comparable information on the Internet, but not elsewhere.

The comments reported by one individual each were that there were still problems with accessing videos and photographs, they were totally dependent on the Internet to access health information, one was concerned about how diligent other people with visual impairment were about retrieving health information, that they went on what people told them over the telephone, that they could get most information they wanted from the Internet, they got comparable information due to their relationship with their doctors, that it aids independence and freedom, they got their information verbally from doctors, and that one individual could not judge whether they will eventually get comparable health information.

Variable	Total Sample (n=24)	Suburban/urban participants (n=13)	Rural participants (n=11)
Getting comparable health information?			
Yes	17 (70.8%)	9 (69.2%)	8 (72.7%)
Fairly	1 (4.2%)	1 (7.7%)	0
No	5 (20.8%)	3 (23.1%)	2 (18.2%)
Can't judge so far	1 (4.2%)	0	1 (9.1%)
Ways getting/not getting comparable information?			
Not being able to browse at library/books	5	2	3

Takes longer	4	3	1
For the most part with Internet	3	1	2
Having to rely on other people	2	1	1
Frustrated when given written information	2	2	0
Yes, on the Internet, otherwise not	2	2	0
More focused	2	1	1
Problems with videos and photographs	1	1	0
Totally dependent on Internet	1	1	0
Concerned about other visually impaired people	1	1	0
Can't judge so far	1	0	1
Go on what people tell you on phone	1	0	1
Able to access information on Internet	1	0	1
Due to relationship with doctors	1	0	1
Aids independence	1	0	1
Get verbal information from doctors	1	0	1
Other comments regarding health info?			
Problem of getting accessible information	5	2	3
Internet as 2 nd opinion	2	0	2

Before, no chance of getting information	1	1	0
As vision degenerates, answers will change	1	1	0
Nothing beyond use of Internet	1	1	0
Doctors to not send print	1	1	0
Personal ambitions	1	0	1
Getting answers to questions	1	0	1
Use Internet when skills improve	1	0	1

Table 21. Questions 4 and 5 of Section E for computer literate respondents

The final question of the interview asked the respondents whether they had any other comments they would like to make regarding their previous experiences of retrieving and accessing health information. The most common response with five respondents was that the biggest problem they were encountering was getting accessible information. A couple of examples of the comments made on this theme were “hospitals and clinics are lacking accessible information”, and “big problem is printed form and producing accessible information”. Two respondents reported that using the Internet for seeking health information was a good way to check information from other sources including the comment that “Internet is best way of getting information if you can’t get it from your doctor, always seek a second opinion from the Internet”. The other responses purported by one individual each included the comments that “10-15 years ago did not have option

of getting information”, “as vision degenerates, answers would change”, “no complaints beyond use of Internet”, “wish the doctors would not send print, but put on tape or e-mail”, “depends on the personal ambitions of people to help themselves”, “more improvements to honesty and directness of doctor/source regarding the answer to questions”, and “will use Internet when computer skills improve”.

DISCUSSION

When discussing the results of the study, it is worth revisiting and seeking answers to the main research questions as specified earlier within the thesis proposal, and also to compare the results of the study with the previously published research into health information retrieval using the Internet and with the use of computers and technology by people with visual impairment.

Discussion of main research questions of the study

1. Where do people with visual impairment in Oregon go to satisfy their health information needs and requirements?

The response to this question given by the respondents was that they most frequently either talked to a doctor or another health professional, or they used either a computer or the Internet to retrieve these needs and requirements. Both of these responses were given by eighteen out of the twenty-eight participants, although there was a disparity between the geographical areas with nearly all of the suburban/urban participants reporting that they used a computer or the Internet, whereas the rural participants were more likely to seek their health information by talking to a doctor or health professional. When these trends were examined using statistical methods it was found that only the suburban/urban respondents trend to be more likely to use a computer or the Internet as a method to seek health information was found to be statistically significant ($p < .01$). In addition to the major two categories, nearly a third of the respondents stated that they might get some health

information by talking to friends, family or someone else who had knowledge of the specific information that they were seeking.

When the respondents were asked the people that they would trust to answer health questions for them and who they would ask, the majority stated that they would primarily ask a doctor or physician health questions, while they would most commonly trust either friends or family (although the number of respondents who would also trust doctors and physicians was large too). Other common responses to who people with visual impairment would ask included other health professionals (besides their doctor or physician) or someone who was suffering from the condition in which they were seeking information.

