## Clinical Practice **Discussion Health information**

**Keywords** Misinformation/Fake news/ Patient safety/Vaccination

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#### In this article...

- Positive and negative impacts of online health information on patients and the public
- How different patient groups find and respond to information online
- How health professionals and patients can identify reliable health information

# Benefits of good-quality online health information and risks of 'Dr Google'

#### **Key points**

Online health information is commonly used and can inform patients about wellbeing and health conditions

Poor-quality information can have negative impacts, such as nonadherence to treatment plans and vaccine hesitancy

Misinformation is inadvertently false, while disinformation is created to intentionally cause harm

Patient education and high levels of health literacy can lead to positive health outcomes

Quality marks can help patients differentiate between reliable information and misinformation **Author** Jill McLean is cancer information development nurse, Macmillan Cancer Support.

**Abstract** Using online health information can contribute to patients' health outcomes. 63% of people in the UK are searching for health information online, but some is unreliable. Misinformation, vaccine conspiracy theories and content about alternative therapies can lead to poor health outcomes or worrying health behaviours. Credible, high-quality information can be identified by checking for trustworthy sources, quality marks and balanced information.

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t is not uncommon for patients to worry about long-term medical conditions after matching their symptoms to online information without seeking medical advice or proper diagnosis. In the UK, 63% of people search for health information online (Statista, 2023) and <60% access it on social media health channels or through virtual health tools (Antheunis et al, 2013). However, not all health information available online is reliable. Medical misinformation has been an issue for a long time; self-diagnosis, vaccine conspiracy theories and alternative therapies are just some of the problems associated with health information being obtained from the sprawling, uncontrolled information source that is the internet. Fortunately, however, use of labels such as misinformation, disinformation and 'fake news' suggests increasing awareness of the issue among the public.

### The impact of online health information

The availability of online health information means patients can now become more informed about and actively involved in their health and wellbeing than they previously could. Studies have demonstrated that online health information can be used to support lifestyle changes to improve general health, such as stopping smoking, engaging with physical activity or improving diet (Suziedelyte, 2012).

A Canadian study by McLeod et al (2017) also reported that 78% of patients with gynaecological cancers felt they had increased their understanding of their diagnosis because of online health information. This knowledge can support and reinforce information patients have been given by health professionals; it can also have an empowering effect by arming them with information to help them ask questions about their disease and treatment. Improved understanding may also lead to compliance with treatment plans or advice from health professionals. A literature review by Purnomo et al (2018) identified that HIV patients taking antiretroviral therapies who reported using online health information had, when compared with those who did not:

- Improved HIV outcomes;
- Better adherence to antiretroviral treatments;
- Higher rates of HIV testing.

#### Clinical Practice

#### **Discussion**

Conversely, a similar study by Chang et al (2020) showed that 47% of thyroid cancer patients said online information had no influence on them at all. The patients reported that this was because they always relied on the cancer centre's staff for treatment decisions and assented to the doctors' opinions.

However, there may be differences in patients' characteristics depending on age. Beck et al (2014) highlighted that 33% of people aged 15-30 years "changed their health behaviours" as a result of searching for health information online, for example increasing the number of visits or calls they had with their healthcare team.

An Australian systematic review by Deependra et al (2020) assessed the influence of engaging with online health information; it explored the health and medical decision-making behaviours of patients, their family members and the general public as a consequence of searching for health information online. The review included 48 articles from 19 countries, including the UK; most were qualitative studies in which patients completed questionnaires or telephone surveys about the self-perceived impact of online health information on their decision-making.

The review concluded that the use of online health information is inevitable and it will only become more abundant and widely available; producing online health information that "maximises the benefits of the consumers" is, therefore, essential. If health professionals can incorporate this source of support as a standard of practice, patients can use their increased understanding to their advantage to inform decision making (Deependra et al, 2020).

Online health information can also help patients find out more about local health and social care services that may be available to them. This might include GPs, health centres and social services. Patients could also self-refer to personalised care approaches, such as social prescribing or health coaching.

When patient education and health literacy are cultivated and prioritised, online health information can contribute to positive health outcomes. However, online searches for health information can yield hundreds of results, and patients are not always equipped to refine search terms in order to sort the good from the bad. Lu et al (2018) demonstrated that the quality of online health information has a greater impact on patient compliance than the source of the information.

Just as good-quality health information can improve patient understanding, poorquality information or, indeed, misinformation may have a detrimental effect on decisions made about health. A Dutch study by Linn et al (2019) into chronic patients who were prescribed a new medication found that those who searched for online health information were more likely to be nonadherent to treatment plans as soon as three weeks after their consultation than those who did not. Similarly, 11% of participants in a study by Weaver et al (2009) reported that online health information led to them refusing or discontinuing treatment that had been recommended by a doctor or dentist.

