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Title: Experiences, practices and barriers to accessing health information: a qualitative study

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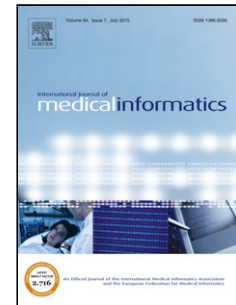
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Experiences, practices and barriers to accessing health information: a qualitative study

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Highlights

- HPs and patients primarily use the internet to access health information
- Health information informs HPs and patients/members of the public's decision making
- A range of barriers to accessing health information were identified.
- Various 'informal' methods were used to determine information quality.
- There is a need to ensure that decisions making is based on good quality information.

Abstract

Background: With technology advancements making vast amounts of health information available whenever and wherever it is required, there is a growing need to understand how this information is being accessed and used.

Objective: Our aim was to explore patients/public and health professionals' experiences, practices and preferences for accessing health information.

Methods: Focus groups were conducted with 35 healthcare professionals (31 nurses and 4 allied health professionals) and 14 patients/members of the public. Semi-structured interviews were conducted with 5 consultants, who were unable to

attend the focus groups. Data collection took place between March and May 2013 and all data were analysed thematically.

Results: Health professionals and patients/members of the public reported primarily accessing health information to inform their decision making for providing and seeking treatment respectively. For all participants the internet was the primary mechanism for accessing health information, with health professionals' access affected by open access charges; time constraints and access to computers. Variation in how patients/members of the public and health professionals appraise the quality of information also emerged, with a range of techniques for assessing quality reported.

Conclusions: There was a clear preference for accessing health information online within our sample. Given that this information is central to both patient and health professionals' decision making, it is essential that these individuals are basing their decisions on high quality information. Findings from this study have implications for educationalists, health professionals, policymakers and the public.

Keywords: Information; Information Technology; Health information; e-health: Qualitative research

1. Introduction

Since the 1990's there has been a global 'Information Revolution' [1], which has resulted in a wealth of information and resources being available whenever and wherever individuals have access to the internet. Advancements in technology and subsequent improved access to information has led to an increasing dependency on technology for a variety of daily tasks [2]. For instance, booking holidays and transferring money are tasks for which society is now largely dependent on Information Technology (IT); with technology transforming these tasks from things that were previously considered complex and time consuming, to tasks that can be undertaken quickly and simply, as long as there is access to the internet.

In 1999 the term e-health was introduced to represent the 'promises, principles and excitement' around electronic commerce in the health domain and to encompass the new opportunities the internet provides in healthcare [3]. Eysenbach (2001) proposed the following definition for e-health, which highlights that the term is inclusive not only of technological advancements but also individual's attitudes, behaviours and information [3]:

"e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of

thinking, an attitude, and a commitment for networked global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology” [3].

Given the way in which IT has transformed other industries, it is perhaps unsurprising that IT is considered a tool for transforming the healthcare industry [4, 5]. Information is considered ‘pivotal to good quality care’ and a mechanism for improved: decision making; integrated care; standards, safety and the prevention of ill health [2]. Coinciding with the Information Revolution and emerging beliefs of the potential for IT to transform healthcare there have been a number of NHS IT policies since 1992 [2, 6-10]. Central to these policies is an ambition to encourage health professionals (HPs) to access information through electronic records, health and care apps and digital information. More recently, policies such as “The Power of Information” [2] and “Personalised Health and Care 2020”[7] have placed a strong emphasis on giving citizens and patients access to health information calling for people to “take better advantage of the digital opportunity”.

Despite the advances in information availability and accessibility and subsequent policy pressure, there is little empirical evidence in this area. Although there is a vast amount of literature on general health information seeking behavior, there has been little research exploring how HPs and patients/members of the public search for, access, appraise and use online health information, particularly within the UK [11]. A literature review, [12] explored the evidence on online health information-

seeking behavior from the health 'consumer' and HP perspective and named a number of priorities for future research that included research exploring HPs and members of the public's: access to the internet; motivations for using the internet; how internet searching is undertaken; barriers to use; how information is used and how the credibility and trustworthiness of health information is determined.

This study aimed to address the gaps in existing evidence by exploring patients/public and HPs experiences, practices and preferences of accessing health information.