Examining whether the respondents had actually used the Internet to search for health information at least once also indicated a disparity between geographical areas as all of the suburban/urban respondents had used the Internet in this manner compared to just over half of the rural respondents. Further statistical analysis showed that this variation between geographical areas showed statistical significance ($p < .01$) with the suburban/urban respondents more likely to use the Internet for this purpose.

2. What barriers or obstacles exist that prohibits or stops those people with visual impairments from using online health information resources?

To completely answer this question, the different groupings within the study need to be looked at independently. For those individuals who were classified within the study as being non computer literate (n=4), the main issues why they did not use computers was the lack of knowledge and experience with using them, issues to do with the security of the systems, and that they preferred to use other methods in order to retrieve the information. It is interesting to note, however, that all of these individuals stated that they would consider asking someone else to retrieve health information for them by using the Internet.

The next grouping of respondents was those who were classified as being computer literate respondents (n=7), but who had not used their computers or the Internet in order to specifically seek health information. The main reason given why this group of respondents had not used online health resources was that they simply had either not considered it or had not currently got round to it. Consistently with the non computer literate grouping specified earlier, all of the individuals within this group stated that they would consider asking someone else to retrieve health information for them using the Internet.

The final group to answer this research question were those respondents who had actually used the Internet to search for health information previously (n=18) and would provide a good indication of the problems and barriers they had encountered during their previous searches. The respondents gave a large number of problems that they had faced including the common theme which was connected to problems with the inaccessibility of websites

and their poor methods of labeling and navigation that led to frustration and problems with people using screen readers and other software tools to access the information that was stored on them. The main methods that were employed to circumnavigate these issues were not ideal as they would generally either go to a more accessible website or they would rely on somebody (usually normally sighted) to help them navigate around the website and locate the information they required.

3. Are there variations in the health information seeking patterns of people with visual impairment in rural areas compared to suburban/urban areas in Oregon?

In answer to this question, the researcher was fortunate in that the study sample consisted of an equal number of respondents recruited from both geographical areas. However, there were variations in both the highest level of education and the employment status between the two geographical samples, with the suburban/urban respondents having an average higher level of education and were more likely to be full-time employees. The variation in highest level of education, when grouped into whether the respondents had completed a college degree or not, between geographical areas was subject to further analysis and found that the suburban/urban respondents were statistically significantly more likely to have completed a college degree ($p < .01$) than the rural respondents.

The initial variation identified between the geographical areas is one that was alluded to above in the methods that would be employed to find out some information on a medical or health-related issue with nearly all of the suburban/urban respondents stating that they

would use a computer or the Internet, while less than half of the rural respondents reported this method and this variation was found to be statistically significant to a level of $p < .01$. Conversely, the rural participants were much more likely to retrieve this information by talking to a doctor or a health professional. This was in contrast with the suburban/urban participants where only half of the respondents stated they would use this method, however this trend was not found to be statistically significant. This disparity in methods to retrieve health information was also repeated when the respondents were asked to describe the methods they most recently used to retrieve health information. Once again, the suburban/urban respondents' most common response was that they used the Internet, whereas the rural participants stated that they had talked with a doctor or physician.

Variation between the respondents based on geographical areas when using the Internet was also observed when the participants were asked if they had ever used the Internet to search for health information at least once. Statistical analysis found that the suburban/urban respondents were statistically significantly more likely to have used the Internet at least once to search for health information ($p < .01$).

The rural respondents were, however, much more confident that their visual impairment did not hinder them when getting health information with a large proportion stating that they did not consider their visual impairment a hindrance compared to those who thought that it was a hindrance. In the suburban/urban respondents the answer was evenly split with the same number of participants stating that it was a hindrance to those who did not.

Further analysis showed that the rural respondents were statistically significantly more likely to state that they did not consider their visual impairment to be a hindrance when searching for health information online ($p < .05$).

The satisfaction levels of the respondents based on their health information searching experiences generally tended to be positive and though the comments of the participants in the level of satisfaction is subjective on the specific individual, nearly all of the rural participants stated that they were 'very' satisfied with the health information they had retrieved. This was in contrast to the suburban/urban respondents where the majority reported only that they were 'pretty' or 'quite' satisfied. Further analysis on this variation showed that the rural respondents were statistically significantly more likely to be 'very' satisfied with the health information they had received and retrieved ($p < .01$).