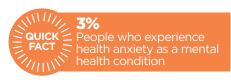
"When patient education and health literacy are cultivated and prioritised, online health information can contribute to positive health outcomes"

Poor-quality information found online can also have a negative impact on public health behaviours and decision making. An example is increased vaccine hesitancy, which Borges do Nascimento et al (2022) identified has occurred partly due to the sharing over social media of both "falsehoods which can be detrimental to the acceptance of the Covid-19 vaccine" and "misconceptions about [the] measles, mumps and rubella vaccine and autism". They also noted that illegal promotion of controlled substances may occur on social media platforms, which, in turn, may lead to worse health outcomes.

#### The dangers of self-diagnosis

By using online health information, patients may be able to match their symptoms to a diagnosis; however, they are likely to miss the subtleties that a health professional would notice. Using a fictitious scenario, we can show how the dangers of incorrect self-diagnosis can quickly escalate and negatively affect a patient's outcomes.

Yolanda Haile is a 35-year-old woman who is experiencing shortness of breath, palpitations and dizziness. These are symptoms of a panic attack (BMJ Best Practice, 2023b); this is a common problem, about which search engines and social media platforms can provide a substantial amount of information. However, these are also symptoms of other clinical conditions, for example anaemia (BMJ Best Practice, 2023a) or, although usually



asymptomatic, severe hypertension (Goodhart, 2016). Only an experienced clinician could take a detailed patient history and carry out a simple diagnostic test that would differentiate between these possible conditions.

If Ms Haile assumes that her shortness of breath and dizziness are caused by panic attacks, her next step might be to try some approaches to manage panic attacks. These include breathing exercises and stress management (BMJ Best Practice, 2023b). Although generally useful, these are not proven treatments for anaemia, hypertension or other more serious conditions, meaning Ms Haile's incorrect self-diagnosis may now be leading to ineffective therapy.

If Ms Haile has severe hypertension and continues to 'manage' it with breathing exercises or relaxation techniques and does not consult a doctor, her ineffective therapy will mean she has an untreated medical condition. She might now also be at risk of life-threatening health conditions such as heart failure (National Institute for Health and Care Excellence, 2022).

Self-diagnosis can also lead to patients taking unprescribed medication or mixing medications without checking with a health professional. Ms Haile might discuss her self-diagnosis with a friend who has also experienced panic attacks, for which their doctor prescribed propranolol; they might tell Ms Haile how effective it was and offer her their remaining tablets.

Without a proper diagnosis, prescribed treatment or subsequent monitoring, there will be no way to know whether propranolol is an effective treatment for Ms Haile or whether she experiences any side-effects. NICE's (2022) guidance for hypertension management will not be followed, meaning Ms Haile will not be assessed for cardiovascular risk or interactions with other prescribed drugs. She will also not receive counselling around lifestyle changes she could make to support treatment, such as exercising or stopping smoking.

#### **Health anxiety**

After an online search of symptoms that has produced frightening results, many patients may experience generalised health anxiety. However, about 3% of

#### Clinical Practice

#### **Discussion**

people experience health anxiety as a mental health condition (Tyrer et al, 2019). People with health anxiety typically worry unnecessarily about health to the point that it takes over their life (Doherty-Torstrick et al, 2016). The symptoms include:

- Constant health worries;
- Repeatedly checking for signs of illness, such as lumps or pain;
- Repeatedly asking for reassurance about not being ill;
- Worrying that a health professional or medical test may have missed something;
- Obsessively looking at health information;
- Avoiding anything related to serious illnesses, such as medical television programmes;
- Behaving as if one is ill, such as avoiding physical activities (NHS, 2020).

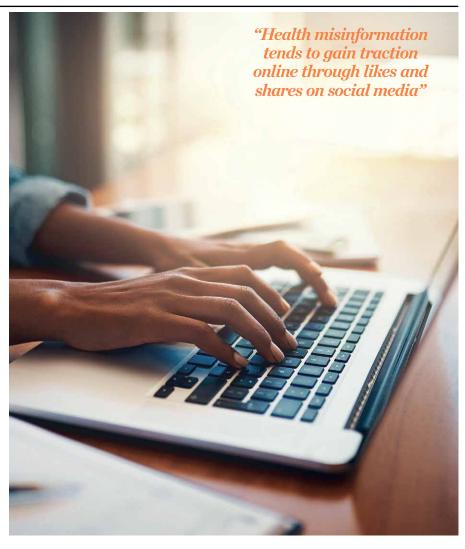
For people with health anxiety, extensively searching for information online may only re-enforce their belief that they have an undiagnosed or misdiagnosed condition; it may, therefore, be detrimental to their health (Doherty-Torstrick et al, 2016). Furthermore, reading misinformation that has been shared and commented on multiple times within an echo chamber will increase their fear and anxiety. This has a negative impact on not only the life of the individual, but on the family members, carers and health professionals supporting them.

