AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

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Consumer health information needs and preferences:

A rapid evidence review

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Preface

The Australian Commission on Safety and Quality in Health Care (the Commission) is committed to supporting meaningful partnerships with consumers as a way of improving the safety and quality of health care in Australia.

Providing understandable and accessible health information can improve people's knowledge, understanding and recall about their health and care. It can also increase their feelings of empowerment, improve their ability to cope, increase satisfaction, support shared decision making and contribute to improved health literacy, so that people can be partners in their health care.

Today, people expect a large amount of information to be easily available in a format that they understand. People seek out, or are provided with, health information from a variety of sources including:

- their social community, including their parents, families, friends, neighbours and work colleagues
- the education system, including preschools, primary and secondary schools, adult education centres and universities
- the health, social and community care systems, including care providers, health organisations, and government and non-government care organisations
- private industry, including manufacturers and providers of food, pharmaceuticals, alcohol, exercise products and services
- mass media, including health promotion campaigns, the internet and private companies promoting their health-related products.

The Commission wants to support consumers to understand safety and quality issues for health care, and aims to develop information materials for consumers in key areas of interest. Consequently, the Commission engaged the Sax Institute to broker a review of the evidence and identify what consumers are interested in knowing about healthcare safety and quality, where they get their information and how they use that information.

This report describes the findings of the evidence review on consumer health information needs and preferences brokered by the Sax Institute.

In addition to this evidence review, the Commission engaged a separate organisation to undertake targeted consultation on the health information needs and preferences of consumers from Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) backgrounds. A separate report entitled *Consumer health information needs and preferences: Perspectives of culturally and linguistically diverse and Aboriginal and Torres Strait Islander people* has been prepared to describe the findings of this work.

Key findings

There is limited research about the type and format of information that consumers want on healthcare safety and quality. As a result, this evidence review largely reports on findings of research that has explored consumer needs and preferences for general information about health and health care.

The evidence review made several recommendations, largely emphasising the individuality and variability of consumer information needs, and how they are dependent on the individual's context. The researchers found information needs:

- vary at different stages of the patient journey and that relevant information needs to be available to consumers at the appropriate time
- may also depend on the physical, mental and social wellbeing of consumers at that point in time.

The researchers identified that although the internet is an increasingly popular source of healthcare information, it is generally seen as supplementary to advice from a healthcare professional. Healthcare professionals remained the preferred source of information and were particularly valued when consumers needed an accurate diagnosis, information about medicines, alternative treatments or recommendations about other doctors or hospitals.

The researchers' conclusions were that:

- healthcare information should be readily available in a range of different formats, not exclusive to any single medium
- a focus should be on supporting consumers with low health literacy, recent migrants, people from CALD communities and Aboriginal and Torres Strait Islander people to have equal access to healthcare information
- healthcare information should cater to different levels of consumer engagement and health literacy.

Next Steps

The Commission's work on health literacy, partnerships with consumers and actions within the National Safety and Quality Health Service (NSQHS) Standards recognises the importance of developing high-quality, easy to understand health information to support effective partnerships.

The Commission will consider the findings of this evidence review and the targeted consultation with Aboriginal and Torres Strait Islander peoples and CALD communities to develop guidance and key principles that should be considered when developing health information for consumers, including information on safety and quality. This guidance will be used by the Commission when developing resources for consumers, and will also be provided to stakeholders to support the development of consumer health information and to help support health services to meet the requirements of the NSQHS Standards (second edition), which is due for release in late 2017.

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Evidence Check

Consumer health information needs and preferences

An **Evidence Check** rapid review brokered by the Sax Institute for the Australian Commission on Safety and Quality in Health Care.

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

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Disclaimer:

This **Evidence Check Review** was produced using the Evidence Check methodology in response to specific questions from the commissioning agency.

It is not necessarily a comprehensive review of all literature relating to the topic area. It was current at the time of production (but not necessarily at the time of publication). It is reproduced for general information and third parties rely upon it at their own risk.

Consumer health information needs and preferences

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University of
South Australia

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1 Executive summary

Background

It is important to understand consumer communication preferences for healthcare information content and access points. This rapid review presents a summary of the evidence around consumers' needs and preferences for information about healthcare safety and quality.

Healthcare quality and safety is defined as information about a person's own care and the options associated with it, such as information about: illness, symptoms, treatment, how to prevent errors and increase safety during the course of a person's care, where to access healthcare services, and the value and variation in healthcare. Excluded from this review is information about the performance of specific healthcare services, information about medication, and health promotion and lifestyle factors.

The Australian Commission on Safety and Quality in Health Care (the Commission) commissioned this Evidence Check review. The evidence from this review will complement primary research with consumers to inform the development of consumer resources, tools and publications, as well as an internal communication resource for staff at the Commission.

Objective and review questions

The aim of this Evidence Check review was to determine what information on healthcare quality and safety consumers are interested in and where they source this information. Four key questions guided the review:

- When do consumers look for information about healthcare safety and quality?
- Where do consumers find information about healthcare safety and quality and where do they want to find it?
- How do consumers use information about healthcare safety and quality?
- About which topics or subjects do consumers need healthcare quality and safety information?

Methodology

The review team conducted the literature search in a hierarchical manner with evidence first sought from systematic reviews (not restricted by year) identified using Medline (via PubMed), CINAHL, EMBASE, and the JBI Database of Systematic Reviews and Implementation Reports. The researchers conducted a subsequent search for primary studies (published from 2006 onwards) in PubMed and Scopus to supplement evidence relating to the Australian context and add depth of understanding to the review findings. The researchers also conducted a grey literature search using Google Scholar.

A total of seven systematic and non-systematic review papers relevant to the research questions were identified in the initial scoping search. The search for primary studies located 7329 articles for all questions combined. After screening selection at full text level, and examination of the reference lists of included papers, 21 primary studies remained for quality appraisal and inclusion in the review. In general, the included reviews and primary studies were of moderate to high quality. All primary publications were observational descriptive studies.

Results

When do consumers look for information about healthcare safety and quality?

- Two reviews and five primary studies addressed this question.

- Patients seek information at various times, including during screening, diagnosis, treatment, decision-making, recovery and discharge. Overall, the reviews and studies suggest that when consumers look for information tightly correlates with the type of information they are seeking, the source they use to find that information and how they plan to use it.
- Information needs change throughout the stages of a patient journey, reflecting the need for relevant information to be available at the appropriate time.
- Studies that examined information-seeking associated with a medical consultation suggested that consumers seek information before a consultation and after a consultation, although the latter appears to be more common.

Where do consumers find information about healthcare safety and quality and where do they want to find it?

- Six reviews and 20 primary studies explored information source preferences among health consumers.
- Two of the included reviews report that health professionals are the primary source of health information for most cancer patients, followed by printed materials (such as medical pamphlets), and interpersonal communication with family and/or friends.[1, 2]
- Two of the included reviews focused solely on use of the internet as a source of health information.[3, 4] The internet was the most frequently identified resource for primary care patients in the 19 articles pertinent to information sources included in a systematic review published in 2015, followed by physicians, television, and family and friends.[5] Despite its growing popularity, there was general consensus among the included publications that the internet is generally perceived as a supplement, rather than an alternative, to advice from a health professional.
- Two studies addressed information preferences among culturally and linguistically diverse (CALD) populations. A qualitative study of CALD consumer needs in Australia found that participants relied on their healthcare professional for information — as well as information source referral — and rarely used the internet.[6] A qualitative study of older Italian and Greek migrants living in South Australia found a low rate of computer use with most participants expressing a preference for receiving information directly from another person or in printed form.[7]
- Whether consumers turn to health professionals or non-professionals for health-related information is contingent on the circumstances prompting their need to seek it. Health professionals are considered more helpful when in need of an accurate medical diagnosis, information about prescription drugs, information about alternative treatments, a recommendation for a doctor or specialist, or a recommendation for a hospital or other medical facility.[8] Non-professionals are considered helpful for emotional support in dealing with health issues and quick remedies for everyday health issues.[8]
- Results from some of the included studies indicate that an individual’s level of health literacy may be associated with the source and amount of information sought, with lower health literacy associated with less information-seeking and greater reliance on health professionals to provide information.

How do consumers use information about healthcare safety and quality?

- Four reviews and 12 primary studies included information about how consumers use health-related information.
- How patients use the health information they find is often dictated by their information needs, stage of illness and the source of information.[5] For example, the information patients seek prior to consultation is used to determine the type of physician they need to see and to prepare for consultation.[5] Patients may use the information provided by their physician at consultation to validate information they have received from other sources such as the internet.[5]

- There was substantial literature regarding the use of online information by health consumers to develop a current and comprehensive understanding of illness and its management, gain an understanding of treatment options and their likely consequences, enhance clinical interactions and facilitate the decision-making process.[9]

About which topics or subjects do consumers need healthcare safety and quality information?

- Six reviews and 13 primary studies provided insight into the topics or subjects for which consumers seek information.
- It is difficult to separate patients' information needs from their surrounding context, which encompasses the stage of illness, information source and intended use of information.[5] Patients' information needs may also depend on their current physical, mental and social wellbeing. For example, a newly diagnosed breast cancer patient may require information on the advantages and disadvantages of various treatment options.[9]
- The following information topics were identified in the included reviews: general, cancer-specific, treatment-related, information for an illness or medical condition, treatment side effects, prognosis, rehabilitation, psychological support, nutrition, alternative medicines or new/experimental treatment available, prescription and over-the-counter drugs, exercise and physical activity, body image/sexuality, surveillance and health, financial/legal, medical system and complementary therapies.[1, 2, 5]
- The information topics identified in the included primary studies included: alternative/complementary therapy, relevant associations or societies, caring for an elderly or disabled person, doctors and other health professional, emotional support, end-of-life decisions, environmental health hazards, financial advice, food or drug safety/recall, health and lifestyle behaviours, health insurance, hospitals or other medical facilities, immunisation/vaccinations, legal support, medical terms, medical treatment or procedure, mental health, other local health services, prescription or over-the-counter drugs, recovery, return to work, side effects of treatment medication, specific disease or medical condition, and symptoms.

Discussion summary including consumer engagement

Consumer preferences for information seeking are context-dependent. Consumers access information from a range of sources and for varying purposes, based on their specific needs at the time they seek it. Although research indicates that a great deal of consumers use the internet to obtain health information, this appears to be because they find its high accessibility convenient, not because they considered it to be a better alternative to face-to-face communication with a health professional. Despite the widespread use of the internet, evidence suggests that the doctor-patient relationship is still highly valued and that health professionals remain the preferred source of health information for consumers. However, the internet provides a cost-effective channel for information sharing.