Conversely, this finding was not consistent with a later question that asked the participants about how they would rate their experiences of searching for health information online. Once the individual responses to this question were classified into either positive or negative comments, it was found that the majority of suburban/urban respondents stated that their experiences were positive while the rural respondents seemingly commonly expressed negative comments about their experiences (it was frustrating, having problems with their screen readers, and the inconsistencies of the websites). Statistical analysis examining this variation found that suburban/urban respondents were statistically significantly more likely to rate their experience of searching for health information online to be a positive one ($p < .05$).

When the respondents were asked about their opinions regarding the accuracy and trustworthiness of the health information that exists on the Internet, there was a disparity between the geographical areas as all those respondents in the suburban/urban area gave a positive response (if they indicated a positive or negative response), compared to the majority of those in the rural area giving a negative response. When this trend was further examining, it was found that suburban/urban respondents were statistically significantly more likely to provide a positive response when asked whether health information on the Internet was trustworthy or accurate ($p < .05$). This result needs to have the caveat attached to it that it only used a subset of the study sample as the majority of respondents claimed it depended upon the website and source.

An additional apparent trend of the participants seen between geographical areas existed within the recommendations and improvements that the participants and this will be discussed within the following section as it describes the response to the fourth and final research question.

4. What suggestions or improvements would people with visual impairment like to see in relation to health information resources?

The answer to this specific question was only requested of the twenty-four computer literate respondents within the study and the question was almost identically worded within the interview script. As mentioned previously, there was disparity between the

responses given dependent upon geographical area. The respondents within the suburban/urban area recorded a number of recommendations that sought to improve the accessibility and to lessen the sophistication of the websites by lessening the amount of photographs and the use of Adobe Acrobat PDF type files within the sites as these were proving problematic for the screen readers that they were using. The rural respondents, while still stating that they would like less photographs and more accessibility, tended to focus more on the creation of health information websites that were specific to the needs of the visually impaired.

Comparison of the study results with previous research

This section of the discussion examines the findings of this study and compares them to the results found within previous research which were outlined within the background section of the report. It should be noted that the results of this study came from a much smaller study sample than the majority of the previous studies, and so the results indicate potential trends that can be investigated on a wider-scale using a much bigger study sample. Having added this caveat, it is still interesting and relevant to examine whether the results of this study compare with those found within the larger previous studies.

One of the recent reports of the Pew Internet & American Life Project reported that 79% percent of Internet users had searched for information on at least one major health topic. Within this study, the number of participants who had searched for health information using the Internet at least once was slightly lower than this figure, but was still reasonably comparative at 79%. Unfortunately, there is no comparable figure within any previous

research to weigh this percentage against other studies looking at health information seeking practices and the use of the Internet to retrieve this information by people with visual impairment, but it does indicate a willingness on behalf of people with visual impairment to use the Internet for this purpose at a reasonably high level. It is worth noting, however, that as the aims of the study were known to the individuals recruiting the participants for the study, that the sample may not be completely representative of people with visual impairment and may be skewed towards people with computer and Internet experience.

A different report by the Pew Internet & American Life Project did look at the number of disabled people who accessed the Internet, although whether they searched for health information on the Internet was not asked and people with visual impairment were not subdivided within the sample, and were reported at 38%. Within this study, the frequency of people with visual impairment accessing the Internet was much higher with twenty-four of the twenty-eight respondents (85.7%) being classified as computer literate, which was defined as someone who used or had experience of computers and the Internet frequently enough to consider themselves competent at navigating themselves around. This figure is also much higher than the percentages listed within National Telecommunication and Information Administration report which split respondents into groups of disabilities (and age groups) which reported percentage Internet use of 56.3% of those aged under 25, 51.5% of those aged 25 to 60, and 9.6% of those aged over 60). This report also stated that only 38.7% of those people within the visually impaired grouping used the Internet to search for health information which is also considerably

lower than this study which had the figure at 68% of the sample. This variance in percentages is a large disparity and could be partly explained using the same caveat as mentioned above (i.e. it not being a completely representative sample), but hopefully shows an encouraging trend for people with visual impairment to embrace the Internet technology.

The types of health information that was being sought by the respondents within this sample can also be compared to the health topics listed by the Pew report. The most common health topic sought online was the same between both studies as the seeking of information about a specific disease or medical problem (the Pew report stated that 66% of Internet users sought this compared to this study where 89% of respondents stated they sought this type of information). However, the next three most common topics listed by the Pew report (information about a certain medical treatment or procedure, diet and nutrition, and exercise and fitness), with all percentages in excess of 40%, were much more infrequently mentioned by the respondents within this study. In fact, the only other common health topic which has comparable percentages is the seeking of prescription or drug information via the Internet.

