





Preferred format and strategies for seeking and trusting online health information: a survey of cardiology outpatient attendees across three New Zealand hospitals

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ABSTRACT

Introduction. The volume and quality of online health information requires consumers to be discerning. Aim. This study aimed to explore consumer Internet use for health information, preferred format and what factors helped them to trust the source. Methods. A cross-sectional study was conducted in 2016–2017 with adults attending three cardiology outpatient clinic sites using a short paper-based survey. The survey included questions regarding online health information use and perceived trustworthiness with opportunities for free text responses. Survey data were summarised with key questions adjusted by age group, gender and ethnicity using logistic regression. Results. Of the 708 respondents (51% women, 66% aged 45-74 years, 16% Māori, 12% Pacific), 73% had sought health information online (64% in the previous 12 months), commonly for medication side effects, their health condition and self-help. Most (65%) were successful, although Pacific respondents reported a lower likelihood of search success compared to Europeans. Younger age groups were more concerned about information quality. Fact sheets (80%) were the most popular format and for all ethnic groups, followed by short videos (31%) and discussion groups (23%). Trusting online information required many strategies with 72% wanting health professionals to recommend websites. Discussion. Online health information seeking is a norm for consumers, with simple fact sheets being the preferred format to build knowledge and skills. With the rising tide of misinformation, health portal providers need to offer accurate and easy-to-read fact sheets in their suite of formats and health professionals need to support consumers guiding them to trusted websites.

Keywords: 'Internet use', consumer health information, health literacy, health education, information seeking behaviour, information services, Internet, online systems, trust.

Introduction

We all need reliable, relevant and understandable information to make decisions about self- and family-care, deal with our health and health problems and support the choices we make about managing them. The Internet is an important source of health-related information for global users and has democratised available information and information sharing. However, in recent years, the sheer quantity of information, the surge of misinformation, the blending of fact with fake information and the lack of standardised regulation of the Internet leaves online consumers vulnerable. This 'infodemic', a term coined by the World Health Organization, has been described as one of the greatest threats to global health.

While health professionals are the most trusted and preferred source of health information, 4,5 the COVID-19 pandemic has also served to reduce access to health care providers and has exacerbated unmet preventive and diagnostic health needs. However, even if consumers are able to access health care, unmet information needs may still remain. This may be due to a range of factors, such as: what is communicated

WHAT GAP THIS FILLS

What is already known: The COVID-19 pandemic and its sequelae served to reduce access to health care providers, exacerbated unmet preventive and diagnostic health needs and made online health information even more important for consumers to make decisions about self- and family-care. What this study adds: This survey asked an ethnically diverse group of patients attending cardiology outpatients what format of information was most valued and strategies they use to trust the information they find. Simple fact sheets were the most preferred online format followed by videos and discussion groups with the best 'life-hack' being to get their health professional's advice on the most trusted website for their condition.

(eg unfamiliar medical jargon, language issues); how it is communicated (eg verbal vs written vs pictures); how clear the communication is and how clarity is checked with the patient; the distress or anxiety at the time of communication (eg uncertain prognosis); and significant health service time constraints that limit conversations. Furthermore, it has been estimated that individuals immediately forget 40–80% of information conveyed during a consultation, and may think of other relevant questions afterwards.

People with one of more long-term conditions or a lifethreatening illness have been reported to have higher rates of online information seeking. ^{8,9} These populations are heterogeneous by age, gender, ethnicity, education and digital literacy but they all require access to reliable, relevant health information so they can make sense of uncertainty and navigate opinion from true or false information.

When faced with a heart health concern, consumers may be referred to a cardiology outpatient clinic. However, the load of information they may receive is often complex and complicated, and time to discuss and ask questions and clarify understanding is very short. It was hypothesised that consumers attending cardiology outpatients may have high information needs and be motivated to seek information online. In three New Zealand (NZ) hospital cardiology outpatient clinics, we aimed to investigate the experiences of consumers when searching for online health information, what they would trust, and their preferences for the way it is presented. This knowledge is critical to online health portal providers in their curation of online content, and the provision of formats that support building knowledge and skills for self-management, self-efficacy and ultimately equity of health outcomes.