Many health consumers prefer to access information from a variety of sources, including their family and friends, the internet, health professionals and written materials. It is important to ensure that information is readily available in different formats and is not exclusive to any single medium.

Consumer representatives from Cancer Voices South Australia and Health Consumers Alliance South Australia provided feedback on the draft results. Some of the key considerations highlighted included: having the right information provided at the right time, ensuring that information systems do not widen the gap between people with high and low health literacy, providing information that assists consumers to be active and vigilant participants in their care, and enabling consumers to provide feedback and contribute to more effective information dissemination. Consumers also identified a number of gaps in information related to cancer, which included: the cost of treatment and gap payments, options and timeliness of transfer from private to public systems, what clinical trials are available and how to access this information, how to ask for and obtain a second opinion, medical roles and lines of handover, accessibility of personal clinical data and results, explanation of results, side effects of medication and how to report them, information about wellness and not just illness, relapse and cancer progression, and end of life care.

Recommendations

The following recommendations are based on the findings of the Evidence Check review. These recommendations could serve as guiding principles for the internal resource the Commission's staff is developing to provide consumer health information resources for existing and new programs.

- Healthcare quality and safety information should be provided at all stages of the patient journey, including the pre- and post-treatment phase.
- Information that is relevant and specific to various stages of the patient journey should be made available to consumers at the appropriate time points throughout this journey.
- Health information should be provided through a variety of channels. The appropriate channels should be determined by considering specific patient contexts, stage of patient journey, level of direct engagement with the healthcare system, purpose of the information, and patient population.
- The internet should be considered as complementary to information provided by health professionals. The information provided on government or government-sponsored websites should be evidence-based, without bias, and regularly checked for currency and accuracy.
- Consideration should be given to the role of health information as an enabler of effective patient-clinician communication and shared decision-making.
- Additional effort is required to ensure consumers with low health literacy, recent migrants, people from CALD communities and Aboriginal and Torres Strait Islander (ATSI) people have equal access to information as those with high levels of health literacy. The Commission should aim to ensure that it provides health information to these groups in a way that they can understand it and act on it.
- The Commission should aim to ensure that health information can cater to different levels of patient engagement by enabling motivated and engaged consumers to be proactive in their care if they wish to be; and also ensure that less engaged consumers receive critical information that is relevant to their care and treatment decisions to minimise the chance of errors in their care.

Acknowledgements

The review team acknowledges the time and input of the consumer representatives from Cancer Voices South Australia and Health Consumers Alliance of South Australia who reviewed the draft results of this Evidence Check review and provided feedback.

2 Background

The Australian Commission on Safety and Quality in Health Care (the Commission) is a federal government agency that leads and coordinates national improvements in safety and quality in health care across Australia. Partnering with consumers is one of the Commission's four priority areas. To create effective partnerships across the health system, the Commission has sought to understand what people in Australia would like to know about healthcare safety and quality, and how they would like that information presented.

In recognition of the central importance of consumers, the Commission has shifted its focus from the production of materials to support healthcare organisations, clinicians and non-clinical staff in providing safe and high quality care, to the development of resources targeted at consumers. Appropriate resources can encourage and engage consumers to actively participate in their own care, support shared decision-making and contribute to improved health literacy.

To inform its work on the development of consumer resources and tools to support an update to the National Safety and Quality Health Service (NSQHS) Standards (second edition), the Commission has authorised a literature review to identify consumers' needs and preferences for information about healthcare safety and quality. For the purpose of this review, healthcare safety and quality information was defined as:

- Information about a person's own care and the options associated with it, such as information about illnesses, symptoms, treatment, and information about how to prevent errors and increase safety during the course of a person's care.
- Information about health care more broadly, such as where to access healthcare services as well as value and variation in health care.

For the purpose of this review consumers are members of the public who use, or are potential users of, healthcare services (including patients, families, carers and other support people).

3 Methodology

Purpose of this rapid review

This rapid review determines the current best evidence to inform consumer resources and tools that are being developed to support the NSQHS Standards (second edition).

Objectives of this rapid review

The objective of this rapid review is to provide a brief synthesis of best available research evidence on consumers' needs and preferences for information about healthcare safety and quality.

Methodology

An iterative, systematic, step-by-step approach was employed for this review.

Review questions

Four review questions guide this review:

- When do consumers look for information about healthcare safety and quality?
- Where do consumers find and what platform do they use to access information about healthcare safety and quality?
- How do consumers use the healthcare safety and quality information that they find?
- About which topics or subjects do consumers need healthcare safety and quality information?

Criteria for considering research in this review

In collaboration with the Sax Institute and the Commission, specific criteria for ensuring inclusion of relevant research were considered and agreed upon. Research included in this review relates to consumers' needs and preferences for information about healthcare safety and quality. The criteria and scope for the review are outlined in detail in Supplementary Appendix 2.

Types of studies

Any review of the literature or primary study that investigates consumers' needs or preferences for information about healthcare safety and quality, as defined by the Commission.

Scoping search

To identify pertinent Level 1 evidence (i.e. systematic reviews and meta-analyses), a scoping search of the literature addressing consumer health information needs and preferences was conducted. The initial scoping search was not restricted by year and was performed in Medline (via PubMed), CINAHL, EMBASE and the JBI Database of Systematic Reviews and Implementation Reports. To verify that we had identified the best available Level 1 evidence, the review team conducted a systematic review of repositories including EPPI-Centre, Epistemonikos and the Campbell Collaboration library of systematic reviews. The team screened the reference lists of included reviews for additional relevant papers and conducted a search of grey literature using Google Scholar.

Keywords

The following MeSH terms were used: health education, information-seeking behaviour, and patient education as topic. Other search terms included a combination of the following: patient, user, consumer, health, healthcare, information, needs, preference, choice, decision, source, search, systematic review and meta-analyses. The team derived these keywords from existing systematic reviews and other literature on this topic, and confirmed them with the Commission. A detailed search strategy is included in Supplementary Appendix 1.

Database searching steps

The review team conducted a scoping search of the databases using the above terms. The researchers discussed the results of the scoping search with the Sax Institute and the Commission and it was agreed that due to the presence of high-quality Level 1 evidence, targeted searching for highly relevant evidence to inform the answers to the four review questions would be appropriate for the remainder of the search process. Subsequently, searches were performed for relevant, high-quality, quantitative and qualitative primary studies to supplement the identified Level 1 evidence in PubMed and Scopus, using the search strategy outlined in Table 1.

Table 1. Search strategy for identifying primary studies

#	Concept	Terms
1.	Patient	(patient or consumer or user).ab,ti.
2.	Health	(health).ti. or (health care or healthcare).ab,ti.
3.	Information	(information).ti.
4.	Preference	(preference or prefer or seek or need or needs or source or choice or decision).ti.
5.	Consumer behaviour	behaviour, information seeking [MeSH] or consumer health information [MeSH]
6.	Combine searches	3 & 4
7.	Combine searches	5 or 6
8.	Combine searches	1 & 2 & 7

ab: abstract; ti: title

Inclusion criteria for primary studies

The researchers limited their efforts to retrieving articles written in English published within the past 10 years (from 1 January 2006 onwards). When selecting quantitative studies, the researchers gave preference to studies that used population-based sampling methods over non-representative sampling. Research conducted in Australia was prioritised, followed by evidence from countries with similar cultural and healthcare contexts to Australia, such as the US, the UK, New Zealand and Canada. The researchers also sought evidence pertaining to special interest groups of health consumers such as Culturally and Linguistically Diverse (CALD) people, and Aboriginal or Torres Strait Islander (ATSI) people in a targeted manner.

Data extraction

Two reviewers extracted relevant data to answer the four review questions from the included publications using a specifically developed template (Supplementary Appendix 3). All four reviewers cross-checked the template for completeness.

Data synthesis

The reviewers synthesised the findings and methodological quality of the articles into a narrative summary.

Quality appraisal

Three reviewers independently assessed and appraised the full text of the selected articles by using predetermined criteria to ascertain the quality of the evidence adapted from JBI tools (see Supplementary Appendix 4 and Supplementary Appendix 5).[10] Lack of consensus was resolved via discussion.

Consumer engagement

The review team engaged consumer representatives in the process of the Evidence Check. The review team presented and discussed the results of the review with two consumer representatives from Cancer Voices South Australia and Health Consumers Alliance South Australia. The review team provided the representatives the draft results of the Evidence Check along with a series of focus questions to guide their feedback. Their feedback was compared with the synthesised findings from the included studies. Similarities and differences between the feedback from consumer representatives were identified and key messages provided by the consumer representatives in relation to the results were collected and examined.

4 Results

Search results

The scoping search returned a total of 1643 citations and identified a considerable body of evidence published within the last 10 years. As mentioned, based upon these results and consultation with the Sax Institute and the Commission, it was decided that the search would be restricted to sources of evidence available from 1 January 2006 onwards. Key sources of evidence available prior to this date would be eligible for inclusion if the review group deemed it to contain significant evidence not otherwise located in more recent sources. After screening titles and abstracts, the reviewers retrieved 89 citations and imported them into an EndNote™ database for closer inspection in relation to the overall inclusion criteria of the review as well as the specific criteria developed according to the scope for each question. Eighteen review papers were identified as potentially relevant and two reviewers examined them for correspondence with the inclusion criteria and the relevance of their reported data for addressing the review questions. Three systematic reviews and two relevant literature reviews met the criteria for inclusion.

The search for primary studies returned a total of 7329 citations. The titles and abstracts of the first 200 references in each database were screened and 108 potentially relevant sources of evidence (78 from Scopus and 30 from PubMed) were retrieved in full text for more detailed review. Two articles were located from the reference lists of included articles. After full text review, 21 primary studies were included. An additional systematic review and relevant literature review were identified. A list of excluded studies is provided in Supplementary Appendix 6.

Characteristics of the included publications

The characteristics of the included reviews and primary studies are summarised in Table 2 and Table 3, respectively. The studies were conducted in Australia[6, 11-20], the US[8, 21-26], and Europe.[27-29] Common research methods included questionnaires, interviews and focus groups. The results and analysis are presented by review question below. The reviewers reported gaps in the evidence base that they identified specific to each research question.