The study also confirmed the findings of some of the previous research into this area of health information seeking. These included the increasing access to information in a format that they could access as mentioned by the study by Berry, and the problems of inaccessible websites for visually impaired people and for types of screen readers (the most commonly reported obstacle or barrier mentioned within this study) as stated within

papers by Davis, Chiang et al, Zeng and Parmanto, and the American Foundation for the Blind.

It is interesting to look at the three general hypotheses mentioned in the review article by Beverley et al as acting as the basis of previous research into this subject (the additional fourth model mentioned by this study forms the basis of this research project). While the study conducted seemingly supports two of the three hypotheses (people with visual impairment have the same wide range of health information needs as the general population; and people with visual impairment simply require the same health information, but in alternate formats), it is hard to agree with the other general hypothesis mentioned, that people with visual impairment are disadvantaged. From the conversations and interviews conducted with the sample, it became obvious that these individuals do not see themselves as being particularly disadvantaged. This assumption may be down to the perception of problems of people with visual impairment might experience by normal-sighted individuals, but they are acting without having the knowledge or experience to support their assumptions. These assumptions are usually due to nothing more than pure ignorance and show a contemptuous attitude and lack of proper understanding of the attitudes of people with visual impairment.

When comparing the results of this study with the Pew Internet & American Life Project report on rural areas and the Internet performed in 2003, the percentage variation between geographical areas was very similar, although both of the groupings within this study were proportionally higher, with the suburban/urban respondents being more likely to use

the Internet than their rural counterparts. However, there was disagreement over the frequency of use of searching for health information online as the Pew report stated that within their sample there was very little variation between the percentages of people searching for health information online, in fact the rural respondents were slightly more likely to perform this type of search than the suburban or urban respondents. Within this sample, this finding was not replicated as all of the suburban/urban respondents had searched for health information on the Internet at least once compared to only just over half of the rural respondents.

There are additional interesting findings within this research which also need to be reported within the discussion. One of the most glaring aspects to the interviews was how much the interviewees had embraced the new technology and opportunities for seeking and retrieving all forms of information, including information on health and medical related issues, in an accessible format by using the Internet or other machines. All of the respondents stated that they would be happy to seek health information on the Internet in one form or another. Even those individuals who either did not currently use computers or had not used the Internet to search for health information stated that they would be prepared to ask someone else to retrieve health information for them if the need arose for them.

When looking at the results of the study, it becomes clear that the respondents envisage the Internet as a tool that will enable them to empower themselves in their pursuit of accessible health information. This is shown when looking at the positive response given

to the question regarding whether they thought that being able to access this information online provides potentially greater benefit for people with visual impairment with all but one respondent, who gave a clear response either way, stating that they did think it would provide greater benefit. The greatest benefits appeared to be access to information in a non-printed, accessible format and that this access would be instant and available all the time which would provide the respondents with a newly-found independence and freedom.

One of the interesting questions that could be answered by this research was one of whether the respondents thought they were disenfranchised by the medical profession and did not receive comparable health information to the rest of the population. Although this question was not completely answered by the research, it is encouraging to note that the majority of the respondents did feel that they were getting comparable information to those without visual impairment. This indicates, at least in this small sample, that the respondents do feel they can receive relevant and accessible health information in a timely and useful manner.

CONCLUSION

As the amount of information and the accessibility to that information on the Internet grows at a rapid rate, it is important to ensure that all groups within society have access to and make use of this growing resource. The amount of health information stored online and its retrieval as an important resource used by individuals has been increasing as rapidly and has been noted by many studies, although how frequently this resource has been used by people with visual impairment and their experiences has not been previously reported. This research sought to remedy this gap in knowledge and detail the experiences of searching for health information by the visual impaired within the state of Oregon.

It is clear from the research that the respondents within the study are already using the Internet as a resource for health information at a rate that is comparable with the general population in methods and using ways that are similar. However, this result underlines how valuable and empowering a resource the Internet can be for people with visual impairment. This is shown within the study as the respondents reported on the amount of printed health information they had been previously given and how frustrating it had been. The Internet, while certainly not perfect, can provide the freedom for this group of society to be able to access identical health resources as the rest of the population which should be the aim of all relevant health authorities.