Methods

The description of this cross-sectional survey is given according to the CROSS checklist for reporting surveys. 10

Survey design

International and national questionnaires seeking to understand health information needs of consumers and for population groups with chronic disease were collated and adapted to the NZ context. The survey included 13 questions; 10 regarding online health information seeking and three demographic questions (the survey is provided in the Supplementary material). The categories of questions were as follows:

- use of the Internet and frequency of use for health-related information
- why do they look online and what specific health information they want
- · experiences of looking for health information
- · format of health information that was most useful
- · perceived trustworthiness
- · demographics.

Patients attending cardiology outpatients' clinics in the Auckland and Wellington regions (Counties Manukau, Auckland and Hutt Valley District Health Boards (DHBs)) were invited to participate in the survey between June to December 2016 (Counties Manukau and Hutt Valley DHBs) and February to August 2017 (Auckland DHB).

The survey and study procedures were initially pre-tested at Counties Manukau cardiology outpatient department and minor adjustments made. People attending cardiology outpatient clinics were invited to participate by the receptionist. The only exclusion criteria were participants unable to provide consent, too unwell to complete the survey or non-English language speakers who did not have a support person with them who could assist. Willing patients were then introduced to a research nurse who gave them the paper-based survey and who was on hand to offer help and support if required. Before commencing the survey, participants were provided with information about the study, including its voluntary nature, and were informed that the information collected was anonymous.

Analysis

The survey data were entered into an Excel spreadsheet with double entry of data to ensure reliability. Data were summarised into descriptive tables and further explored by age group, gender and ethnicity prioritised according to Ethnicity Data Protocols. Where differences appeared across sociodemographic strata, or where differences in preferences of the format of health information had been described in the literature, the association between key questions and age, gender and ethnicity were investigated using logistic regression and displayed as odds ratios (ORs) with 95% confidence intervals (95% CI). Five questions (why look online, what health information, experiences of looking, preference for format and perceived trustworthiness) included a textbox for

free text responses. All free text entries were collated and analysed using a general inductive approach, ¹² such that qualitative data from each question's free text option were thematically coded.

Ethics

Ethical approval for the study was obtained from the NZ Health and Disability Ethics Committee (16/NTA/69) with locality approval from Auckland, Counties Manukau and Hutt Valley District Health Boards.

Results

Between June 2016 and August 2017, 708 surveys were filled in (336 at Counties Manukau, 237 at Hutt Valley and 135 at Auckland) with 658 (93%) including data on age, gender and ethnicity (Table 1). Of the survey respondents, 51% were female, two-thirds were aged between 45 and 75 years and 16% self-identified as being of Māori, 12% Pacific, 60% European and 12% as other ethnicities (mainly Indian or Asian).

Table 2 describes survey question total responses. The majority (566/702 (81%)) had used the Internet (or someone in their family had searched for them) at some time in the past, with 442/695 (64%) having looked online in the

Table 1. Patient characteristics.

Patients (total N = 708)	Characteristic N (%)	No response N (%)
DHB site		
Counties Manukau	336 (47%)	
Hutt	237 (33%)	
Auckland	135 (19%)	
Gender		38 (5% of total <i>N</i>)
Women	341 (51%)	
Men	329 (49%)	
Age group (years)		38 (5% of total <i>N</i>)
<25	24 (4%)	
25–44	113 (17%)	
45–64	276 (41%)	
65–74	170 (25%)	
75+	87 (13%)	
Ethnicity		50 (7% of total <i>N</i>)
Māori	106 (16%)	
Pacific	76 (12%)	
European	396 (60%)	
Other	80 (12%)	

past 12 months for health-related information. Adjusting for gender and ethnicity, the frequency of searching for health information was strongly associated with age (Table 3). Compared to the 75+ year age group, the odds of looking online at least every 3 months for health information was strongly associated with being in the younger age groups; for 45–64 years OR 1.88 (95% CI 1.14–3.10), for 24–44 years OR 3.85 (95% CI 2.08–7.13) and for less than 25 years OR 4.34 (95% CI 1.54–12.20).

Why look online and what health information patients want

The main reasons that participants would look at health information online was because they could learn about their health condition (470/645 (73%)), diagnose a health worry (274/645 (42%)) and it was fast and convenient (218/645 (34%)). When given a list of online health-related topics, the most frequent topics searched for were side effects of medications, to learn more about treatment or medications after visiting a health provider, looking for health conditions and self-help information.