#### Misinformation and disinformation

The WHO (2022) defines misinformation as information that is "inadvertently false and is shared without intent to cause harm". However, the definition acknowledges that the term is often used to refer to any false information, because it is not always possible to identify whether the spread of false information is intentional or unintentional. The intentional spread of false information is known as disinformation: this is "information that is created and shared with the explicit purpose to cause harm".

Disinformation often exists in the form of fake news, which "comprises false information transmitted in the form of 'news', often by sources attempting to pass off as online newspapers". However, most false information is spread because well-intentioned people share it in the hope that it is useful (WHO, 2022).

Health misinformation tends to gain traction online through likes and shares on social media. It is often based on something factual, which may be supported by some evidence; however, the scientific study it is based on



GUICK People in the UK who FACT search for health information online

has usually been misrepresented in some way. This might be by omitting information or applying it in a way that is unproven. For example, there are many posts and adverts on social media platforms suggesting that mistletoe (a semi-parasitic plant) can kill cancer cells in vitro when, in fact, most clinical studies have had unreliable results or major shortcomings (Ernst et al, 2003).

Misinformation and fake news are not new concepts and have existed for hundreds of years (Mansky, 2018). However, the development of the internet, and subsequently the smartphone, have given rise to viral sensationalism that enables information to spread rapidly and globally. Free social media platforms mean that health information is cheap to produce and requires little technical expertise. The culture of liking and sharing information

contributes to both the spread and the permanence of online information.

Newer technologies such as artificial intelligence (AI) chatbots are another example of how people are consuming internet-generated information. AI systems can understand text or voice questions through natural language processing. This means that if a patient asks any of the recently launched AI chatbots a healthcare question, they will formulate a plausible - and usually accurate - answer (Johnson et al, 2023). However, AI can only be as clinically accurate and ethical as the humans who design, build and interact with it. The dangers of this were demonstrated by Microsoft's experimental chatbot Tay in 2016: within 24 hours of being launched on Twitter, Tay began to formulate racist, inflammatory and bigoted responses (Hunt, 2016).

The continued development of new technologies such as AI chatbots means that people's intake of online information is here to stay regardless of the quality.

#### Clinical Practice

#### **Discussion**

## Box 1. Resources to help nurses identify and produce good-quality health information

- Standard for creating health content (NHS England)
- A Paper on the Principles and Attributes of Ensuring the Credibility of Health Information in Social Media (Academy of Medical Royal Colleges)
- Find health information you can trust (Patient Information Forum)

Tools for evaluating health information

- DARTS
- Quest
- DISCERN

Nurses, therefore, need to support patients to distinguish good-quality information from misinformation.

#### **Guiding patients**

To guide patients to credible and highquality health information, nurses first need to be able to identify it themselves. Evidence-based practice is routine for nurses and other health professionals, and participating in regular journal clubs with peers can help develop critical thinking; this will support the discernment of credible, scientifically accurate and useful information from that which is misinformation or simply unreliable.

Several resources also exist that can help health professionals assess the quality of information, as well as understand the standards of practice for producing information (Box 1).

Patients cannot be expected to be able to identify trustworthy health information at the same level as health professionals. Some patients are in-depth information seekers with high levels of health literacy, who are capable of finding good references themselves or able to ask more probing questions of health professionals. However, many patients do not have the time or ability to read numerous complex medical journals or guidelines. They may also not have the inclination, particularly when they are coping with the emotional turmoil of a difficult diagnosis such as cancer. These factors mean that useful health information should always be presented in a way that is accessible, simple in its terms and sensitive in its tone.

Nevertheless, it is likely to be unreasonable to ask patients to avoid the substantial amount of information available to them. In addition, many health services may currently not be able to accommodate patients who consult their GP, specialist nurse or allied health professional for every question they have about their condition.

It may, therefore, be a better use of health professionals' time to ask patients during an early appointment whether they are inclined to search online for health information. They can then provide them with a brief list of reliable resources (Box 2) and some basic tips to develop their fact-checking and critical-thinking skills. Personalising patients' care in this way also supports the NHS's (2019) recommendation to make person-centred care individualised and meaningful.

#### Identifying poor-quality information

Anecdotal information should not be seen as reliable. Although personal stories can be useful, the experience of one person does not reflect what happens in larger groups of people, such as in large, controlled studies (Patient Information Forum (PIF), 2023; WHO, 2021). It is important for health professionals to emphasise that everyone responds to treatments differently and there may be unknown factors in an individual's case.