2. Methods

Focus groups and face-to-face, semi-structured interviews were conducted with HPs and patients/members of the public between March and May 2013. Research ethics approval was obtained from the University of York Health Sciences Research Governance Committee and research governance approval from the study site in the North of England.

2.1. Sampling, recruitment and consent

Clinicians, Allied Health Professionals (AHPs) and nurses were recruited using convenience sampling of individuals that indicated an interest in the study. Posters

on notice boards, staff newsletters and the staff intranet were the primary method of recruitment for HPs, with the heads of profession also asked to forward a recruitment email to their staff. Following a poor response from nurses, course tutors also invited nurses attending Continuous Professional Development courses at the University of York to take part in the study. Due to difficulties arranging a mutually convenient time for all consultants to attend focus groups, face-to-face interviews were conducted with this professional group.

We wanted to recruit patients/members of the public as non-health professional 'consumers' are likely to have some experience of using the internet to access health research. We therefore sought people who had some involvement in health-related organisations or groups (self-help, support groups, charities and other patient groups). To achieve this and to identify people with an interest in a variety of health conditions, patients and members of the public were recruited through contact with: York Council for Voluntary Service; the local HealthWatch group; the North Yorkshire and York Forum and patient representatives with whom we already had a relationship.

All individuals that expressed an interest in taking part in the study were provided with a time, date and venue for the focus groups or interviews, the participant information sheet and a consent form. HPs were provided with lunch as an incentive for their participation, whilst patients/members of the public received Amazon gift vouchers.

2.2. Participants

Four focus groups were conducted with 31 experienced and qualified nurses. Nurses were predominately from the North of England and included generalist and specialist (e.g. diabetes and asthma care) nurses working in hospitals, primary care and nursing homes. A number of nurses also reported teaching as part of their role. One focus group with four AHPs (Pharmacists and Physiotherapists) was also conducted. For the five consultants who consented to take part, but could not attend a focus group, qualitative interviews were conducted. Consultants represented a range of disciplines including: Pediatrics, Radiology, Obstetrics and Gynecology and Ear, Nose and Throat.

Three focus groups were also conducted with 14 patients/members of the public, with each focus group consisting of 4-5 participants. Ten participants were active in a voluntary organisation or committee that involved looking for, or at health information, including research. Demographic characteristics for all participants are provided in table 1.

Table 1 Participant characteristics

Group	Number of participants	Specialty	Gender	Age range (years)	Years of experience
Allied Health Professionals	4	2 Physiotherapy 2 Pharmacy	3 Female 1 Male	2 = 31-40 1 = 41-50 1 = 51-60	2 = 11-20 2 = 21-30
Consultants	5	2 Obstetrics and	4 Male	1 = 31-40	1 = 11-20

		Gynaecology ENT Radiology Paediatrics	1 Female	4 = 41-50	4 = 21-30
Nurses*	31	21 Hospital based 10 Primary care/community practitioners	28 Female 3 Male	13 = 21-30 5 = 31-40 9 = 41-50 4 = 51-60	7 = <5 8 = 5-10 6 = 11-20 5 = 21-30 5 = 31-40
Patients/public /charity	14	5 with charity/community voluntary work links 9 Patients/Public	8 Female 6 male	3 = 21-30 3 = 31-40 4 = 41-50 4 = 61-70	Not applicable

* Training attended included courses on the management of diabetes, chronic obstructive pulmonary disease and asthma.

2.3. Focus group and interview design and content

A topic guide (appendix a) provided the framework for the focus groups and semi-structured interviews. Findings presented here are part of a wider study that explored patients/public and HPs experiences, practices and preferences when accessing health research evidence, with a focus on the evidence provided in three databases specifically providing access to research and suggestions for improving the access and utility of these databases.

2.4. Analysis

Interviews and focus groups were audio-recorded and transcribed verbatim, with each participant assigned a unique ID code for anonymity. All data were analysed thematically. Coding and theme development was deductive using a-priori codes driven by the topic guides for interviews and questions during focus groups. Data for interviews and focus groups were analysed independently by two researchers.