There were 81 free text responses to the questions: Why look online? and What health information patients are looking for? Many (41) re-iterated one or more of the question options particularly about a specific health condition, medications or medication side-effects, food and nutrition to keep healthy and understanding their condition better.

I wanted to find more information about what I have ie heart enlargement and my other health issues. (Samoan woman, 45–64 years)

In addition to the reasons above, 25 participants supplied other reasons why they searched the Internet that mainly related to general interest in health and wanting to know more or seeking information after interactions with their doctor or health professional.

Knowledge is power. Using various platform to receive information is useful especially in areas I have no expertise in. (Māori woman, 45–64 years)

Gather information, extend knowledge re health using natural remedies. (Fijian Indian woman, 45–64 years)

To back up information from a health professional or gain a different perspective and to read about others experiences with a condition. (European woman, 45–64 years)

Looking online to learn about a health condition and convenience were similar across age groups. However, the odds of looking online to *diagnose* a health worry was significantly greater in younger age groups (<25 years and 25–44 years) compared to age 75 + years (Table 3).

Table 2. Responses to survey questions.

Question	N (%) ^A
Use of Internet and frequency	
Ever used the Internet ^B	566 (81%)
Searched for health information every 3 months or more frequently $^{\rm B}$	378 (55%)
Looked for health-related information for yourself in past 12 months $^{\rm B}$	442 (64%)
Never looked for health-related information via the Internet	185 (27%)
Why look for online health information? $^{\subset}$	
To learn about a health condition	470 (73%)
To help diagnose a health worry	274 (42%)
It's fast and convenient	218 (34%)
I didn't get enough information from my doctor	87 (13%)
To save me from going to the doctor	78 (12%)
Privacy	49 (8%)
What health-related topics would you look for? $^{\!$	
Side effects of medication	360 (60%)
Learn about treatment or medication after going to the doctor or hospital clinic	350 (59%)
Health conditions	340 (57%)
Self-help information	257 (43%)
Information about symptoms to help me decide if I need to go to the doctor	232 (39%)
Information about diet, smoking, weight, alcohol, fitness, or being active	227 (38%)
Scientific articles or research	163 (27%)
To find a service	129 (22%)
Tests or operations	102 (17%)
People's stories or support groups	94 (16%)
Diagnose myself or a family member	87 (15%)
Experience looking for online health information $^{\mbox{\scriptsize C}}$	
Normally find what I am looking for	386 (65%)
Concerned about the quality of the information	172 (29%)
Feel frustrated trying to find the right information	101 (17%)
Information was hard to understand or confusing	72 (12%)
It takes a lot of effort	58 (10%)
Information I found was not very useful	47 (8%)
Preferred form of health-related information C	
Information you can read like fact sheets	475 (80%)
Short videos	182 (31%)
Discussion groups with the same health issue as me	139 (23%)
Websites or 'apps' that I can interact with	132 (22%)

(Continued on next column)

Table 2. (Continued)

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Question	N (%) ^A
Slideshows	82 (14%)
Information in different languages	38 (6%)
Internet information is trustworthy (agree or somewhat agree)	507 (85%)
Would like GP/nurse to recommend where to look for health information online	446 (72%)
What helps you trust online information? $^{\!$	
Advice came from a knowledgeable source	356 (61%)
Site was recommended by my doctor or nurse	279 (47%)
Advice appeared to be prepared by an expert	261 (44%)
Reasoning behind the advice was explained to me	203 (35%)
Advice appeared to be impartial and independent	191 (32%)
The site was easy to use	178 (30%)

^AN (%) are the total number and % of responses, for some questions, participants provided no response.

Experience looking online

Most (65%) participants normally found what they were looking for and this response was no different according to age group or gender. However, compared to Europeans, those of Pacific ethnicity were less likely to find what they were looking for (OR 0.46; 95% CI 0.26–0.80).

Just under one-third (29%) stated they were concerned about the quality of information online. While this was not associated with gender and ethnicity, compared to those aged 75+ years, people younger than 65 years were more likely to raise this concern. For example, the odds of being concerned about the quality of information in those aged 45–64 years were three times more (OR 3.45; 95% CI 1.59–7.46) than those over 75 years (Table 3).

