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# **Online health information: shortcomings and challenges**

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## **Abstract**

Health is a topic that affects everyone either through their own personal experiences or those of a family member, friend or work colleague, so it is not surprising to hear that there is increasing interest in online health information. For example, a national survey in 2013 into internet use in the United States showed that 59 per cent of people had searched for health information on the internet, and that six out of 10 respondents said the information they found online affected their decision about how to treat an illness or a medical condition. The downside is that there is a saturation of health topics and this makes it hard to maintain interest and also credibility, especially when many health stories promote contradictory advice. This paper provides a brief snapshot into the shortcomings of online health information and suggests some ways to improve both the content and its credibility.

## **Introduction: High demand for health information**

Health is an important topic that affects everyone, either through their own personal experiences or those of their family, friends or work colleagues. Indeed, people are more interested in what hits closest to home, and they want information that is accurate and that they can trust. Yet for a long time, reporting health consisted largely of statistics on the number of deaths and cases of disease, or reporting on epidemiological data that affects people we do not know. While this is important for health officials, it is of little interest to audiences who are increasingly demanding information that is useful to their daily lives, and conserving one's health is perhaps the most useful of all topics. Many have now added the Internet to their personal health toolbox, helping them to gain a better understanding of an illness or medical condition.

Increased interest in health information is evident from the steady increase in health publications, health programs on radio and television, and the soaring demand for online health information. It shows that health is a popular topic and the media is where people turn to find it. A survey conducted in 2013 by the Pew Internet and American Life Project revealed that, while 81 per cent of adults in the United States use the internet, 59 per cent of them searched for health information on the Internet, and that six out of 10 respondents said the information they found online affected their decision about how to treat an illness or a medical condition. More than 55 per cent said it changed how they maintained their own health or the health of another (Pew Internet and Life Project, 2013). The demand for health information suggests that health journalism has a bright future, yet it places on journalists a responsibility to provide accurate and reliable content, especially since so many people make serious decisions based on what they read, hear or see on the media.

The downside of online health reporting is that there is saturation coverage of health topics, and nearly every possible news or feature angle seems to have been covered. This makes it hard to maintain interest and also credibility, especially when many health stories promote contradictory advice. It seems that nearly every week there is a new medical theory on whether the daily use of aspirin is effective or detrimental to one's health, or whether broccoli is a way to slow the spread of certain cancers. So how reliable and well tested is the health information we read, hear or view? Surveys on health reporting conducted in the U.S. and Australia show there is plenty of room for improvement.

*Health Online 2013*, a national survey on online health information in the United States, was released by the Pew Research Centre's Internet and American Life Project in January 2013. It revealed that 81 per cent of American adults use the Internet and 59 per cent said they searched online for health information in the past year. The data was collected from a telephone survey of more than 3,000 adults living in the United States from August 7 to September 6, 2012. The survey only measured the scope and

the number of users in contrast to the outcomes of such activity (Pew Internet and American Life Project, 2013: 2).

One surprising fact was that 35 per cent of respondents said they had gone online specifically to find out what medical condition they or someone else might have. This group was labeled 'online diagnosers'. Asked what happened after seeking health information online, more than half of this group said they had spoken with a doctor about what they found online and just over 40 per cent said it led them to seek medical attention and that the diagnosis was confirmed by a medical professional.

It would be reasonable to suggest that the demand for online health information will rise in the U.S. due to dramatic increases in Internet use. For example, in 2000 only 46 per cent of American adults had access to the Internet. In 2009, it rose to 74 per cent and in 2013 it reached 81 per cent of the population (Pew Internet and American Life Project, 2013: 4). The most popular search engines were Google, Bing or Yahoo. Only 13 per cent began their search at a dedicated health website.