However, the one black spot in this empowering freedom of health information retrieval that the Internet provides is a problem that was repeated a number of times during the

study: that of inaccessible websites. This is a major problem as certain types of websites and formats used within websites make navigation and use of a screen reader, at best frustrating and time-consuming and at worst impossible. The desire more commonly seen within new and existing websites is making the site look glamorous or pretty by the use of fancy graphics and photographs, or by the use of advertisements. These are all problematic to screen readers and contribute to the accessibility problems. There is, however, governance within the United States which is concerned with the accessibility of websites for people with disabilities, but unfortunately this is only currently enforced on companies with government contracts. The solution to the problem is clear, that this governance be enforced on all health websites which purport to give out health information, although with the laws governing the Internet at the moment, this solution is unlikely to happen in the near future.

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Appendix A: Interview schedule for the non-computer literate group

Semi-Structured Interview tool

Questionnaire for those people who are level 0 (no computer usage):

Section A. Demographic Information

1. How old are you?
2. Gender:
3. What was your highest level of education?
4. What is your marital status?
5. What is your employment status?

Section B. Visual Acuity background

1. Can you describe your level of visual impairment?
2. When did you lose your sight?
3. Had you learned to read print before you lost your sight?
4. Is your vision stable?

Section C. Current Health Information Seeking Practices

1. If you wanted to find out some information on a medical or health related issue, what methods do you use to retrieve that information?
2. Who would you ask questions regarding health information?
3. Who are the people you would trust to ask specific health questions or to retrieve health information for you?
4. What type of health information did you most recently seek?
5. What methods did you use to retrieve this information?
6. Were you satisfied with the information that you received?

If NO, why was this?

7. What barriers/obstacles have you encountered when retrieving health information?
8. Do you feel that your visual impairment hampers you in getting adequate health information?

Section D. Computer and Technological Usage

1. What are the main reason(s) you do not use the Internet or computers?
2. What problems/obstacles have you encountered when attempting to use the Internet or computers?
3. Do you use any other modern technological machines such as a television, video recorder or cell phone?

If YES, Do you require any devices that help you to use these modern technological machines?

4. What problems/obstacles have you encountered using any of these modern technological machines?
5. Do you feel there are any potential benefits for you in accessing the Internet?

If YES, what are the benefits?

6. What motivation/requirements (if any) would be required for you to use the Internet or computers?
7. Would you ever consider asking someone else to retrieve health information for you from the Internet?

If YES, who would you ask and what type of health information would you ask them to seek?

If NO, why is this?

8. How trustworthy and accurate do you consider health information on the Internet to be?
9. Are there any other comments you would like to make regarding your experiences of retrieving and accessing health information?

Appendix B: Interview schedule for the computer literate group

Semi-Structured Interview tool

Questionnaire for those people who are computer literacy levels 1 and 2 (baseline and advanced):

Section A. Demographic Information

1. How old are you?
2. Gender:
3. What was your highest level of education?
4. What is your marital status?
5. What is your employment status?

Section B. Visual Acuity background

1. Can you describe your level of visual impairment?
2. When did you lose your sight?
3. Had you learned to read print before you lost your sight?
4. Is your vision stable?

Section C. Current Health Information Seeking Practices

1. If you wanted to find out some information on a medical or health related issue, what methods do you use to retrieve that information?
2. Who would you ask questions regarding health information?
3. Who are the people you would trust to ask specific health questions or to retrieve health information for you?
4. What type of health information did you most recently seek?
5. What methods did you use to retrieve this information?

6. Were you satisfied with the information that you received?

If NO, why was this?

7. What barriers/obstacles have you encountered when retrieving health information?

8. Do you feel that your visual impairment hampers you in getting adequate health information?

Section D. Internet, computer & other technology use

1. Do you have a personal computer (PC) at home?

If NO, where do you usually access a computer from?

2. Do you use the Internet at home?

If NO, what location do you usually access the Internet from?

3. Do you know what type of Internet connection you have at home?

4. Do you require any devices that help you to use computers or the Internet such as screen readers?

5. Do you use any other modern technological machines such as a television, video recorder or cell phone?

If YES, Do you require any devices that help you to use these modern technological machines?

6. What problems/obstacles have you encountered using any of these modern technological machines?

Section E. Health Information retrieval using the Internet

1. Have you ever used the Internet to search for health information?

a. If NO, what are the main reason(s) you do not use the Internet to search for health information?