In addition to supporting the question options about experiences, 21/44 free text responses related to comments on the vast amounts of information available online, which was often conflicting, somewhat scary and required people to sift through it.

There is so very much information it's hard to track down exactly what you are after. (European woman, 45–64 years)

Very contradictory @ times and somewhat alarmist. (European man, 45–64 years)

Format of health information

Fact sheets were the most popular format overall for 80% of respondents and for all ethnic groups (87% European,

^BUsed the Internet themselves or asked someone else to look for them.

^CIndividual participants could check multiple options they agreed with for this question.

Table 3. Responses to key questions adjusted by age group, sex and ethnicity.

Survey question	Variable	OR (95% CI)
Looking for online health-related information three monthly or	Age group (years)	
more frequently	<25	4.34 (1.54–12.20)
	25–44	3.85 (2.08–7.13)
	45–64	1.88 (1.14–3.10)
	65–74	1.22 (0.72–2.07)
	Women	1.09 (0.79–1.51)
	Māori	1.05 (0.66–1.65)
	Pacific	0.84 (0.49–1.42)
	Other	1.62 (0.95–2.78)
Looking for online health-related	<25	4.16 (1.55–11.18)
information to help diagnose a health worry	25–44	2.32 (1.25–4.31)
	45–64	1.60 (0.93–2.76)
	65–74	1.26 (0.70–2.25)
	Women	1.21 (0.87–1.68)
	Māori	1.01 (0.64–1.60)
	Pacific	0.98 (0.73–2.07)
	Other	1.23 (0.57–1.67)
Normally find what I'm looking for	<25	0.64 (0.23–1.75)
– online health information	25–44	1.51 (0.77–2.95)
	45–64	1.46 (0.80–2.66)
	65–74	1.12 (0.60–2.10)
	Women	0.94 (0.66–1.35)
	Māori	0.75 (0.46–1.23)
	Pacific	0.46 (0.26–0.80)
	Other	0.97 (0.55–1.68)
I am concerned about the quality	<25	3.54 (1.19–10.57)
of information	25–44	3.45 (1.59–7.46)
	45–64	2.24 (1.09–4.59)
	65–74	1.00 (0.46–2.21)
	Women	1.04 (0.71–1.52)
	Māori	0.71 (0.41–1.21)
	Pacific	0.80 (0.44–1.45)
	Other	0.57 (0.44–1.45)
Preference for fact sheets	<25	2.06 (0.49–8.69)
	25–44	1.21 (0.51–2.87)
	45–64	1.33 (0.61–2.92)

(Continued on next column)

Table 3. (Continued)

Survey question	Variable	OR (95% CI)
	Women	1.37 (0.89–2.10)
	Māori	0.38 (0.22–0.68)
	Pacific	0.25 (0.13-0.46)
	Other	0.32 (0.17-0.60)
Preference for videos	<25	1.11 (0.39–3.19)
	25–44	0.96 (0.48–1.94)
	45–64	1.16 (0.62–2.17
	65–74	0.63 (0.32–1.25)
	Women	0.73 (0.51–1.06)
	Māori	1.38 (0.83–2.28)
	Pacific	2.38 (1.36–4.16)
	Other	1.35 (0.77–2.36)
Preference for discussion groups	<25	1.86 (0.55–6.32)
	25–44	3.29 (1.40-7.73)
	45–64	1.72 (0.76–3.87)
	65–74	1.32 (0.56–3.15)
	Women	1.19 (0.79–1.78)
	Māori	1.65 (0.77–2.81)
	Pacific	2.31 (1.29–4.16)
	Other	1.27 (0.68–2.37)

Reference categories: 75+ years, male, European. Bold values indicate data that it statistically significant.

74% Māori, 66% Pacific, 71% other ethnicities (Supplementary Table S1)). After adjusting for age group and gender, Māori, Pacific and other ethnic groups were about a third less likely to prefer this format compared to European people (Table 3). While a 'fact sheet' was not further defined in the survey, the research nurses, who were on hand if there were any questions, reported that some people talked about a simple description or bullet points, 'a take-away sheet' to guide them.