Medical doctors in the U.S, however, still play an important role, especially in times of serious sickness. In the survey, more than 60 per cent of the respondents said they had received information, care, or support from a doctor or other health care professional during a serious health episode, while more than 50 per cent received information or support from friends and family and 24 per cent got information or support from others who had a similar health condition. This points to a social life of health information, as well as peer-to-peer support, as people exchange stories about their own health issues to help each other understand what might lie ahead.

## **The unhealthy state of health journalism**

While the *Health Online 2013* survey revealed the extent of interest in health information, the researchers did not examine or evaluate the content or credibility of such information. One researcher who has tried to do this is the editor of the *Health News Review*, Professor Gary Schwitzer, who runs the *Health News Review* website, which has evaluated more than 1000 health stories in the U.S. media. His May 2010 findings included a damning critique of the media's approach to covering health and medicine. Schwitzer argued that journalists tend to be cheerleaders rather than provide a critical analysis of health stories. He said there were too many fluffy, feel-good pieces, and unquestioning, awe-struck stories about breakthroughs, and not enough questioning of claims, investigating of evidence, and looking at conflicts of interests, especially with particular sources.

Another survey by the Australian Centre for Independent Journalism in Sydney analysed more than 200 health stories in the Australian press during a one-week period in September 2009, and found that more than half the stories were driven by PR events or media releases (Duxfield, 2010). Also, a 2009 survey of health stories in *The Australian*, *The Sunday Times* and *The West Australian* by health journalism students at Edith Cowan University discovered a similar pattern of unhealthy reliance on media releases (Callaghan, 2010).

Several researchers argue that when it comes to health news, sober, reliable and expert reporting can be hard to find. As newsrooms cut numbers and reduce the time available for writing about health, there is often a rush to produce pre-packaged stories, using wire services or relying on press releases as the primary and often only sources of research news (Mooney and Kirshenbaum, 2009; Raward and Johnston, 2009; Salleh, 2009; Young, 2009).

Increasing reliance by reporters on embargoes, press releases and wire copy encourages lazy journalism and bland reporting. Davies (2008a) highlights the dangers of media groups relying on wire services, which may have a small pool of reporters producing high-speed but limited 'in-depth' reports, which then receive wide coverage. As journals adopt the use of publicity machines to promote their research, media outlets and wire services have every reason to rely too heavily on the easy media release to save time and effort in preparing science and health stories (Davies, 2008a; 2008b; Mooney and Kirshenbaum, 2009; Murcott, 2009; Orange, 2008).

Also, the engagement of PR firms in health organisations, the selective press releases sent out by medical organisations to the media, and the cost-cutting approach of media organisations all foster what former *Guardian* reporter Nick Davies calls 'churnalism', the churning out of stories with limited, if any, actual reporting by the journalist. Davies (2008b) writes:

[M]ore than ever in the past, we are likely to engage in the mass production of ignorance because the corporations and the accountants who have taken us over, have stripped out our staffing, increased our output and ended up chaining us to our desks so that generally we are simply no longer able to go out and make contacts or find stories or even check facts.

Another area of concern is how narrowly health stories are framed, with little or no reference to the social and economic determinants of health. For example, a study of media coverage of obesity in television news in Australia focused attention on personal responsibility for weight loss without reference to structural issues, such as economic pressures to work long hours in sedentary jobs, urban planning that fails to facilitate physical activity, poor public transport and inadequate provision of cycle paths, and inadequate provision of parks and other recreational facilities (Bonfiglioli et al., 2007). Yet the neglect of environmental and structural solutions suggests advocacy efforts may be needed to draw attention to how these factors, cumulatively, constrain individual choices and contribute to the obesity epidemic (Bonfiglioli et al., 2007: 442-5).

Admittedly, this last point could be viewed as moving towards health promotion rather than the traditional journalist's role of reporting the facts. But with serious health epidemics such as adult diabetes, is it enough to report only 'what' is happening and omit the 'why' it is occurring, which provides a better understanding of the disease and ways to deal with it?