- b. What motivation/requirements (if any) would be required for you to use the Internet to search for health information?
- c. Would you ever consider asking someone else to retrieve health information for you from the Internet?
 - i. If NO, why is this?
- d. If YES, What type of health information have you searched for on the Internet?
- e. What type of health information do you most frequently search for on the Internet?
- f. How frequently do you search for health information on the Internet?
- g. Have you encountered any problems/obstacles while retrieving health information on the Internet?
- h. How did you overcome these problems?
- i. Do you search for health information only for yourself or have you performed searches for other people as well?
- j. What method do you use when searching for health information on the Internet?
- k. What are some of the websites that you have visited recently?
- l. What was your impression of these sites?
- m. How satisfied have you been with the health information that you have retrieved?
- n. How long does it normally take you to perform these searches?

- o. What has been your experience when searching for health information online?
 - p. Do you think your visual impairment hinders you when accessing health information online?
 - i. If YES, in what ways?
 - q. What recommendations/improvements would you like to see to enable you to better access health information online?
2. Do you think that being able to access health information online provides potentially greater benefit for people with visual impairment?
 3. How trustworthy and accurate do you consider health information on the Internet to be?
 4. Do you feel you are getting comparable health information to those people who do not have visual impairment?
 5. Are there any other comments you would like to make regarding your experiences of retrieving and accessing health information?

Appendix C: Consent and Authorization Form



Oregon Health & Science University
Consent and Authorization Form

IRB#: 2381

Protocol Approval Date: 5/10/2006

OREGON HEALTH & SCIENCE UNIVERSITY Consent and Authorization Form

TITLE: Where do the visually impaired in Oregon go to retrieve health information?
Comparison of the experiences of visually impaired Internet and non-Internet users

PRINCIPAL INVESTIGATOR: Holly Jimison, Ph.D. (503) 490-7745

CO-INVESTIGATORS: Richard Appleyard, Ph.D. (503) 494-1230
Julian Lipscombe, M.Sc (503) 494-0492

PURPOSE:

You have been invited to be in this research study because you have some form of visual impairment. The purpose of this study is to investigate the methods that people with visual impairment use to access and retrieve health information, and identify the barriers/obstacles that people with visual impairment face when retrieving this information. The study will consist of an interview with a researcher lasting about an hour.

PROCEDURES:

In the interview, you will be asked some general questions about your age and previous computer use. We will also ask about how you currently obtain health information. We will record your answers on audio tape. This interview will take about an hour.

If you have any questions regarding this study now or in the future, contact Holly Jimison at (503) 418-2277 or Julian Lipscombe at (503) 494-0492.

RISKS AND DISCOMFORTS:

It is unlikely that there are any questions within the interview that will cause emotional distress, but you may refuse to answer any of the questions that you do not wish to answer. You may stop the interview at any time.

BENEFITS:

You will not benefit from being in this study. However, by serving as a participant, you may help us learn how to benefit people with visual impairment in the future.

CONFIDENTIALITY AND PRIVACY OF YOUR PROTECTED HEALTH INFORMATION:

We will not use your name or your identity for publication or publicity purposes.

If you sign this form, you are agreeing that OHSU may use and disclose protected health information collected and created in this research study. The specific health information and purpose of each use and disclosure is your opinions/experiences when getting health information needs.

The persons who are authorized to use and disclose this information are the investigators listed on page one of this form and the OHSU Institutional Review Board. The persons who are authorized to receive this information are the Office for Human Research Protections.

We may continue to use and disclose protected health information that we collect from you in this study until 5 years after the completion of the study. However, your name will not be recorded with your answers.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of this research consent form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date she receives your request. However, the Principal Investigator is allowed to use and disclose information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU.

The information about you that is used or disclosed in this study may be re-disclosed and no longer protected under federal law.

COSTS:

There will be no cost to you, nor will you be paid, for participating in this study.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Holly Jimison at (503) 418-2277.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your

legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

You may be removed from the study if the investigator stops the study.

We will give you a copy of this signed form.

SIGNATURES:

Your signature below indicates that you have read this entire form and that you agree to be in this study.

<p>OREGON HEALTH & SCIENCE UNIVERSITY INSTITUTIONAL REVIEW BOARD PHONE NUMBER (503) 494-7887 <u>CONSENT/AUTHORIZATION FORM APPROVAL DATE</u></p> <p style="text-align: center;">May. 10, 2006</p> <p><i>Do not sign this form after the</i></p> <p>Expiration date of: 5/9/2007</p>

Subject signature:

Subject Date:

Interviewer signature:

Interviewer printed name:

Interviewer date:
