



Choose who to listen to

Being Your Own Advocate, with the Help of Trusted Sources

Remember to check your sources before making informed decisions.

- Always check the credentials of who you're listening to
- Check facts against their original source
- Search outside of social media
- Create a trusted resource list to quickly verify information

Finding accurate and reliable health information has become more confusing for patients than ever before. Knowledge can undoubtedly help to make important decisions about our health. But if the information we're absorbing is inaccurate, it can also be harmful.

A recent US survey from Patients like me highlights the range of online sources that patients are using when searching for advice and guidance on their medical conditions:

- News (NBC, CNN, FOX, etc.) - 16%
- Social Media (Facebook, Twitter, etc.) - 11%
- Search Engines (Google, Bing, etc.) - 39%
- Symptom Checker Websites (WebMD, Mayo Clinic, etc.) - 34%

Whilst these channels may have varying degrees of reliability, it's always best to consult the most reliable websites for health information such as well-known health charities, national health service or government sites.

Clinical nurse specialists, or another member of your specialist team, will be able to give you information on local support services that you may find helpful. It is important to seek advice and information from reliable sources to prevent misinformation.

National cancer charities offer support and information about kidney cancer. These patient organisations can work closely with you and your family to provide support and resources. As well as providing high quality information for people affected by cancer, these patient organisations often have telephone helplines and discussion forums.

When looking for information online, is the information:

- Clear
- Accurate
- Impartial
- Evidence-based
- Up to date
- Regularly reviewed

For example, the [PIF Tick](#) is a UK-wide



quality mark for health information, enabling NHS organisations, health charities and companies to demonstrate that the health information they create and publish meets certain criteria.ⁱ Look out for this when checking if a source is reliable that you can trust. Please check with your IKCC affiliate member for which quality marks to look for within your country.

If you're not looking through scientific literature, such as peer-reviewed journals and medical papers, here are some simple checks you can do to assess whether the information you're absorbing is likely to be of a similar high standardⁱⁱ:

1. When was it published?

Information that was accurate a few years or even months ago might now be out of date, and medical advice changes to reflect that. Check the date of the material to see how recently it was published.

2. Who has written or published it?

Think about whether the author or publisher has an agenda in sharing the information. They might be trying to promote or sell something, in which case there's a chance it contains bias. If the information is sponsored, it's less likely to be impartial.

3. Is it relevant to me?

Check that the information applies to you and is relevant to your circumstances. Two people with the same long-condition won't necessarily have the same experiences, so balance whether the information is based on someone's opinion or if it's stating facts, and whether advice it gives reflects that.

4. Does it cite evidence sources?

Good-quality health information will list the sources of evidence used to produce it.

For more information, please following this link to the World Health Organization site, which provides guidance on using the internet and media to get health information.

ⁱ Patient information. 2020. How to find reliable information online. Available at: <https://patient.info/news-and-features/how-to-find-reliable-health-information-online>

ⁱⁱ Patents like me. 2024. Health information: What sources do people trust? Available at: <https://blog.patentslikeme.com/research/perceptions-of-health-information-sources/>