### **Ways to improve health reporting**

Attempts have been made in Australia to try to improve the standard of health reporting. The website *Media Doctor* was created in 2004 to evaluate health stories that report on medications and treatments in the Australian media. It grades them according to a set list of criteria: the mention of potential adverse effects, the inclusion of alternative therapies, and the type of diagnostic tests. The panel includes a group of academics and also clinicians from the Newcastle Institute of Public Health, who have an interest in promoting better and more accurate reporting in the area of medical treatments. The aim is to improve the accuracy of health reporting by offering an evaluation of the quality of health stories, and providing feedback for journalists and media organisations on the quality of their stories.

In the U.S., the *Health News Review* website provides health writers with a checklist to evaluate health claims and sources in news and feature stories: How strong is the evidence? Is this condition exaggerated? Who's promoting this? Do they have a conflict of interest? What's the total cost? How often do the benefits occur? Describe possible side effects. How often do the harms occur? Are there alternative options? Is this really a new approach? Both websites encourage a more critical and proactive approach to health reporting with a strong emphasis on investigating claims and statements, rather than adopting a reactive response where the journalists wait for the story to come to them and seldom check the evidence.

Schwitzer (2010) refers to other pitfalls that health journalists need to avoid, including the use of words such as ‘miracle’, ‘breakthrough’ and ‘cure’. These words are misleading and unhelpful since the realities they refer to seldom occur. Also, Schwitzer points out that it is important to refer to more than one study, and to identify the sources of the studies as a way to weed out (or expose) bias and self-interest; for example, to reveal which pharmaceutical company funded a particular project and challenge company media releases that look too good to be true. There are other considerations. Ask yourself these questions before you write. What good is likely to result from your investigation? What harm could result? Is it fair, or does it favour someone over another? Are there alternatives to consider? These questions point towards an important area, the ethics of health reporting. For example, when writing about depression, cancers or drug use and abuse, how far should a journalist go to acquire the story, especially when it involves intruding upon the privacy of reluctant participants?

In Australia, health writers are guided by the *Media, Entertainment and Arts Alliance (MEAA) Ethical Code*. This requires from journalists a commitment to honesty, fairness, independence and respect for the rights of others. The Code has 12 clauses, and while it is not legally binding, it does provide guidelines about how to proceed or act. Here is a summary of its implications for health journalists.

**Clause 1** emphasises the need for fair and accurate reporting, getting facts straight and seeking comment.

**Clause 2** is designed to prevent discrimination on the grounds of personal characteristics. Use terminology that you feel the community as whole would find acceptable and reasonable.

**Clause 3** stresses the need to attribute information to its source. This can be tricky in health reporting. When investigating issues, a journalist may find that people making allegations about health system problems are unwilling to be named.

**Clauses 4 and 5** overlap to an extent, and relate to not allowing personal interests or beliefs to affect balance and fairness. At its core, the ethics of health reporting is about being responsible for what we write and broadcast. Journalists should present information that is technically correct and morally sound.

**Clause 6** relates to not allowing commercial interests to affect journalistic practice; for example, if a health writer was asked to produce a story focusing on a service, company or group advertised in a healthy lifestyle section.

**Clause 7** focuses on chequebook journalism, in which news organisations pay for exclusive rights to a story; for example, about the separation of conjoined twins.

**Clause 8** encourages the use of fair and honest means to secure a story. At times, a journalist can get more information from a health clinic or website by phoning

or logging in as a potential patient or customer rather than as a journalist and hence the trap.

**Clause 9** refers to digital editing techniques that allow cut-and-paste images and audio. Digital technologies have increased the potential for pictures and sound to be manipulated in ways that can mislead.

**Clause 10** relates to plagiarism. A journalist should not lift the work of another from print, broadcast media or the Internet. This issue is often overlooked or ignored. Plagiarism is stealing and any borrowed material should be sourced conscientiously. It is fair to say the huge amount of information on the Internet has made this clause harder to police, but not impossible.