Methodological quality of the included studies

The reviewed literature was based on observational descriptive studies, or systematic and non-systematic reviews of these studies. This represents Level 1, Level 2 and Level 3 evidence based on the JBI levels of evidence used.[10] The overall quality of the evidence was high and very high, particularly among the primary studies (see Table 4).

Question 1: Evidence for question 1 was based on two systematic reviews and five primary studies. The two systematic reviews were high and moderate quality. The quality of the evidence from the five primary studies was very high (n = 3), high (n = 1) and moderate (n = 1).

Question 2: All but one of the included publications provided evidence for question 2. This included: four systematic reviews (two high quality, one moderate quality, and one low quality); three non-systematic literature reviews (moderate quality); and 20 primary studies that were mostly high quality (n = 5) or very high quality (n = 14).

Question 3: Evidence for question 3 was based on one systematic literature review, three non-systematic literature reviews and 11 primary studies. The systematic review was very high quality, the non-systematic reviews were moderate quality and the primary studies were high or very high quality.

Question 4: Evidence for question 4 was based on four systematic reviews, two non-systematic literature reviews and 13 primary studies. The systematic reviews were very high, high, moderate and low quality, the non-systematic literature reviews were moderate quality, and the primary studies were high and very high quality.

Evidence mapping

Table 5 shows the evidence base mapped against the review questions.

Table 2. Characteristics of the included reviews

Reference	Type	Population	Studies	Dates	Aim
Ankem 2005[1]	Systematic review	Cancer patients	12	1993–2003	To synthesise existing findings on cancer patients' use of information sources in order to: rank the most and least used information sources and the most helpful information sources, and find the impact of patient demographics and situations on use of information sources.
Clarke 2015[5]	Systematic review	Primary care patients	46	2000–2015	To identify and analyse the research on information needs of patients in a primary care setting; determine the information sources used to satisfy those information needs (especially the internet because of its accessibility); and identify barriers to accessing the identified information sources.
Dey 2004[9]	Overview	Breast cancer patients	46	1995–2003	To explore patients' perspectives in gaining health related information from the healthcare system and provide an overview of the issues encountered by consumers with information currently available.
Higgins 2011[3]	Literature review	Health consumers and health professionals	43	2006–2010	To provide an overview of online health information seeking behaviour by adults from the perspective of both the health consumer and the health professional.
Kinnane 2011[4]	Literature review	Carers of cancer patients	112	1980–2003	To review the best available evidence for how carers use the internet for cancer-related information and support.
Rutten 2005[2]	Systematic review	Cancer patients	112	1980–2003	To identify cancer patients' information needs during their cancer journey; identify the sources cancer patients use to obtain cancer relevant information; and examine whether, and to what extent, needs and information sources sought vary by phase of the cancer care continuum.

Tariman 2014[30]	Systematic review	Cancer patients	13	2002–2011	To summarise relevant studies that have examined information needs priorities in patients with various types of cancers, identifying the prioritised information needs across the studies. Moreover, to summarise the association of age with patients' priorities of information needs and describes the trend over time.

Table 3. Characteristics of the included primary studies

Reference	Method	Population	Location	Aim
Beck 2015[27]	Telephone survey	1052 young adults aged 15–30 years old, from the initially representative sample of 27,653 participants in the French Health Barometer 2010	France	1) To provide information about the prevalence of internet use for health-related purposes in France among young adults and define the socio-demographic, socio-economic, and health-related profile of users, 2) to investigate the context and the impact of the information found on health-related behaviours, and 3) to assess the level of trust young adults have in the information found on the internet.
Fiksdal 2014[21]	Focus groups	19 adult residents of Olmsted County, Minnesota	US	To gain a deeper understanding of online health-searching behaviour in order to inform future developments of personalising information searching and content delivery.
Fox 2010[22]	Telephone survey	2253 US adults	US	To investigate how many people use online resources to find information or connect with others about health conditions.
Fox 2011[8]	Telephone survey	3001 US adults	US	To illuminate the different ways people seek health information as well as how people use online social tools to share knowledge with loved ones, fellow patients and caregivers.
Gaglio 2012[23]	Questionnaire and qualitative interviews	150 adults aged over 40 who had completed a primary care visit in the past 12 months and had at least two health risks for cardiovascular disease	US	1) To describe where a diverse sample of primary care patients who are at risk for cardiovascular disease and have varying health literacy and health numeracy abilities obtain their health information and 2) to describe their preferences for methods of receiving health information using a qualitative approach.
Halkett 2010[11]	Qualitative interviews	34 women who had been diagnosed with early breast cancer and 14 health professionals	Australia	To determine the specific information needs of breast cancer patients who are receiving radiotherapy and identify when patients prefer to receive specific information relating to different aspects of their radiotherapy treatment.

Lee 2014[12]	Qualitative interviews	17 consumers recruited from community pharmacies, radio and university advertising channels	Australia	To explore the navigational needs of consumers when searching for health information online for the purpose of self-management of chronic health conditions.
Lee 2015[13]	Questionnaire	400 online participants with at least one chronic health condition	Australia	1) Estimate the proportion of consumers with navigational needs among consumers of web-based health information living with chronic health conditions, 2) describe the following characteristics of consumers with navigational needs: web-based HISB, patient activation, and eHealth literacy, and 3) explore variables predicting navigational needs of these consumers.
Lee 2013[14]	Focus groups, qualitative interviews and questionnaire	268 migrant and refugee women from 50 countries	Australia	To explore CALD women's views about access to health information and to identify their preferences for information delivery.
Li 2014[24]	Questionnaire	311 adult members of an online support group who had visited a doctor within the previous 30 days	US	To examine predictors of patients' post-visit online health information seeking, reasons for seeking information and information sources used.
Lui 2015[15]	Questionnaire	3652 internet users with diabetes	Australia	To investigate the relationship between online information seeking and a broad range of health and social characteristics among a large sample of Australian adults with type 2 diabetes. Specifically, the analysis examined the relationship between internet use and five key domains of interest: patients' socio-demographic characteristics, patients' diabetes-related characteristics, the level of patient activation, how satisfied patients are with their healthcare, and the number of comorbid chronic diseases.

Maddock 2011[28]	Questionnaire	476 participants from over 20 European countries, most of which had a cancer diagnosis (82.9%)	Europe	To assess current online information needs of people with cancer, particularly those who seek information using new media technologies. To broaden public policy understanding of patients' specific needs when seeking online cancer information and identify gaps in the current online cancer information provision across Europe.
Moghe 2014[16]	Questionnaire	1013 adults with insomnia	Australia	To characterise the patterns of online information seeking and utilisation among patients with insomnia.
Mohammad 2015[6]	Qualitative interviews	31 CALD Australians with low or negligible English proficiency	Australia	To investigate the needs of CALD Australians with low or negligible English proficiency, specifically in regards to their understanding of health and medicines, and the role of pharmacy in achieving best medicine use outcomes for this population.
Nagler 2010[25]	Questionnaire	1638 breast, prostate and colorectal cancer patients from the Pennsylvania Cancer Registry	US	To investigate whether patients with different types of cancer vary in their information needs and seeking behaviours, considering both active seeking of information, as well as passive information acquisition (''information scanning'').
Nielsen 2014[17]	Focus groups and qualitative telephone interviews	28 adults with lower back pain (LBP)	Australia	To identify the information needs and preferred methods for presentation of this information online for people with LBP in Australia.
Reinfeld-Kirkman 2010[18]	Questionnaire	3034 South Australians	Australia	To investigate the relationship between self-reported health and searches for online health information, and to explore whether the characteristics of South Australians who use the internet to seek health information have changed since they were last investigated in 2001.
Rodger 2013[19]	Qualitative interviews	35 pregnant women at a South Australian hospital	Australia	To gain an in depth understanding of access to and use of information communication technologies (ICTs) among pregnant women in South Australia.

Sørensen 2009[29]	Telephone survey	7934 participants from seven European countries	Europe (Norway, Denmark, Germany, Latvia, Greece and Portugal)	To investigate European health consumers' use of, attitudes to and desires with regards to Information and Communication Technologies (ICT) for health purposes.
Volkman 2014[26]	Questionnaire	5307 American adults	US	To gain insight into the health information habits of patients by understanding characteristics of patients turning towards a doctor or healthcare provider first when confronted with a recent health or medical information need.
Wong 2014[20]	Questionnaire	2944 general practice patients	Australia	To measure the extent to which general practice patients use the internet to obtain health information, particularly about information related to the problem(s) they bring to the general practitioner, and whether this differs by patient age, sex, socioeconomic status, rurality and proficiency with English.

Table 4. Study quality and level of evidence of the included publications

Reference	JBI Level of Evidence	Study quality
Ankem 2005[1]	Level 1	High
Beck 2015[27]	Level 3	High
Clarke 2015[5]	Level 1	Very high
Dey 2004[9]	Level 2	Moderate
Fiksdal 2014[21]	Level 3	Very high
Fox 2010[22]	Level 3	Very high
Fox 2011[8]	Level 3	Very high
Gaglio 2012[23]	Level 3	Very high
Halkett 2010[11]	Level 3	Very high
Higgins 2011[3]	Level 2	Moderate
Kinnane 2011[4]	Level 2	Moderate
Lee 2013[14]	Level 3	High
Lee 2014[12]	Level 3	Very high
Lee 2015[13]	Level 3	Very high
Li 2014[24]	Level 3	Moderate
Lui 2015[15]	Level 3	High
Maddock 2011[28]	Level 3	High
Moghe 2014[16]	Level 3	High
Mohammad 2015[6]	Level 3	Very high
Nagler 2010[25]	Level 3	Very high
Nielsen 2014[17]	Level 3	Very high
Reinfeld-Kirkman 2010[18]	Level 3	Very high
Rodger 2013[19]	Level 3	Very high
Rutten 2005[2]	Level 1	Moderate
Sørensen 2009[29]	Level 3	Very high
Tariman 2014[30]	Level 1	Low
Volkman 2014[26]	Level 3	Very high
Wong 2014[20]	Level 3	Very high

Table 5. Evidence mapped to review questions and quality of included publications

Reference	Q1. When consumers look	Q2. What sources	Q3. How they use information	Q4. Which topics
Ankem 2005[1]	✓	✓		✓
Beck 2015[27]	✓	✓	✓	✓
Clarke 2015[5]		✓	✓	✓
Dey 2004[9]		✓	✓	✓
Fiksdal 2014[21]		✓	✓	
Fox 2010[22]		✓	✓	✓
Fox 2011 [8]		✓	✓	✓
Gaglio 2012[23]		✓	✓	
Halkett 2010 [11]	✓	✓		✓
Higgins 2011[3]		✓	✓	✓
Kinnane 2011[4]		✓	✓	
Lee 2013[14]		✓		✓
Lee 2014[12]	✓	✓	✓	✓
Lee 2015[13]		✓	✓	✓
Li 2014[24]	✓	✓		
Lui 2015[15]		✓		
Maddock 2011[28]		✓	✓	✓
Moghe 2014[16]		✓	✓	✓
Mohammad 2015[6]		✓	✓	
Nagler 2010[25]	✓	✓		✓
Nielsen 2014[17]		✓		✓
Reinfeld-Kirkman 2010[18]		✓	✓	✓
Rodger 2013[19]		✓		
Rutten 2005[2]	✓	✓		✓
Sørensen 2009[29]			✓	
Tariman 2014[30]		✓		✓
Volkman 2014[26]		✓		
Wong 2014[20]		✓		✓

Question 1: When do consumers look for information about their healthcare safety and quality?

Key points and summary

Consumer use of information sources at different times during illness was examined in only two of the included reviews, which included studies that examined patients' information needs and sources at specific times — most commonly during diagnosis or treatment (Table 4).[1, 2] The findings indicate that patients seek information at various times throughout their healthcare journey, including during screening, diagnosis, treatment, decision-making, recovery and discharge.[1, 2, 9] Overall, the reviews and studies suggest that when consumers look for information is inextricably linked to the type of information they are seeking, the source they use to find that information and how they plan to use it. For example, consumers will often seek information prior to a medical consultation to determine the type of health professional they need to see and use the internet to search for it. Similarly, cancer patients are likely to search for information about their disease during the diagnosis and treatment phases, and to search for information about recovery and rehabilitation during the post-treatment phase.[2] Five primary studies explored aspects of when people look for health information, two of which were qualitative (Table 4). Of the quantitative studies, two reported that consumers prefer to seek information before or after a consultation and one investigated consumers' information seeking behaviour at different stages of cancer. Apart from consumers in general, the study populations included cancer patients, adults with chronic health conditions, young web-users and online support group members.

Information seeking throughout cancer

Due to the progressive and changing nature of cancer, people with the disease are often likely to seek information at its stages, which may include diagnosis, decision-making, treatment, recovery and rehabilitation. In a population-based survey of breast, prostate and colorectal cancer survivors from the US, the different health-seeking behaviours reported by cancer patients were contingent on their disease stage.[25] Patients with earlier stage breast or prostate cancer were much more likely to search for information than were early stage colorectal patients.[25] At later stages, the differences between cancer groups were reduced. These results could be due to a greater availability of information about early stage breast and prostate cancer than colorectal cancer.[25]

A qualitative study of Australian breast cancer patients receiving radiotherapy found that patients require additional information that relates specifically to radiotherapy at each of the following time points: meeting the radiation oncologist, the planning appointment, the first day of treatment and approaching the end of treatment.[11] According to Halkett, health professionals must take into consideration that patients continue to have information needs throughout their treatment despite having been provided with information previously.[11] When consumers look for information is crucially linked to the type of information they are seeking and their information needs will therefore differ over time. For example, breast cancer patients sought information about what radiotherapy is and what it will involve when meeting the radiation oncologist, information about radiotherapy planning, treatment procedures and expectations at the planning appointment, what daily treatment will actually involve on the first day of treatment and information about what happens next when approaching the end of treatment. In other words, they sought information before, throughout and after their treatment, and experienced different information needs as they proceeded from meeting their radiation oncologist to treatment completion.[11]

Information seeking pre- and post-consultation

In a survey of US adult members of an online support group, 80% of respondents reported that they had searched for health information online following a primary care visit.[24] Similar results were found in a qualitative study of Australian consumers with chronic health conditions, where the most common time at which participants were likely to seek information was after consulting a health professional, followed by before a consultation.[12] In a population-based survey of 1052 web-users in France, almost 3 in 10 online health seekers aged 15–30 years old reported having often used the internet as a source of health information instead of seeing a doctor (30%) or before seeing a doctor (29%).[27] By contrast, 17% used the internet after having seen a doctor, which significantly varied by age group. Participants aged 26–30 years old were significantly more likely to look for information on the internet after having seen a doctor (22%) than participants aged 15–19 years old (13%) or 20–25 years old (14%).[27]

Question 2: Where do consumers find and what platform do they use to access information about healthcare safety and quality?

Key points and summary

Six reviews and 20 primary studies explored information source preferences among health consumers (Table 5). Two of the included reviews report that health professionals are the primary source of health information for most cancer patients, followed by printed materials (such as medical pamphlets), and interpersonal communication with family and/or friends.[1, 2] The internet has become an increasingly popular and accessible source of health information in the decade since these findings were published[5] and two of the included reviews focused solely on use of the internet as a source of health information.[3, 4] The internet was the most frequently identified resource for primary care patients in the 19 articles pertinent to information sources included in a systematic review published in 2015, followed by physicians, television, and family and friends.[5] Despite its growing popularity, there was general consensus among the included publications that the internet is generally perceived as a supplement, rather than an alternative, to advice from a health professional.

Internet use

In France, a national survey conducted in 2010 found that 49% of web users aged 15–30 years old had used the internet in the 12 months prior to the study to look for information or advice on health.[27] The results from a 2009 survey of 2253 adults by the Pew Internet and American Life Project indicate that 8 in 10 internet users or 61% of adults in the US have looked online for health information.[22] According to the Pew survey findings, “the internet supplements, but does not replace, traditional sources of health information”, suggesting that despite its growing use, the internet is not considered a substitute for professional advice delivered face-to-face.[22] The majority of adults surveyed (86%) reported that they consult a health professional when faced with health or medical issues, 68% ask a friend or family member and 57% use the internet.[22] A national cross-sectional survey of 5307 health information-seekers in the US in 2014 found that 68% of participants most frequently sought information from the internet first while 16% reported it was a doctor or healthcare provider. A further 9% nominated publications (books, brochures, magazines and newspapers) and 5% said they would turn to non-professionals (family/friends/co-workers).[26] The tendency of consumers to look online for health information first, suggests that consumers consider the internet to be a useful starting point for seeking immediate and anonymous access to health information. However, cancer patients’ carers did not see the internet as a replacement for face-to-face consultation with a health professional for obtaining cancer-related information. They reported that doctors were their preferred source of information.[4]

According to the 2009 Pew Internet survey, the majority of online information-seekers (66%) access information using search engines, while 27% begin the search process from a specific health-related website.[3, 22] Key sources of internet-based health information include:

- organisation websites
- webpages of individual doctors

- online support groups and forums
- blogs authored by health advocates, caregivers or people pursuing self-help.[3]

Despite the increasing popularity of social media and networking sites, there is conflicting information about how consumers use these resources to retrieve and share health information. The Eurocancercoms project found that cancer patients use forums (33%), emails (33%), social networking sites (9%), chat rooms (7%) and blogs (6%) to exchange and share health information.[28, 31, 5] By contrast, the 2009 Pew survey findings indicate that 39% of patients who use the internet use a social networking site like Facebook and, of those, only a small portion have followed their friends' personal health experiences or updates, posted their own health-related comments, obtained any health information, or joined a health-related group.[22] In the 2011 Pew Internet survey, when asked to think about the last time they had a health issue, 71% of respondents said they received information, care, or support from a health professional, 55% said they received such help from friends and family and 21% said they turned to others with the same health condition.[8] The vast majority of respondents said those interactions happened offline.[8] The same study reported that:

- 80% of internet users, or 59% of all adults have looked online for information about any of 15 health topics
- 34% of internet users, or 25% of all adults have read someone else's commentary or experience about health or medical issues on an online news group, website or blog
- 25% of internet users, or 19% of all adults have watched an online video about health or medical issues
- 24% of internet users, or 18% of all adults have consulted online reviews of drugs or treatments
- 18% of internet users, or 13% of all adults have gone online to find others who might have health concerns similar to theirs
- 16% of internet users, or 12% of all adults have consulted online rankings or reviews of doctors or other healthcare providers
- 15% of internet users, or 11% of all adults have consulted online rankings or reviews of hospitals or other medical facilities.[8]

Australian context

Compared with these studies, a lower proportion of online health information-seeking was reported among the included Australian samples. For example, a study of 3652 Australian adults with diabetes found that only 24% reported using the internet as a source of information about their condition in the last 12 months.[15] In 2008, approximately 33% of South Australians (49% of internet users) used the internet to search for health information.[18] In a national study of 2944 general practice patients in Australia, 28% of participants reported having sought health information online and 17% (which was 62% of those who sought health information) obtained information related to problems managed by their GP at the visit when the survey took place.[20] In an Australian survey of the online health information-seeking behaviours of 400 web users with at least one chronic health condition, sources of online information included: search engines (e.g. Google: 86%), general health websites (e.g. WebMD: 57.5%), association websites specific to medical conditions (e.g. Cancer Council: 50.3%), Wikipedia: 37.8%), websites recommended by health professionals (37.8%), private health insurer websites (18.3%), websites recommended by people on discussion forums (18%), research databases (18%) and eNewsletters or emails (12.3%).[13]

A qualitative study of Australian web users with chronic health conditions reported that the most common approach to information-seeking was the use of a search engine.[12] After search engines, the most commonly identified sources of online information were: disease-specific association websites, forums/support groups, Wikipedia, general health websites, websites recommended by a health professional, research databases, e-newsletters and private health insurer websites.[12] In a qualitative study of Australian women with breast cancer undergoing radiotherapy, patients preferred to receive verbal and/or written information via other information sources (such as videos and web-based information), and 50% of participants stated that they appreciated being provided with a combination of both written and verbal information.

CALD populations

A qualitative study of CALD consumer needs in Australia found that participants relied on their healthcare professional for information, as well as information source referral and rarely used the internet.[6] This was partially due to poor computer operational skills and low confidence in the credibility of online information and those with the capacity to use the internet did so only to verify information provided by a health professional.[6] There was also a tendency among participants to assume that if their health professional did not provide them with language-specific information, then it was not available.[6] Similarly, a qualitative study of older Italian and Greek migrants living in South Australia found a low rate of computer use with most participants expressing a preference for receiving information directly from another person or in printed form.[7] However, despite low engagement with information and communication technology, participants still used a variety of digital and non-electronic sources to access health information.[7]

Research suggests that consumers' information source preferences are largely determined by the nature of the health condition for which information is being sought. When asked what source they would consult first if they wanted information about pregnancy, most South Australian women in a qualitative study stated that they would use the internet, with 89% of participants having used it to access pregnancy-related information.[19] Approximately 40% of participants had used a pregnancy-related smartphone app to access information about pregnancy, 20% had used YouTube and none had used Twitter.[19]

The link between source and context

Whether consumers turn to health professionals or non-professionals for health-related information is contingent on the circumstances prompting their information seeking. For example, when asked whether professionals (e.g. doctor, specialist physician, nurse) or non-professionals (e.g. close friend or relative) are a more helpful source of health information, the majority of participants in the Pew Internet survey (62–91%) reported that they prefer a professional when in need of: an accurate medical diagnosis, information about prescription drugs, information about alternative treatments, a recommendation for a doctor or specialist, or a recommendation for a hospital or other medical facility.[8] The majority (51–59%) preferred non-professionals for emotional support in dealing with a health issue and a quick remedy for an everyday health issue. The two groups were considered equally helpful for practical advice for coping with day-to-day health situations.[8]

Accessing multiple sources

In a population-based survey conducted in the US, on average, breast, prostate and colorectal cancer patients sought information from 3.3 sources.[25] The most frequently cited source was treating doctors (75%), although they also reported using other medical professionals (34%). Use of interpersonal sources — including family members, friends or co-workers (48%) and other cancer patients (38%) — and books, brochures or pamphlets (50%) were common. Only 27% of patients reported seeking information about their cancer from the internet and few patients used support groups (3% face-to-face, and 2% online) or telephone hotlines (6%).[25] Although treating doctors were the most frequently reported source, most patients did not seek information solely from their doctor. Across cancers, 38% of information seekers exclusively sought advice from their treating doctors and/or other health professionals, and 5% did not seek it from medical sources.[25] Many patients sought information from all three source categories: medical, interpersonal and media. More than half (56%) of information seekers reported using at least one source in each of these three groups.[25] Across cancers, 78% of patients also reported encountering information about their condition when they were not actively searching for it.[25] Patients sought information from an average of two sources and most frequently came across information from: books, brochures or pamphlets (41%); family, friends and co-workers (40%); other cancer patients (33%); television and radio (32%); and mail sent by health organisations (21%).[25]

Health literacy and numeracy

Results from some of the included studies indicate that an individual's level of health literacy may be associated with the amount of information sought and its source. Limited health literacy was identified as a barrier to online information seeking in a qualitative study of Australians with chronic health conditions.[12] A qualitative study of 150 US adults aged over 40 with risk of cardiovascular disease found that individuals with inadequate functional health literacy and low numeracy rely primarily on their physicians and healthcare organisations to provide health-related information.[23] Individuals with adequate functional health literacy and higher numeracy skills typically used a variety of information sources, most often the internet and their physicians.[23] The most preferred way to receive information, regardless of health literacy and numeracy ability, was face-to-face from a healthcare provider.[23] Those with inadequate functional health literacy least preferred to receive health information in written form (in print or via the internet) and those with adequate functional health literacy least preferred mail or the internet.[23] In a cross-sectional study of 3652 diabetic internet users in Australia, higher levels of eHealth literacy were associated with post-consultation online information seeking and a tendency to access more specialised health information.[15]

Question 3: How do consumers use the healthcare safety and quality information that they find?

Key points and summary

Four reviews and 12 primary studies included information about how consumers use health-related information (Table 5). It was evident from the included publications that how patients use the health information they find is often dictated by their information needs, stage of illness and the source of information.[5] For example, the information patients seek prior to consultation is used to determine the type of physician they need to see and prepare for consultation.[5] Patients may use the information provided by their physician at consultation to validate information they have received from other sources, such as the internet.[5] There was substantial literature regarding the use of online information by health consumers to develop a current and comprehensive understanding of illness, managing it, gaining an understanding of treatment options and their likely consequences, enhancing clinical interactions, and facilitating their decision-making process.[9]

Treatment decisions

Health professionals are also key providers of patient education and facilitators of information. They may empower patients by providing them with decision-making tools, which are used to facilitate effective access to health resources.[32] It has been found that doctors and other health professionals are most important in influencing patients' treatment decisions: 72% of participants in a European study said they were always influenced by them and 25% were frequently influenced by them.[28] Printed materials were slightly more influential (44% = always and frequently influenced) in respondents' treatment decision-making than the internet (37%); advocacy or other support organisations had a similar influence (37% always or frequently influenced).[28]

Use of online information

A qualitative study of online information searching identified three main motivations for information searching: symptom troubleshooting, searching to enhance a clinic visit, and proxy searching.[21] Patients commonly use the internet to learn more about a specific symptom or disorder, and help identify underlying causes. For non-serious medical issues, participants were generally comfortable using the internet as a troubleshooting tool. The internet provides a level of anonymity that may be helpful in situations where individuals perceive their problems to be bothersome or a nuisance to doctors.[21]

Consumers may use information found online for their decision-making about whether to consult a health professional.[9] The World Health Organization (WHO) eHealth survey found that 29% of consumers had used information from the internet to decide whether they needed to see a doctor, and of those that did attend, one in four had used the internet in conjunction with the doctor's appointment.[3, 13, 29] A French study found that out of 11% of youths that sought health information on the internet in the 12 months prior to the study, 5% reported that it led them to see a doctor more often than usual while 6% reported that it led them to seek a doctor less often than usual.[27] Although 27% looked for online health information without having had any kind of medical consultation, 33% reported they modified the way they take care of their health based on the information they found on the internet (no further significant difference by age group).[27]

In the 2009 Pew survey, 59% of newly diagnosed patients reported that the online information they had accessed prompted them to consult a doctor or seek a second opinion regarding their health.[22] Among the 6 in 10 e-patients who said their most recent search had an impact on decisions or actions regarding their health or the way they care for someone else: 60% said the information found online affected a decision about how to treat an illness or condition; 56% said it changed their overall approach to maintaining their health or the health of someone they help take care of; 53% said it lead them to ask a doctor new questions, or to get a second opinion from another doctor; 49% said it changed the way they think about diet, exercise, or stress management; 38% said it affected a decision about whether to see a doctor; and 38% said it changed the way they cope with a chronic condition or manage pain.[22] In the 2010 Pew survey, one in three adults (30%) said they or someone they know had been helped by following medical advice or health information found online, and 3% said they or someone they know had been harmed.[8]

Many participants in a qualitative study of US adults indicated that they used the information they found through internet searches to enhance their interactions with their healthcare providers.[21] Participants reported using online health searching as a means of enhancing clinic visits, either through preparation or post-appointment follow-up. Patients tended to view online health information seeking as an additional resource to complement the patient/physician relationship.

Carer use of online information

According to a review of the role of the internet in supporting and informing carers of cancer patients, carers used information they found in a variety of ways: to inform treatment-related decisions, to check up on medical decisions, to increase knowledge and understanding of cancer and to confirm existing treatments and treatment-related decisions for the patient as the best possible options.[4] Reading internet information obtained by carers can result in a small percentage of patients requesting tests or treatment, and can also lead to increased confidence as they are better informed and more able to discuss the information with a healthcare professional.[4] Carers seek online information and support for themselves as well as the person with cancer.[4] Online information-seeking is often a coping mechanism in response to the stress of the cancer diagnosis and carers may use the information they find to feel better equipped to share and, in some cases, to manage the cancer experiences for the patient.[4] Interactive applications may be used to facilitate self-management, patient-centred care and support for cancer patients as they combine accurate and tailored information with online support (e.g. discussion groups) and contact with health professionals.[4]

Australian context

In a qualitative Australian study, some participants reported that the information they found online assisted in decision-making about whether to use therapeutic products or to trial lifestyle modifications to supplement advice given by their health professionals.[12] Online health information was also reportedly used by participants as a source of emotional support, an avenue for seeking out alternative treatment options, a means of taking charge of one's life or self-managing a perceived minor condition, or as a supplement to information provided during consultation.[12]

In a survey of 400 Australian adults, participants reported that they used information sought online to: be more informed (81%), help manage a health condition (68%), clarify information from a health professional (56%), check information that was discussed during a consultation with a health professional (50%), or identify alternative or additional treatment options (48%).[13] Participants also reported that they may use online health information to supplement information provided by a health professional under various circumstances.[13] For example, when asked why they looked for health information online, 29% of participants said it was because of limited time during a consultation, 25% said it was because they had not been provided with enough information during a consultation and 10% said it was because they disagreed with certain points made by a health professional.[13]

Of South Australians who searched for health information on the internet in 2008, 82% described the information they found as useful, 23% reported using it as a second option and 27% discussed it with a doctor or pharmacist.[18] Some people indicated it had changed the way they managed their healthcare (13%) and 4% said they had used online information to choose a healthcare provider.[18] Once the participants obtained health information online, their actions tended to revolve around consultations with their health professionals.[12] For example, they either decided to relay the information found online to their health professionals or made decisions about whether to consult their health professionals for advice or medical attention.[12] In a study of consumers using the internet to seek treatment for insomnia, information retrieved online influenced participants' health behaviours, including their decisions to seek help, take medication and their beliefs about insomnia. Less than a quarter of the participants (21%) discussed the information they retrieved with a healthcare professional.

In a qualitative study, CALD Australians reported finding health information brochures in various languages useful in enhancing understanding of health or a medical condition.[6] The study also found that visual images and diagrams were useful in helping to overcome language barriers.[6]

Health literacy and numeracy

The findings from one included qualitative study suggested that health literacy might impact on how and whether individuals use health information. Participants in the study with limited health numeracy trusted the information they received from their physician and reported that they understood; it however, when asked to give an example of how they used the information they were given, none of them could give an example.[23] In addition to how to use the information to manage their health, they also had difficulty explaining basic knowledge regarding some of their current health conditions.[23] Individuals with adequate functional health literacy and high numeracy were able to provide examples of the application of information and even gave unsolicited examples of following up with their physician when more information was needed.[23]

Question 4: About which topics or subjects do consumers need healthcare safety and quality information?