Overall, the next preferred formats were video (31%) and discussion groups (23%). By ethnicity, a video format was rated by 48% Pacific, 35% other ethnicity, 33% Māori and 26% European respondents. The discussion group option was rated by 38% Pacific, 25% other ethnicities, 29% Māori and 19% European respondents (Supplementary Table S1). When adjusted by age group and gender, Pacific participants, but not other ethnicity groups, were more likely than Europeans to prefer videos (OR 2.38; 95% CI 1.36–4.16) or discussion groups (OR 2.31; 95% CI 1.29–4.16).

There were 19 free text responses regarding preferred online health information format. Apart from reiterating the options already given, 10 people put forward other ideas; wanting to see pictures or diagrams (4 responses), wanting to read about other people's stories (2 responses), wanting to access their own/whānau health records online (2 responses) and wanting information directly tailored to their needs (2 responses).

To see illustrations/photographs so I can visualise where things are relative to my condition (ie prostate). (European man, 65–74 years)

Trustworthiness

Although most (85%) thought the Internet was trustworthy, the majority (72%) would like their doctor or nurse to recommend where to look online for health information. Participants reported that they would trust the information appearing on the website if the advice came from a knowledgeable source (61%), appeared to be prepared by an expert (44%), the reasoning behind the advice was explained (35%) or appeared to be impartial and independent (32%).

Of the 41 free text responses, trusting the information found was more likely if it came from a reputable source that they recognised (eg Arthritis NZ) or at least from New Zealand or Australia (12 responses) and if there was evidence of peer review (6 responses).

Furthermore, 11 respondents indicated that they were more likely to trust information if multiple sites gave the same data.

I wouldn't trust one page. I'd look at quite a few to see a common answer. (Māori woman, 25–44 years)

Discussion

Our study sought to understand differences in health information seeking in a diverse population receiving care at three NZ cardiology hospital outpatient clinic sites. These hospitals serve a high proportion of Māori and Pacific people, many of whom live in the most deprived neighbourhoods and who experience a high burden of chronic health conditions, ¹³ barriers to accessing health care and for whom health services create high health literacy demands. We found that most participants had searched for online health information usually triggered after visiting a health provider and often to check side-effects of medications. Pacific respondents reported a lower likelihood of search success compared to the European reference group, and those younger than 65 years were more concerned about the quality of information than older age groups. Overall, fact sheets (80%) were the most preferred format (87% European, 74% Māori, 66% Pacific, 71% other ethnicities), followed by short videos (31%) and discussion groups (23%). The respondents were discerning in terms of which websites they would trust, with the majority (72%) agreeing that it would

help if their doctor or nurse recommended where to look online for health information. Trust strategies included if the advice appeared to come from a knowledgeable source (61%), was prepared by an expert (44%), the reasoning behind the advice was explained (35%) or appeared to be impartial and independent (32%).

The proportion of people using the Internet for health information was similar to that reported in the United Kingdom (68%),¹⁴ a survey including seven European countries (71%)¹⁵ and in the United States (72%),¹⁶ and has been increasing over time.^{17,18} A similar proportion to our study have used the Internet to help diagnose a health worry¹⁶ and online health seeking behaviour is reported to be higher in younger age groups.^{14,19}

The motivations behind seeking help online are also similar. A United Kingdom qualitative study reported four main reasons: the desire for reassurance; the desire for a second opinion to challenge other information; the desire for greater understanding to supplement other information; and perceived external barriers to accessing information through traditional sources.¹⁴

From this survey, the provision of fact sheets was the most preferred means of having information delivered with about one-third of people also interested in other formats such as video and discussion groups. There were distinct Pacific ethnic preferences for these other formats. The way information is presented can affect patients' understanding and perception of their risk and can influence their decisions. 20,21 In NZ, ethnic differences have been found in patient preferences for communication formats with respect to cardiovascular disease (CVD) risk (eg pictures such as 100 people charts or bar graphs, numbers such as absolute risk or natural frequencies, or verbal communication from their health provider).²² Internationally, cultural variation in preference of online health information sources has also been reported.²³ A recent national survey found that Iranian people preferred presentation of health information in the form of images, educational videos and texts. 18 Song et al. reported that compared to Americans, Koreans and people from Hong Kong had more trust in blogs, online support groups and social networking sites and were less likely to prefer expertise-based information sources (eg WebMD and CDC).²³ However, trust in expertise-based information sources demonstrated no cultural differences.²³