Discussions were held to create themes and sub-themes, with the transcripts revisited until agreement was reached. Following each interview and focus group, facilitators discussed their personal reflections and observations. Reflexive notes [13] were also taken following each interview and focus group, which informed the analysis.

3. Results

During the focus groups and interviews HPs and patients/members of the public discussed their experiences of accessing health information. The findings for HPs and patients/members of the public are presented together according to the following themes: why is health information accessed; how is health information accessed; factors affecting access to health information; and determining the quality of information.

3.1. Why is health information accessed

The majority of HPs acknowledged the importance of accessing health information to: inform their decision making; find additional resources; solve problems; consult or identify guidelines; find out more information about specific and/or rare conditions and treatments and for keeping up-to-date with the latest evidence. Across all professional groups, HPs used evidence to influence their colleagues and

for educational purposes, particularly when studying for formal qualifications, undertaking continuous professional development and for training staff or giving presentations. HPs also used information when peer reviewing journal papers with nurses also reporting regularly using the internet to find and download information for patients.

Nurse 30: I think it helps you challenge other people as well, particularly where you are in a position where you may be sharing the care of somebody and somebody has initiated something that you disagree with and you know it is potentially outside of what the treatment pathway should look like. If you can pull on the evidence you have more chance of then being able to persuade them to your way of thinking.

The primary motivation for patients/members of the public accessing health information was to determine whether they felt the need to seek medical treatment and/or advice. Although the potential safety risks were acknowledged, patients/members of the public reported looking up their symptoms online first, to see if they appeared serious enough to warrant medical attention. This was largely due to individuals not wanting to be considered bothersome or 'bother' doctors with something trivial. Patients/members of the public specifically, also discussed searching for information for reassurance, seeking comfort in the fact that others had experienced similar issues; particularly for sensitive or embarrassing ailments. For others, who wanted to maintain a sense of control, information regarding next steps or treatment options was sought, with some who mistrust the medical

profession searching for information to corroborate with that provided by HPs. A small number of individuals also reported searching for information in order to provide support to family members and friends.

P9: you kind of fear going to the doctor and troubling them with something trivial but equally you also want to come across as a relatively informed patient or if you have got an illness and want to know about it and you want to know what the treatment options are available to you and what the side effects of those treatments are.

Participants who worked for charitable organisations or had voluntary roles in the NHS used the internet largely to keep up-to-date with topics related to their work and/or changes in national NHS policy. Information was also sought for self-education purposes as these individuals are involved in various projects across a range of conditions, despite lacking formal training in healthcare.

P12: I've had to look for evidence if we've been writing a report about something or we've been raising a particular issue with the PCT or hospital for instance then you need to find out what is happening nationally, you need to know what's happened in the past and have something to back up what you are saying so it does give you some evidence and something to sort of hang your information on, but an awful lot of it for me personally is my own education because I didn't come from any kind of health background.

3.2. How is health information accessed

HPs and patients/members of the public reported using a range of search engines, websites and online resources for accessing health information, which for HPs were often accessed on a daily basis (appendices b and c).

The internet was the preferred method of accessing health information for both HPs and patients/members of the public. Although one member of the public reported going to their doctor first as they viewed the internet as “a hypochondriac’s paradise”, all patients/members of the public agreed that the internet has changed the way information is sought and found, with the almost real-time access to sites and email correspondence considered beneficial. For HPs, the internet was considered the quickest and most convenient method for accessing health information; particularly due to mobile devices. HPs’ preference for the internet may also be explained by the fact that some information such as locally approved guidelines and protocols are only available online.

Allied Health Professional 2: Well some of our recommended resources are only electronic, you can't get paper versions, you have the web version, so you know it is up to date, whereas a book is out of date as soon as it is published isn't it whereas a web version is frequently updated.

Although a strong preference for the internet was reported, HPs described some situations where non-internet based information sources are used. For example, some AHPs felt that checking a drug in the printed version of the British National Formulary (BNF) was quicker than accessing the same information via a computer as printed copies of the BNF are more easily accessible on wards. Textbooks were also occasionally used particularly when preparing for conferences, with more mature HPs also disclosing a preference for reading paper copies of journal articles. Patients/members of the public also reported other methods of accessing health information including: books, print journal libraries, family health books and consulting individuals with an interest in a specific topic.