Sensationalism should also be viewed suspiciously. Headline-making phrases such as 'new wonder drug', 'miracle cure' or claims that an article contains information that 'your doctor won't tell you' are often used and designed to grab the reader's attention. It can help to explain to patients that these types of claim are rarely backed up by evidence (PIF, 2023) and are sometimes generated by fake news 'farms' to generate clicks, likes and shares.

Poor-quality information can also be unbalanced in its view, meaning it may be subject to bias. Patients should understand that a piece of information that is only positive or negative in its outlook may have been written for reasons that are not solely focused on being informative (PIF, 2023; WHO, 2021).

Lastly, it is best not to put too much value in claims derived from small studies, as they usually have less reliable results (Andrade, 2020). Credible small

studies usually conclude that more research needs to be undertaken with a larger cohort. It can be difficult to quantify what constitutes a small study and what size of study makes for more reliable reading, as this depends on the type of research. For example, studies into common diseases such as breast cancer usually have large sample sizes in the tens of thousands, whereas studies into rarer diseases may include only a few hundred people.

Health professionals base their practice and rationale on the best-available evidence, and using an evidence hierarchy tool can help identify this. The Oxford Centre for Evidence-Based Medicine's (2011) hierarchy of evidence demonstrates the varying levels of evidence and research; it generally shows that systematic reviews of high-quality randomised controlled trials are likely to be the most thorough type of research, meaning they have the highest evidence rating.

#### Identifying high-quality information

It is important to check the source of the information. The average patient is unlikely to want to read medical journals, but encouraging them to check the

## **Box 2. A sample of reliable UK information providers**

- The NHS England, NHS Scotland and NHS Wales websites have trustworthy health information, covering symptoms, conditions, treatments, health and social care services, self-referral options, and improving health and wellbeing
- Health and Social Care Northern Ireland provides information about these services in Northern Ireland
- Patient.info has trusted health information written by a team of healthcare professionals, including expert health articles and tips

Common health conditions

- The British Heart Foundation provides reliable information about heart and circulatory diseases
- Macmillan Cancer Support produces quality-assured information and support about symptoms, treatments and living with cancer
- Alzheimer's Society provides information about symptoms and treatments, as well as dementia support services

## Clinical Practice **Discussion**



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"Critical thinking about health information can be as simple as asking who wrote the information and for whose benefit"

information's source could increase the trustworthiness of what they are reading. Critical thinking about health information can be as simple as asking who wrote the information and for whose benefit. Health professionals could also explain to patients that, if health information mentions evidence, it should be referenced or cited in some way (WHO, 2021).

Trustworthy information should be balanced; if it is promoting or selling any kind of product or service, it should usually be avoided. Good-quality health information also gives explanations in a balanced way; for example, information about treatments should outline both the known risks and benefits. This might include side-effects and any longer-term impacts on a patient's quality of life (WHO, 2021).

If health information is quality-assured, it has been through rigorous processes to ensure it is accurate, up to date and reflects what is happening in clinical areas. Many organisations that produce health content are transparent about the processes they follow to produce their information, as well as the qualifications of the people who produce it. Patients can also check both online and printed information for review dates; good-quality health information is frequently revised and updated.

An increasing number of organisations now use quality marks to show the credibility of their information. The PIF has developed the PIF Tick quality mark; information producers can only be accredited with the PIF Tick if their information, and the processes used to produce it, have passed the assessment to meet its acceptability standards.

For information in video format, You-Tube has also developed its own mark of quality in collaboration with the Academy of Medical Royal Colleges (AoMRC), NHS England, the General Medical Council, the Royal College of Nursing and the PIF. Together, they produced the AoMRC's (2023) principles to help YouTube effectively assure health information providers' credibility (YouTube, 2023). New health panels denote information that has been produced by an authoritative source (AoMRC, 2023).

#### Conclusion

The potential benefits of online health information are vast. Patients can use it to augment their understanding of medical conditions, treatments and lifestyle choices. Studies show that credible online resources can enhance patient compliance, encourage informed decision making, and facilitate communication with healthcare providers. Increased empowerment can lead to improved health literacy and, ultimately, health outcomes.

However, misinformation, disinformation and sensationalism can make health information a confusing arena. So-called 'miracle cures' and unrepresentative anecdotes can steer patients away from evidence-based information. The implications of poor-quality information can be far-reaching, leading to incorrect self-diagnosis, nonadherence to treatment and unnecessary anxiety.

Nurses have a key role in ensuring that the benefits of online health information are maximised by patients, while helping them to avoid the dangers. The challenge ahead is to provide guidance and foster critical thinking. A collaborative approach that puts patients at the centre of their own care means nurses can continue to be patient advocates who educate and empower. **NT** 

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