Key points and summary

The team identified six reviews and 13 primary studies that met the selection criteria for Question 4 (Table 5). It is difficult to separate patients' information needs from their surrounding context, which encompasses the stage of illness, information source and intended use of the information.[5] Patients' information needs may also depend on their current physical, mental and social wellbeing. For example, a newly diagnosed breast cancer patient may require information on the advantages and disadvantages of various treatment options.[9] From the included reviews, the Evidence Check identified the following information topics and subjects upon which consumers sought information: general, cancer-specific, treatment-related, information for an illness or medical condition, treatment side effects, prognosis, rehabilitation, psychological support, nutrition, alternative medicines or new/experimental treatment availability, prescription and over-the-counter drugs, exercise and physical activity, body image/sexuality, surveillance and health, financial/legal, medical system, and complementary therapies.[1, 2, 5] These information topics identified in the included primary studies are presented in Table 6.

Cancer patients

Cancer patients want a variety of information about cancer spanning the complete cancer journey. These ranged from: treatment choices and side effects; activities promoting recovery, help for daily tasks, and advice on diet and nutrition; and long-term planning, including financial advice and legal support.[28, 31] In a systematic review of the information needs of cancer patients, the top three information priorities included prognosis (ranked first in information needs in 47% of included studies and in the top three in 67%), disease (ranked in the top three in 80% of included studies and first in 23%) and treatment (ranked in the top three in 77% of included studies and ranked first in 20%).[30] Results from a population-based survey of cancer patients in the US showed that patients reported seeking information about a range of cancer-related topics. On average, patients sought information about 2.9 topics, with treatment-related information the most frequently sought after type of information (60%).[25] They also reported seeking further explanations of what their doctors had said (42%), information on chances of survival or cure (48%), which doctors or hospitals would be best for them (42%) and how to manage treatment side effects (38.9%).[25] Other topics included second opinions about treatments recommended by a doctor (25%) and emotional support for dealing with cancer (20%).[25]

Cancer patients in a European study wanted information on all aspects of cancer.[28] More than 60% of participants strongly agreed that they wanted information on side effects of treatment and secondly treatment options.[28] The next most commonly identified information needs (45–50% strongly agreed) were local information (e.g. support groups, health facilities), causes and spread of cancer and finally diagnosis.[28] More than 50% of respondents strongly agreed or agreed that they wanted all the types of information listed.[28]

Table 6. Evidence mapping for all topics about which consumers need healthcare safety and quality information

Information topic	**Beck 2015**[27]	**Fox 2010**[22]	**Fox 2011**[8]	**Halkett 2010**[11]	**Lee 2013**[14]	**Lee 2014**[12]	**Lee 2015**[13]	**Maddock 2011**[28]	**Moghe 2014**[16]	**Nagler 2010**[25]	**Nielsen 2014**[17]	**Reinfeld-Kirkman 2010**[18]	**Wong 2014**[20]
Alternative/complementary therapies or medicines		✓				✓	✓					✓	
Associations or societies						✓	✓						
Caring for an elderly or disabled person			✓										
Doctors or other health professionals		✓	✓		✓	✓	✓			✓	✓		
Emotional support					✓					✓			
End of life decisions			✓										
Environmental health hazards			✓										
Financial advice					✓			✓					
Food or drug safety/recall			✓										
Health and lifestyle behaviours (e.g. diet and exercise)	✓	✓	✓		✓	✓	✓	✓					✓
Health insurance		✓	✓										
Hospitals or other medical facilities		✓	✓			✓	✓	✓		✓	✓		

Immunisation/vaccinations													✓
Legal support								✓					
Medical terms						✓	✓						
Medical treatment or procedure		✓	✓	✓			✓	✓	✓	✓	✓	✓	✓
Mental health		✓											
Other local health services (e.g. support groups)				✓				✓			✓	✓	
Prescription or over-the-counter drugs		✓	✓			✓						✓	✓
Recovery								✓					
Return to work				✓									
Side effects of treatment or medication				✓				✓		✓			
Specific disease or medical condition	✓	✓	✓			✓	✓	✓	✓	✓	✓	✓	✓
Symptoms									✓				✓

Online information

The Evidence Check suggests that the majority of health-related internet searches by patients are for specific medical conditions.[3, 8, 12, 13] The 2010 Pew survey found that 80% of internet users have looked online for information about at least one of the following topics: specific disease or medical problem (66%); certain medical treatments or procedures (56%); doctors or other health professionals (44%); hospitals or other medical facilities (36%); health insurance including private insurance, Medicare or Medicaid (33%); food safety or recalls (29%); drug safety or recalls (24%); environmental health hazards (22%); pregnancy and childbirth (19%); memory loss, dementia or Alzheimer's (17%); medical test results (16%); how to manage chronic pain (14%); long-term care for an elderly or disabled person (12%); and end of life decisions (7%).[8] Other topics identified in the 2009 Pew survey included prescription or over-the-counter drugs (33%); alternative treatments or medicines (26%); depression, anxiety, stress or mental health issues (21%); experimental treatments and medicines (15%); hospitals and other medical facilities (28%); health insurance, including private insurance, Medicare or Medicaid (27%); how to lose or control weight (24%); and how to stay healthy on a trip overseas (9%).[22]

The findings of a study conducted in France suggest that online search themes may differ by age.[27] Young adults aged 15–30 years old primarily looked online for information on general health or specific diseases, particularly influenza (45%). However, older participants (31–85 years old) sought information concerning healthy behaviour, children’s health and parental health.[27]

Australian context

Participants in a qualitative Australian study most commonly reported seeking health information related to understanding their medical conditions and the medications prescribed by their health professionals. Other topics upon which Australian consumers sought information included: lifestyle information (e.g. diets and exercise), information about individual health professionals, medical clinics and hospitals, natural products, disease-specific associations and medical terms.[12] An Australian survey of web users with chronic health conditions found that participants sought information about medical conditions (89.3%); medicines or medical devices (69%); diet (58%); medical terms and jargon (58%); natural products (58%); health professionals, clinics and hospitals (56%); exercise (55%); and associations or societies (37%).[13] In another study, general practice patients reported that they most commonly searched for information related to a specific illness or disease (57%), followed by diet/fitness (32%), undiagnosed symptoms (29%), medications (25%), other medical treatments (13%) and immunisation/vaccinations (6%).[20] In a South Australian study, a high proportion of participants searched for descriptions of health conditions (31.8%) or information about their management or treatment (25.2%). Fewer people searched for information about prescription or over-the-counter medicine (10.3%), complementary medicine (10.3%) and support groups (5.2%), and 19% indicated they searched for 'other health information'.[18]

One qualitative Australian study demonstrated that search topics are dictated by the nature of the condition or disease of interest as well as the stage of illness.[11] Breast cancer patients undergoing radiotherapy had information needs relating to why radiotherapy is recommended, what treatment involves, combining chemotherapy and radiotherapy, possible side effects and how to manage these, whether they can return to work and other health services.[11] Additionally, patients were also concerned with who is able to provide information and the roles of staff in the department, the planning appointment and the procedure involved, how much of their breast would receive treatment, what happens on the first day of treatment, the treatment machine, why there are cameras and computers in the treatment room, how the treatment machine works and what happens when treatment is complete.[11]

The key sub-categories of information sought by Australians with lower back pain include: causes, treatment and management options, self-help information and strategies (dos and don'ts), the psychological and social dimensions of pain, lay stories, quality assurance of information, and roles of different healthcare providers and locally available healthcare services.[17] Topics of interest for online health seekers with insomnia were related to its treatment, symptoms and sleep initiation.[16]

CALD populations

One Australian study examined the information priorities and preferences of CALD women.[14] The most popular information topics for migrant women were: how to get work (79.2%); women's health (76.2%); exercise classes for women (62.3%); eating better on a budget (59.1%); how to find and talk to a general practitioner to get healthcare (61%); and support for women who feel very sad, stressed, worried and depressed (50.3%).[14] The most popular information topics for refugee women were: how to get work (78.9%); women's health (73.4.%); exercise classes for women (72.5%); eating better on a budget (60.6%); family violence, what it is and where to go for help (46.8%); how to find and talk to a general practitioner to get healthcare (41.3%); and support for women who feel very sad, stressed, worried and depressed (33.9%).[14]

Study populations

The literature appeared to be weighted toward particular populations. For example, there were many studies that focused specifically on cancer patients or women (i.e. breast cancer patients, pregnant women, and mothers).

5 Discussion

The findings from the included reviews and studies suggest that consumer preferences for information seeking are context dependent. Information is accessed from a range of sources and for varying purposes, based on the specific needs of the individual at the time of information seeking. Information should be therefore available throughout all stages of illness, and provided at relevant and appropriate times.[9]

Despite the widespread use of the internet, the evidence suggests that the doctor-patient relationship is still highly valued and that health professionals remain the preferred source of information for health consumers. Although research indicates that many consumers are using the internet to obtain health information, this appears to be due to its accessibility and convenience, not because it is considered a better alternative to face-to-face communication with a health professional. The internet provides a cost-effective channel for health information sharing. Uses include:

- Supplementary resource (confirm what a health professional has said during consultation)
- Connect with others via social media platforms and support groups
- Useful when troubleshooting symptoms/determining whether a visit to the doctor is necessary
- Enables comparison of services, treatments etc.
- Updated with most current news/information in the field
- Information found online can enhance interactions with a health professional.

Many health consumers prefer to access information from a variety of sources, including their family and friends, the internet, health professionals and written materials. It is important to ensure that information is readily available in different formats and is not exclusive. Consumer input highlighted the necessity of ensuring that information dissemination strategies do not inadvertently widen the gap between people with high and low health literacy. Patients with high health literacy have the ability to plug gaps in information provided by health professionals more easily than patients with low health literacy. Additional resources or varied strategies may therefore be required to ensure equity of access to health-related information.

There is a tendency towards enhanced consumer participation in healthcare decision-making, and many patients like to be informed about the potential benefits and harms of different options available to them.[9] Consumers may seek and use health information to assist with decision-making regarding care and treatment pathways. However, it was beyond the scope of this review to consider which information resources and tools are the optimal enablers of knowledge acquisition, patient activation and decision-making processes. Exploring the effectiveness of information when presented via different formats and dissemination strategies is therefore an avenue for further investigation. Evidence obtained on this topic would inform the development of pragmatic consumer resources designed to enhance learning and decision-making capacity.