P11: Probably the internet would be the first place to go to look at that; and libraries and things no. But people, yes potentially if there is something that I know somebody else is very interested in, I would go to them.

3.3. Factors affecting access to health information

Obtaining access to full journal articles was a key barrier affecting access to health information for HPs across all professional groups. Although HPs were aware that articles could be ordered, this was considered unhelpful as information is often needed quickly to inform decision making and some organisations impose restrictions on the number of articles clinicians can order each year. HPs also expressed universal frustration with Athens and described the site as “absolutely

hopeless” and “unusable”. This was largely due to issues with logging in and loading information. As a result, the site is rarely used, leading to HPs perceiving the site as unfamiliar and difficult to navigate.

Consultant 2: I find the Athens system absolutely hopeless, frankly unusable and frustrating really. I think it's incredibly annoying that the amount of and range of journals that you have access to as a clinician is less than you would if you were an academic. It's just absurd, I'm sitting you know poor thing, MRI scans and want an actual concrete answer to a question, so I try searching for a journal and you get a pay per view hit with a relevant looking article and it's not available on your Athens account, that is assuming you can make the Athens account work which is quite hard to do in the first place.

For nurses limited access to computers and a lack of time to look up evidence were considered barriers to accessing health information at work, resulting in some individuals accessing information at home instead. Additionally, for a number of nurses, time constraints or insufficient computing skills prevented them from regularly accessing health information, despite being aware of the benefits of evidence-informed practice.

Nurse 11: Usually at work there is only one or two computers, so if you are working, you can't actually sit down and use the computer, so on the whole as a staff nurse I might only be on the computer once a week at work, on a Sunday when I finish at 3.30,

I might check my email because I am not sitting at a computer all day, I am out looking after patients and giving meds, so I don't access my email every day, and I presume most staff nurses are like that because we don't get a chance to sit down.

HPs and patients/members of the public reported varying searching skills, which may influence their ability to access health information. For example, some patients/members of the public reported using single search terms such as disease or condition (+/- the word "symptoms"), whilst others reported using different phrases, acronyms or directly entering the name of websites, conditions and key individuals into a search engine. The majority of HPs showed knowledge of how to search for information, with the majority reporting using Boolean operators (AND, OR) - although nurses were not aware that they were doing this - the plus sign on google and inverted commas. AHPs appeared to be particularly knowledgeable of how to search for information and described how they combine results, use wild cards (e.g. physio*), MESH terms and include a Human restriction. For a number of less skilled HPs, whole questions or descriptions of what they were looking for were entered into search engines, with these individuals also perceiving the first word in search terms to be the most important.

AHP1: It varies, sometimes it is just a question but other search engines or databases, you may use Mesh terms, if you know which ones to look at, it's a lot more tricky searching that way.

Although the content of websites was considered important, HPs and patients/members of the public discussed how certain features of websites determined whether they are used and whether they become 'favourites'. Layout (e.g. tabs), ease of use (e.g. limited number of clicks) and simple navigation were considered important by both HPs and patients/members of the public. All participant groups also stated a preference for sites that cater for different levels of knowledge and interest. However patients/members of the public preferred websites to have lots of information in layers, whilst HPs preferred sites to have different sections for HPs and patients. Language was also important to both nurses and patients/members of the public, with these individuals preferring websites that used a limited number of acronyms and simple, engaging language. Reflecting the fact that one of the reasons for patients accessing information is to enable them to have informed discussions with their GP, patients liked websites that sounded scientific but that are pitched at a level that they can understand and interpret for use during these conversations. Additionally patients/members of the public stated preferences for websites that: look professional (dark backgrounds and big blocks of text were disliked); are kept up to date; have limited pop-ups or flashing adverts; have share buttons; have automatic video presentations; quick loading times; an Arial font and which have the ability to print information.

P7: Whatever the site is, whether it is for medical reasons or whatever, presentation is so important and to make it easy to follow and read.