**Clause 11** covers the areas of respect, grief and privacy and is one of the most subjective clauses. For example: what is considered to be an intrusion? Stories of tragedy and suffering are an integral part of health writing and reflect society to itself. Health journalists should exercise their discretion, taking into account the particular circumstances of each case.

**Clause 12** refers to correcting errors. To ensure trust, the media must repair errors. A prompt and fair correction (in time and prominence) retains the integrity of the journalist and publication.

### **The determinants of health provide context and understanding**

Often health stories are framed too narrowly with little or no reference to the broader determinants of health—social, economic, cultural, religious and political factors—which provide both context and a better understanding of communicable and non-communicable diseases. As early as 1986, with the adoption of the *Ottawa Charter*, the social and cultural dimensions of health became increasingly more mainstream. In more recent years social scientists have come to realise that socio-cultural factors influence complex health behaviours. Take, for example, the relationship between sexual behaviour and HIV infections. Beyond an individual's own social network there are larger structural and environmental determinants that affect sexual behaviour, such as living conditions related to one's employment. Also, in some countries, there is a lack of sexually transmissible disease services, and condoms can be costly or unavailable. This puts pressure on many sex workers to act in unsafe ways to keep customers satisfied. All of this works against people adopting safer behaviours.

Kippax (2007: 5) argues that individual behaviour and 'choice' is always mediated and structured by social relationships, which are in turn influenced by important differences of community, social status, class and other structural differences, such as gender and age. In other words, individual behaviour is always contextual, always socially embedded (Kippax, 2007: 5). This is not a new insight. A special session of



the United Nations General Assembly on HIV/AIDS in June 2001 adopted a Declaration of Commitment on HIV/AIDS and emphasised in paragraph 20 the important role of cultural, family, ethical and religious factors in the prevention of the epidemic and in treatment, care and support (UNAIDS, 2001: para 20).

This shift in thinking forms a key part of the social change communication (SCC) theory, where the focus is on seeing people and communities as agents of their own change. This theory is based on a belief that behavioural change is dependent on social change and is a long-term process (Deane, 2002: 1). The social communication approach to understanding HIV, and the need to highlight the context in which the epidemic is embedded, has wide support (McKee et al., 2004: 41).

The implications of SCC theory, if adopted by editors and journalists, would widen the predominant narrow framing of HIV stories from a focus primarily on health to one that covers related issues, such as gender equality, domestic violence, inadequate access to treatment, poor health facilities, complex sexual networking, and challenging governments on their policies towards treatment, human rights and overall strategies. Indeed, this perspective on the disease provides a new and extensive list of news and feature stories for print, online and broadcast journalists.

Not everyone agrees, however, and questions remain about the role of journalism in health promotion and development contexts. While this matter remains part of a larger ongoing argument that does not have any immediate or simple resolution, the author believes that the SCC theoretical approach offers an important contribution to the debate as it tries to broaden the scope and context of health stories. This, in turn, creates a better understanding and in-depth discussion of effective measures to deal with communicable diseases such as HIV, sexually transmitted infections and tuberculosis (Byrne and Vincent, 2012: 290).

## **Conclusion**

The growing demand for health information means that health writers are in demand. The findings of the Pew Internet and American Life Project (2013) places a responsibility on health journalists to provide accurate and reliable content, especially since so many people make serious decisions based on what they read, hear or see in the media. However, surveys in the U.S.A. and Australia that examined the state of mainstream and online health reporting exposed the extent of spin, the lack of medical evidence, and the narrow frame and context of many health stories, with little or no reference to the social determinants of health. In an attempt to respond to such criticisms and challenges, this paper also looked at several ways to improve health reporting. These include a greater emphasis on critical analysis of evidence and claims, adherence to ethical and professional codes, and the need to widen the narrow frame and focus of many health stories through the inclusion of the determinants of health and human behaviour.

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