Consumers need information on a wide range of topics spanning the patient journey. These include: information about specific medical conditions and their management, treatment and prognosis; information regarding health professionals and their various roles, medical facilities, and health insurance; as well as information supporting recovery, including physical (e.g. rehabilitation and nutrition) and psychosocial support (e.g. psychological and financial support, and other support services). Importantly, health consumers' information needs and preferences are likely to reflect the issues that people are aware of and not the entire scope of sources or topics available. Information needs and preferences may therefore change as consumers gain awareness of other issues relevant to them. Consumers highlighted a number of information topics that people affected by cancer need to be aware of but which are currently missing or difficult to find. This further demonstrates that the information topics identified by consumers are based on what they know and not the potential gaps or pieces of missing information.

Gaps in the evidence

CALD and ATSI populations

People from CALD and ATSI backgrounds may not have the resources and competence to support equity of access to and use of some health information sources and technology. Given that use of the internet to deliver health related services and information is increasing, knowledge about the effects of ethnicity, rurality, migration, socioeconomic status, cultural beliefs or education on the use of online health information is important.

Little evidence was located to indicate the information needs and preferences of people from CALD backgrounds. Addressing this should be a priority in Australia, which has a large population of migrants from non-English speaking countries.

The search for primary studies only recovered one that focused on ATSI people. There is little research about the role that different cultural and educational background, and socio-economic conditions of many indigenous Australians has on their access to relevant information, and their understanding about healthcare safety and quality. A priority for future research should be investigating whether there is sufficient provision of, and access to, culturally appropriate sources of health information for indigenous Australians, and whether this information meets their needs and preferences.

Challenges and barriers to information seeking

Direct consumer input indicated that they experience a number of information gaps not mentioned in the included literature. One issue raised by a consumer was that finding information about cancer could be extremely time-consuming and frustrating for cancer patients. Highly specific details about the cancer type, stage and grade, as well as care plans and treatment summaries, are required in order to search for and obtain relevant information. There is a lot of information available about being diagnosed with cancer for the first time but little about subsequent patient pathways and experiences. Complicating this picture is the fact that information or advice retrieved from different sources may be conflicting or misleading. Research studies should enquire not only about preferred source format but also the challenges associated with finding the right information, time spent searching, frequency of searching and the information gaps encountered throughout the search process.

The utility of different sources

The majority of the included studies investigated consumer perceptions about how they would like information presented rather than evaluating the actual usefulness or reach of different modalities. Consumer input indicated that although a cancer patient may receive clinical information verbally from a physician, these results may not be explained in a way that enables the patient to be proactive in managing and understanding their own treatment and care. These gaps in information can be a significant barrier to patients becoming active partners in decision-making. Research should therefore consider, not just where consumers access or receive health information, but also the usefulness, relevance and quality of the information and its delivery (e.g. characteristics of websites visited and satisfaction with physician communication).

Consumer perspectives on the results

The right information at the right time

According to consumers, it is important that people are able to access the right information at the right time. In the case of cancer, individually tailored documents such as care plans and treatment summaries are useful aids that enable consumers to find relevant information, be proactive in their own care and recognise errors.

Another point consumers raised with regard to cancer — but relevant to other chronic diseases — is the need for ongoing information provision. The need for information does not end when treatment ceases and the post-treatment period presents a unique set of challenges. To feel informed and supported in managing this phase, cancer consumers may require information about what to expect after treatment, how to manage ongoing health concerns and which health professionals are able to provide support. A broad range of information is needed to prepare the individual as they make the transition from regular monitoring to living with the after effects of cancer.

Consumers identified a number of other gaps in cancer information, which were described as missing or difficult to find. These included:

- Cost of treatment and gap payments for private patients
- Options and timeliness of transfer from private to public systems
- What clinical trials are available and how to access this information
- How to ask for and get a second opinion
- Medical roles (i.e. who does what and where are the lines of handover)
- Individual clinical data and results (including an explanation of the results)
- Side effects of medication – what are they are how to report them
- Information that focuses on wellness and not just illness
- Relapse and cancer progression
- End of life care (i.e. what to expect and what help is available).

Relevant information should be available for the people who are affected including patients, their relatives and friends, and in some cases others, such as employers and work colleagues.

Information that empowers consumers

Consumers highlighted the critical role of information in empowering patients to be active participants in their own care and partners in the decision-making process (e.g. being vigilant and proactive, making informed treatment decisions, querying prescribed treatment regimens and asking for a second opinion). This can be facilitated through access to key pieces of information such as clinical guidelines or recommendations for a specific condition, question prompts to indicate what consumers may wish to ask about, decision-making tools, information sheets about a procedure or medication dose, and treatment summaries and care plans. Carers were also recognised as having an important role in supporting the individual with cancer, particularly when the patient is too unwell to be able to process the information.

Health literacy

Consumers indicated that health literacy is a key factor to consider when deciding on an approach to information dissemination. It is important to ensure that strategies for providing information about healthcare safety and quality do not further increase inequities in access to it.

Consumers as information givers

Another issue that consumer advocates identified was that health service users' input is often not considered to be a constructive part in the process of improving information about healthcare safety and quality. Individuals may wish to provide feedback about specific health services or information providers so that they can be improved for future users but are rarely given the necessary information or opportunity to do so. Improved dissemination of information about where and how to provide constructive feedback on healthcare safety and quality would empower consumers to become givers as well as receivers of information. Future research should examine what mechanisms are available that allow engaged consumers to give feedback or contribute to the design of more effective information dissemination processes. Additionally, research should explore ways of interpreting and disclosing valuable consumer input, and feeding this information back to appropriate health services.

Implications for future research

The findings from this review reiterate that consumers seek health information at varying times along the healthcare journey and through various modes of delivery. Complacency with historical health information modes is no longer appropriate and flexibility is essential to suit growing consumer demands. It is recommended that future research be considered that focuses on the following key areas:

- Consumers seek targeted health information at the outset of their diagnosis but providing adequate pre-intervention health information is a challenge with current diminishing health resources. Future research should seek to enhance our understanding of how specific information provided at a specific time improves the healthcare journey.
- Further consideration should be given to the types of comprehensive health information that translate to better health outcomes.
- The internet has been identified as a key source of health information for some consumer groups. Further research is required to determine whether information obtained via the internet meets consumers' needs, improves knowledge acquisition and empowers decision-making.
- Given that internet use was lower among consumers with low health literacy and CALD populations, further research is required to examine how supplemental modes of health information (such as the internet) could better meet the needs of disadvantaged consumer groups.
- Information providers would benefit from research identifying the most appropriate modes of health information provision (i.e. internet, written information), other than the health professional, for different groups such as carers, CALD populations, ATSI people and individuals stratified by gender or age.

6 Recommendations

The following are a set of principles identified through this Evidence Check review. The Commission could use these principles as a guiding framework for the development of a resource to support the development of high-quality consumer health information.

- Healthcare quality and safety information should be provided at all stages of the patient journey, including the pre- and post-treatment phase.
- Information that is relevant and specific to various stages of the patient journey should be made available to consumers at the appropriate time points throughout this journey.
- Health information should be provided through a variety of channels. The appropriate channels should be determined by considering specific patient contexts, stage of patient journey, level of direct engagement with the healthcare system, purpose of the information, and patient population.
- The internet should be considered as complementary to information provided by health professionals. The information provided on government or government-sponsored websites should be evidence-based, without bias, and regularly checked for currency and accuracy.
- Consideration should be given to the role of health information as an enabler of effective patient-clinician communication and shared decision-making.
- Additional effort is required to ensure consumers with low health literacy, recent migrants, people from CALD communities and ATSI people have equal access to information as those with high levels of health literacy. The Commission should aim to ensure that it provides health information to these groups in a way that they can understand it and act on it.
- The Commission should aim to ensure that health information can cater to different levels of patient engagement by enabling motivated and engaged consumers to be proactive in their care if they wish to be, and also ensure that less engaged consumers receive critical information that is relevant to their care and treatment decisions to minimise the chance of errors in their care.

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8 Appendices

Appendix 1: Scope of the review and selection criteria

Selection criteria for the overall review

Selection criteria for this review were developed according to each review question and are reported below. Overall selection criteria were:

- Population: Adult (18 years and older) healthcare consumers who are members of the public either potential or current users of healthcare services, patients, family members, carers, or other people in supportive roles
    - Focus: in addition to consumers, groups of particular interest: Aboriginal and Torres Strait Islander people and people from Culturally and Linguistically Diverse Backgrounds
    - Exclusion: Children and people with cognitive impairments/disabilities
- Concept: Healthcare safety and quality information. Meaning information about a person's own care and the options associated with it such as information about:
        - Illnesses
        - Symptoms
        - Treatment
        - Information about how to prevent errors and increase safety during the course of a person's care
        - Information about healthcare more broadly such as where to access healthcare services
        - Information about value and variation in healthcare
    - Timing: Patient information-seeking needs and preferences at the following stages of their journey:
        - As they have symptoms
        - Receive a diagnosis
        - Contemplate treatment
        - During treatment
        - Discharge and transferring between healthcare settings
    - Exclusion: (Apart from Question 4): Information about the performance of specific healthcare services (e.g. hospitals and providers). Information about medication. Health promotion and lifestyle factors
- Context: Patient information-seeking needs and preferences regarding the following healthcare settings:
        - GP clinics
        - Specialist services
        - Acute hospital care including Emergency Departments
        - Ambulance
        - Rehabilitation services
        - Community health services
        - Hospital in the home
        - Allied health
        - Dental

    - Preferentially, NSW and Australian jurisdictions, the group formed by UK, New Zealand, Canada and US (conditional on the evidence being applicable to the Australian context)
- Sources of evidence: English language sources only. Evidence to be sought in a hierarchal manner with preference given to higher quality/higher level evidence (e.g. systematic reviews) and sources containing highly relevant evidence in relation to the review questions. Evidence available from 2006 onwards unless containing especially relevant information identified by the review team as not being available in more recent studies. Following the scoping search, evidence would be sought in a targeted manner to address each review question.

Scope for question 1

When on the patient journey do consumers seek information e.g. symptoms, diagnosis, treatment, discharge?

Scope for question 2

What are the actual behaviours and preferences regarding where consumers seek information? These could include: advocacy groups, GPs, peer support groups, websites, mobile websites, brochures, posters, Apps, videos, TV.

Do different consumer segments have different behaviours and preferences in terms of where they find information?

Scope for question 3

How do consumers use the information they find? E.g. use it to be more informed, make treatment decisions, discuss care with their doctor, understand how the health system works, understand what to expect from healthcare professionals and care settings, better manage their own health and talk to family and friends about their health and care.