3.4. Determining the quality and trustworthiness of health information

All HPs acknowledged the importance of assessing the quality of information, with the source of information one method through which quality is determined. Sources considered to contain good quality evidence included: academic sites; research databases (PubMed); locally provided resources (UpToDate); profession/specialty sites (Royal College of Nursing); YouTube; and Department of Health/NHS sites (NICE). Further indicators of quality included: study design (systematic reviews and RCTs were preferred); peer-review; evidence-based resources; authors and funding sources, with funding from the government and pharma considered good and poor indicators of quality respectively. All professional groups also reported using critical appraisal techniques to decide whether information was of good quality; with the rigour of appraisals dependent on the reason for which evidence was needed. Despite this, only one HP reported using an established quality assessment tool (CASP), with others using their experience or comparing conclusions drawn to their own beliefs to determine whether information was trusted.

Nurses appeared to be mistrustful of general search engines such as Wikipedia, largely due to nurses having to explain the flaws of information brought to them by patients from these sites. Reflecting one nurse's perceptions that 'Joe Public takes information at face value', patients/members of the public appeared to be less aware of how to determine the quality of information and despite displaying an awareness of the importance of doing so, used less formal methods for checking the

quality of information. For instance, although the source and funding behind information sources was considered, the language used by articles and websites was considered important, with trust placed in information that used clear, succinct, language, avoided technical terms and acronyms and which had no grammar or spelling mistakes. Text that included emotive language or personal accounts was also preferred with 'personal rants', aggressive language and reporting of solely objective facts disliked. Additional methods used by patients/members of the public to quality assess information included: cross referencing information with other sources and/or HPs; looking at the number of citations; the year of publication and the number of references included. A number of individuals also reported that they undertake a process of 'subconscious filtering' when considering information found online, particularly in terms of potential political or gender bias.

P13: I think [Cochrane] is an organisation that I trust, and I think as P14 mentioned referencing, it is very heavily referenced, you know, 'we looked at these studies and the other studies we looked at we decided not to include', you know they really set it out to you. So a website I wouldn't trust is one that said this is what it is...you know, this is what it is, I want to know how they come to that conclusion, that would make me trust a website if they sort of explained their thinking.

HPs and patients/members of the public also discussed the factors that influence whether they choose to open search results and consider websites trustworthy. These included: individuals' familiarity with websites; open access; study design;

relevance to search question/key words; date published; language and source (reputable author or journal). The majority of HPs were aware that the first few links on Google were typically sponsored. However, only half of patient participants were aware of this with a minority reporting that they relied on a feeling that something was relevant and/or starting at the top of search lists as that is where the most important links are. Additional factors that influenced whether patients/members of the public trust or use websites included: where information was irrelevant; registration was required; opinion pieces; politically biased articles and sites that are difficult to navigate and understand. A number of nurses and patients/members of the public also reported avoiding scholarly articles because they were considered too wordy.

P9: then you go to the NHS site because it is a kind of branded thing isn't it, the brand you can trust.

4. Discussion

4.1. Summary of results

This study explored the preferences and experiences of HPs and patients/members of the public when accessing health information. Although a strong preference for the internet was reported when accessing health information for all participants,

situations where other media are used were also cited. For instance, HPs qualified for longest preferred reading paper copies of journal articles. For all participants, the primary motivation for accessing health information was for education and to inform decision making. HPs also discussed factors affecting access to health information which related to: open access; IT skills and time and resource constraints (nurses). Although the importance of assessing the quality of information was discussed by all participants, HPs relied on more formal methods of critical appraisal, whilst patients/members of the public used factors such as language.

4.2. Comparison with existing literature

It is well documented that members of the public, patients and HPs are increasingly using the internet to access health information [12, 14, 15]. Whilst the volume of information that is made available through the internet is perhaps one of its biggest strengths, it also brings the challenge of how to identify reliable, accurate and current information [15]. One problem associated with the volume of online health information relates to how information quality can be determined. In our study, participants identified a range of factors that influence whether information is considered to be of good quality (e.g. the source of information). Whilst, this suggests that both HPs and patients/members of the public have the ability to separate good and poor quality research, formal quality assessment methods (e.g.

CASP) were rarely mentioned, with individuals largely dependent on more informal indicators such as the source or language used.