As with our study, the wish for health professional involvement in navigating online health information has also been reported in a 2017 survey of 400 Australian adults, especially given the volume of web-based health information available and inconsistency of information between sources. As treatment and side effects of medicines were the most frequent topics searched in our study, it would seem quite critical for health professionals to specifically recommend where to look up this information. Brand recognition has also been found to be important in determining trust. However, while brands may be trusted,

Gunter *et al.* warned about an apparently illusory truth effect – that repetition is mistaken for accuracy – with social media repeating information with re-tweets and re-postings but often mixing fact with fiction and also not disclosing biases (eg sale of a product).²⁴

In this infodemic era, the general advice for health professionals is to find good online resources, curated content from trusted sites, and offer them as handouts or direct email links.²⁴ In addition, clinicians could post trusted information on a social media platform that works for them (eg Facebook or Twitter). Furthermore, by clicking the 'like' button on these trusted sites, it will increase the chance that the information will be picked up by social media algorithms.²⁴ Conversely, health professionals have been advised to not share or actively engage against 'false information' as this too will make bad content more likely to be picked up by algorithms. In order to support health professional and consumer online patient information needs, website tools, such as the CRAAP test (Currency, Relevance, Authority, Accuracy and Purpose) and DISCERN²⁵ have been used to evaluate the reliability and trustworthiness of health websites.²⁶ However, these take time to apply and are themselves reliant on awareness and digital literacy.

A strength of the study relates to understanding the preferences of NZ consumers attending cardiology outpatients, which are likely to represent people with one or more long term conditions needing advice and management from a cardiology specialist. A further strength is the diversity of participants, in particular the proportions of Māori and Pacific participants (16 and 12%) compared with the NZ population (16.5 and 8% in 2018). However, we were unable to further investigate the potential reasons for the differences by ethnicity and we did not collect any information on education, area deprivation or occupation, which could potentially augment these results. Furthermore, there are no data on the proportion of attendees at the outpatient clinics who declined to take part, although anecdotally the short nature of the survey aided completion. The free text responses both corroborated and added to the survey question options.

We acknowledge that this study was conducted in 2016/17 in a pre-COVID-19 era. However, we believe the findings are still relevant due to increasing use of the Internet (88% in 2012²⁷ to 93% in 2022²⁸), misinformation and concerns with the quality of online content^{1,2} and need for consumer strategies to trust online content. Understanding how NZ consumers assess trustworthiness and preferences with respect to what and how information is delivered and the clarity of communication are key principles of health education resource development.²⁹ The widespread popularity of fact sheets is an important new finding overall, particularly for those of Māori and Pacific ethnicity who have a higher burden of long term conditions and have been traditionally underserved by health services. This format preference makes it particularly salient for NZ policymakers and

providers of consumer health portals to include fact sheets in their offerings, as well as videos and discussion groups.

In January 2024, Te Whatu Ora launched a new consumer-facing website with limited topics and initially focussed on COVID-19 content and immunisations (www. info.health.nz). Healthify (https://healthify.nz/) provides a summary for each health topic followed by more in-depth information which may include videos, graphics, FAQs and less commonly links to discussion/online forums (only if known to be well moderated). Consumer feedback to Healthify often includes requests for NZ-based videos. A number of topic- and medicine-specific factsheets have also been created and translated into te reo and Pacific languages. Additionally, there are over 30 different languages pages of dedicated health information, including NZ Sign Language with a range of sign language videos created in collaboration with Platform Trust and DeafRadio (personal communication J Bycroft).

Conclusion

This study has described the internet and online experiences and preferences of a diverse sample of New Zealanders attending cardiology outpatients and provides a window into the extent and variation of online health information needs to support knowledge and choices regarding self-management. With the rising tide of misinformation and 'fake news', now more than ever before, policy makers and health portal providers need to be vigilant with respect to quality of content and consumer preferences for information formats, and health professionals need to support consumers by guiding them to NZ-appropriate trusted health information websites.

Supplementary material

Supplementary material is available online.

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