Scope for question 4

What are the full breadth of topics and subjects about which consumers would like information? This is not to be constrained by the scope identified for questions 1–3, e.g. healthcare cost; available services and how to access them; infection control; information about medicines; end of life care; cancer care; decision-making aids; question-building tools; self-care strategies; health literacy, health promotion and lifestyle information; safety and quality information about specific services, hospitals or healthcare providers; and value and variation in healthcare.

Appendix 2: Scoping search strategy

#	Concept	Terms
1.	Patient	(Patient or consumer or user).ab,ti.
2.	Health	(Health).ti. or (health care or healthcare).ab,ti.
3.	Information	(Information).ti. or (informatics).ab.ti
4.	Preference	(Preference or prefer or seek or need or needs or source or choice or decide or decision).ti.
5.	Consumer behaviour	Behaviour, information seeking [MeSH] or consumer health information [MeSH] or health education [MeSH] or patient education as topic [MeSH]
6.	Review	(Review or meta-analysis).ab.ti or (review or meta-analysis).pt.
7.	Combine searches	3 & 4
8.	Combine searches	5 or 7
9.	Combine searches	1 & 2 & 6 & 8

Appendix 3: Data extraction template

Reviews	**Primary studies**
Reference	Reference
Review type	Design and methods
Population	Population
Number of studies and dates:	Location
Evidence relating to Q1	Aim
Evidence relating to Q2	Evidence relating to Q1
Evidence relating to Q3	Evidence relating to Q2
Evidence relating to Q4	Evidence relating to Q3
CALD/ATSI findings	Evidence relating to Q4
Conclusions	CALD/ATSI findings
	Limitations
	Conclusions

Appendix 4: Quality of evidence

A measure of the quality of evidence has been assigned to each included paper to reflect how well the studies were conducted in order to eliminate bias and provide meaningful analysis and interpretation of results. This includes clarity of the research question, adequate sample size, appropriate methodology, and interpretation of findings. Each included paper has been assessed in terms of its quality using the following critical appraisal criteria adapted from the Joanna Briggs Institute's approach to critical appraisal.

Studies that are assigned a 'yes' for all five items will receive an evidence quality rating of 'very high'.

Studies assigned four 'yes' answers will be rated as 'high' quality.

Studies assigned three 'yes' answers will be rated as 'moderate' quality.

Studies assigned two 'yes' answers will be rated as 'low' quality.

Studies assigned one or no 'yes' answers will be rated as 'very low' quality.

Systematic reviews

1. Is the review question clearly and explicitly stated?

   Yes/No/Unclear/Not Applicable

2. Was the search strategy appropriate?

   Yes/No/Unclear/Not Applicable

3. Were the inclusion criteria appropriate for the review question?

   Yes/No/Unclear/Not Applicable

4. Were there methods used to minimise error in data extraction?

   Yes/No/Unclear/Not Applicable

5. Were the methods used to combine studies appropriate?

   Yes/No/Unclear/Not Applicable

Quantitative survey studies

1. Were the study subjects and the setting described in detail?

   Yes/No/Unclear/Not Applicable

2. Was the sample frame appropriate to address the target population?

   Yes/No/Unclear/Not Applicable

3. Were valid methods used for the identification of opinions/beliefs?

   Yes/No/Unclear/Not Applicable

4. Was the sample size adequate?

   Yes/No/Unclear/Not Applicable

5. Was the response rate adequate, and if not, was the low response rate managed appropriately?

   Yes/No/Unclear/Not Applicable

Qualitative studies

1. Is there congruity between the research methodology and the research question or objectives?

   Yes/No/Unclear/Not Applicable

2. Is there congruity between the research methodology and the methods used to collect the data?

   Yes/No/Unclear/Not Applicable

3. Is there congruity between the research methodology and the representation and analysis of data?

   Yes/No/Unclear/Not Applicable

4. Are participants, and their voices, adequately represented?

   Yes/No/Unclear/Not Applicable

5. Do the conclusions drawn in the research report flow from the analysis or interpretation of the data?

   Yes/No/Unclear/Not Applicable

Appendix 5: JBI levels of evidence

Level	Evidence type
I	Qualitative or mixed-methods systematic review
2	Qualitative or mixed-methods synthesis
3	Single qualitative or quantitative study
4	Systematic review of expert opinion
5	Expert opinion

(http://joannabriggs.org/assets/docs/approach/JBI-Levels-of-evidence_2014.pdf)

Appendix 6: Excluded studies

Reference	Australian	Include	Reason
Adams 2010	No	No	Does not fit the questions. Focuses on blogging practices and uses.
Backman 2012	No	No	Convenience sample of small size. Research conducted in Sweden. Limited information on Q1 and Q2.
Bastian 2011	No	No	Does not fit questions. Sample not representative.
Beesley 2015	Yes	No	Does not fit the questions. Explores supportive care needs amongst other psychosocial aspects of cancer.
Bernstein 2011	No	No	Small sample size. Research conducted in Canada.
Burns 2012	Yes	No	Purposive sample of small size. Not enough information relevant to the questions. Discusses internet use generally, rather than for health information seeking purposes.
Cho 2011	No	Low priority	Limited information on Q2 and Q4. Participants recruited through a Korean website. Low priority.
Crabb 2012	No	No	Convenience sample of small size.
Davidson 2011	Yes	No	Does not fit the questions. Concerned with health-seeking beliefs, not information-seeking behaviour.
Dietrich 2015	No	No	Small sample of graduate students. Does not fit the questions. Concerned with information evaluation and choice more than information-seeking.
Earl 2012	No	No	Evaluation of the impact of a particular health information service.
Goldberg 2011	No	No	Not a primary study.
Halkett 2010	Yes	No	Does not fit the questions. Mainly concerned with support needs.
Hall 2015	No	No	Convenience sample. Research conducted in the US.
Hill 2012	Yes	No	Study protocol.
Hou 2010	No	No	Does not fit the questions.
Househ 2014	No	No	Literature review.
Hung 2013	No	No	Literature review.
Jamal 2015	No	No	Convenience sample. Research conducted in Saudi Arabia.
James-Martin 2014	Yes	No	Focuses on information needs regarding lifestyle behaviours (diet and exercise).
Kruse 2012	No	No	Does not fit the questions. Focuses on barriers to internet use and patient characteristics associated with internet use.

Lam-Po-Tang 2010	Yes	Low priority	Discusses use of the internet for mental health information seeking. Limited information on Q3 and Q4.
Lau 2013	Yes	No	Does not fit the questions. Evaluation of how consumers used a specific health management system to manage wellbeing.
LeRouge 2014	No	No	Research conducted in the US. Does not fit the questions. Limited information on Q2. Explores readiness and barriers to using health technologies.
Kav 2012	No	No	Convenience sample of small size. Research conducted in Turkey.
Kinnane 2012	Yes	No	Does not fit the questions. Evaluation of a cancer centre. Convenience sample of small size.
Laverty 2015	No	No	Does not fit the questions. Discusses factors most important to patients in choosing a hospital, not how they obtain this information.
McMillan 2014	Yes	No	Does not fit the questions. Focuses on service priorities not information preferences.
Milton 2015	Yes	No	Not relevant to the questions. Explores preferences for how service users would like clinicians to deliver news of a mental health diagnosis.
Newman 2012	Yes	No	Does not fit the questions. Focuses on access to and use of digital technology and the implications for communication and information exchange with health services.
Nguyen 2011	Yes	No	Does not fit the questions. Presents case studies on the information needs and behaviours (not strictly health-related) of two elderly stroke patients.
King 2015	Yes	No	Focuses on complementary therapy use.
Pandey 2013	No	No	Analysis of smartphone applications.
Pang 2014	Yes	No	Does not answer questions. Explores online search behaviour.
Pluye 2014	No	No	Describes the development of a consumer assessment.
Priest 2016	No	Low priority	Research conducted in the US. Analysis of user queries on an online question and answer service. Information on Q4.
Radina 2011.	No	Low priority	Research conducted in the US. Information on Q2 and Q3.
Reavley 2011	Yes	Low priority	Information on Q2. Focuses on association between mental health factors and information seeking from different sources.
Reavley 2012	Yes	No	Does not fit the questions. Discusses the development of guidelines for supporting employees to return to work after a mental health episode.

Reid 2012	No	No	Does not fit the questions. Factors that influence information seeking involving healthcare associated infections.
Rose 2010	Yes	Low priority	Small and non-representative sample. Limited information on Q1 and preference for written information (could be applied to Q2)
Rowlands 2015	Yes	Low priority	Limited information on Q2 but not the others. Investigates demographic factors associated with searching online for health information.
Sanders Thompson 2013	No	No	Not a primary study.
Schmidt 2016.	No	Low priority	Research conducted in Germany. Very specific to disease condition and stage.
Siah 2012	No	No	Does not fit the questions. Explores how families prioritise particular information needs (e.g. support, proximity, comfort) rather than how they seek and use information.
Sick 2011	No	No	Analysis of provider cost and quality information availability.
Silver 2015	No	No	Does not fit the questions. Explores concerns about using the internet for health information, and barriers and facilitators to doctor communication.
Suziedelyte 2012	No	No	Does not fit the questions.
Teixeira 2014	No		Does not fit the questions.
Thompson 2012	Yes		Does not fit the questions. Discusses the importance of different information items when making a decision about birth facility.
Vanagas 2012	No	No	Research conducted in Lithuania. Does not fit the questions. Explores the availability of health information and the factors affecting primary care patients' information needs.
Wale 2013	No	No	Does not fit the questions. Identifies priority review topics for healthcare users.
Warren 2014	No	No	Evaluation of cancer websites' information provision using a tool.
Wen 2011	Yes	No	Some data on the percentage of first-time mothers who use the internet for health information, but the focus is primarily on demographics that predict inequities in access.

Weymann 2013	No	No	Development of an interactive health communication application to provide treatment decision support to people with type 2 diabetes.
White 2014	No	No	Does not fit the questions. Explores how internet users decide (if and when) to visit a health professional, as indicated by patterns of search behaviour. Some information could be applied to Q3.
Xie 2014	No	No	Convenience sample. Research conducted in the US. Focuses on preference for receiving information and participating in decision-making, and influence of age.
Zelmer 2014	No	No	Not a primary study. Explores use of digital health solutions, i.e. booking healthcare appointments and viewing test results online.

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