Our study supports existing evidence of online health information-seeking behavior, in identifying that the main reasons that patients/members of the public and HPs access health information is for education and to inform decision making [12, 15]. Findings from our study and those of a qualitative study of adults' online health information preferences, suggest that patients may use online health information as a tool for enhancing their interactions with HPs [15]; by exploring treatment options, or preparing for appointments. Whilst patients may believe online health information may be used to enhance their interactions with HPs [15], HPs may consider it to be of detriment [16, 17]. For example, in our study, nurses reported issues with patients taking online information at face value, questioning patients' ability to determine the quality of information.

4.3. Strengths and limitations:

We have addressed a number of gaps in existing evidence by exploring, how individuals search and access online health information and how the credibility and trustworthiness of online information is assessed. The qualitative approach taken, allowed for an in-depth insight into these issues, that would not have been possible through other methods. The main limitation of the study is that participants were all recruited from an area of the UK where the population is predominately educated,

affluent and white British and so the views of individuals who are from other socio-economic and cultural backgrounds may be different. Additionally, a number of the patients/members of the public that were recruited were associated with voluntary or charity organisations and so are required to access health information routinely. The preference for online health information, particularly among the patients/members of the public in our sample may therefore have been over-estimated. Our sample also included a large number of nurses and comparatively small number of AHPs and doctors. The study may have benefited from obtaining a greater number of HPs that represented a wider range of professional grades and specialties from other areas of the United Kingdom. An additional limitation of the study is the length of time between data collection and publication. However, given the focus of recent NHS IT policy on giving HPs and patients/members of the public access to health information this study remains relevant. It is likely that with the ongoing policy pressure on health information to be readily available, that online methods for accessing health information will become increasingly dominant. However, whilst there was a clear preference for accessing health information online within our sample, there were some situations where paper-based methods were preferred.

4.4. Implications and recommendations

There is a clear appetite amongst HPs, patients and the public to both access and use health information. Our study found that online health information plays a pivotal

role in informing HPs. Patients and members of the public's decision making. It could therefore be argued that a significant challenge for policymakers, researchers and educationalists is to ensure that HPs, patients and the public are provided with the skills and resources necessary to identify reliable and up-to-date health information. Our findings also suggest that patients are increasingly turning to online health information to inform their decision making around accessing medical advice, treatment options and to corroborate medical advice they have received. As a result, HPs should encourage the use of online health information by patients and members of the public, and help them to identify appropriate, reliable and updated information sources. However, HPs should acknowledge that not all individuals will want to, or have the capacity to access information online and so should be able to provide information to patients through a variety of different media. Additionally, given that one of the primary motivations for patients/members of the public in seeking health information is to determine whether medical advice/treatment should be sought there needs to be greater emphasis on educating the public on how to determine the quality and trustworthiness of information. One mechanism for achieving this could be through raising the profile of NHS Choices through social media. Future research focused on qualitative work to explore the preferences and practices of different populations in relation to health information seeking behavior would be of benefit.

Authors contributions:

AB and BH designed the study. AC drafted the manuscript. AB and BH, conducted the data analysis and produced and were involved in initial data reporting and commented on the draft manuscript. All authors read and approved the final manuscript.

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Statement of conflicts of Interest

The authors declare no conflicts of interest.

Ethics, consent and permissions:

Research ethics approval was obtained from the University of York Health Sciences Research Governance Committee and research governance approval from the study site in the North of England. All participants provided written informed consent prior to being interviewed and taking part in the focus groups.

Availability of data and materials:

To protect the anonymity and confidentiality of participants, data will not be made available.

Summary table:

What is already known on this topic?
<ul style="list-style-type: none"> • The 'Information Revolution' has made a wealth of information and resources available. • Whilst there is a significant evidence base on general health information seeking behavior, literature exploring how health professionals and patients/members of the public search for, appraise and use online health information is limited.
What this study has added to our knowledge?
<ul style="list-style-type: none"> • Health information was primarily accessed to inform decision making and for education. • Individuals were able to distinguish between good and poor quality information and used a range of informal methods for doing so. • Our study supports findings from Fiksdal (2014) which suggest that although health professionals may have concerns regarding patients using health information during consultations, patients view online health information as a tool for enhancing their interactions with health professionals. • There was a preference for accessing health information online. However, this needs to be

explored within a more diverse sample.

Abbreviations

AHP: Allied Health Professional

HP: Health Professional

IT: Information Technology

NHS: National Health Service

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