

PATIENTS ON REDDIT



Connectivity is high, but credibility is lacking.

BY RICHIE KAHN, MPH

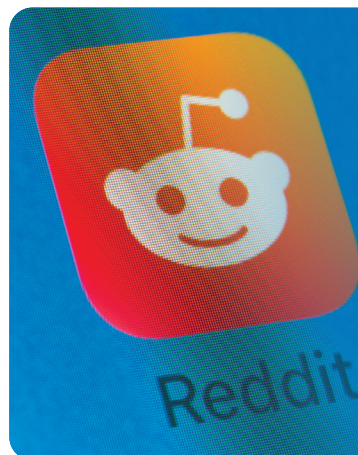
The internet has been connecting patients around the world since the early days of dial-up and chat rooms. Although functionality varies from platform to platform, patients today use social networking tools to share their stories, seek advice, and ask health care–related questions.

For nearly 20 years, Reddit, a forum-style social network, has allowed anonymous users to follow and participate in subreddits or threads that focus on specific topics ranging from soccer to vision loss and all points in between. Users can create and interact with original content, show their approval or disapproval, and promote popular posts (content with the most positive interactions).

Due to the anonymous nature of the platform, many users feel comfortable using Reddit to ask questions about their eye health and do so on numerous subreddits related to ophthalmology, glaucoma, and vision loss. I personally am a member of the vision loss community *r/Blind*. On this and other vision-focused subreddits, individuals with a range of ophthalmic conditions use the platform to do the following:

- Connect with other patients;
- Seek information about their disease;
- Share their experiences;
- Ask for advice; and
- Express their concerns.

Recently, I spent some time on the *r/Glaucoma* subreddit to learn more



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about what’s on the minds of self-identified patients with glaucoma.¹ Some post titles include the following:

- “I really need some wisdom, some advice—23 y/o woman with very advanced congenital/glaucoma condition”
- “Glaucoma specialist/surgeon in Minneapolis/St. Paul area”
- “Should I be concerned?”
- “On 1,500 mg/day of Diamox at the moment, looking for others’ experiences”
- “Irritation due to Cosopt or Tafluprost”
- “Do you ever worry about potential long-term side effects with your eye drops?”
- “I was lazy with my drops, now I have lost more”

The *r/EyeTriage* subreddit is designed for patients seeking advice from eye care professionals. On the opposite end of the spectrum, *r/Ophthalmology* is intended to serve as a forum for eye

care professionals to converse with other eye care professionals; posters looking to ask questions about their own ocular health are referred to *r/EyeTriage*.

INCREASING DIALOGUE, OBSCURING INFORMATION

The anonymity of Reddit may lower patients’ inhibitions and facilitate more constructive dialogue about their medical conditions, but the accuracy of the medical information shared is less clear. A recent study showed that roughly two-thirds of the posts in the *r/CosmeticSurgery* subreddit demonstrated a misunderstanding of pathophysiology; almost one-third of posts included medically inaccurate information.²

Although Reddit sometimes functions as a useful resource, patients may benefit more from their physicians helping them to identify reputable sources for trustworthy and accurate

information about their condition, such as the National Institutes of Health and the Centers for Disease Control and Prevention. For patients looking to become more discerning about information on the internet, UCSF Health has produced an excellent guide.³ When reviewing health information, the organization suggests patients consider the following questions.

- What is the source, and is it trustworthy?
- Who is the author, and what are their credentials?
- Has the publication been peer-reviewed?
- Who is the publisher?
- How accurate is the information?
- Is the content supported by scientific studies, reliable data, or expert opinion?

- If the information provided is not the original source, is the original source listed and reliable?
- When was the information published, and how recently was the source updated?
- Are there red flags?
- Is there no discernible author?
- Is the author trying to sell something?
- Is the information based on opinion and not fact?
- Is the information out of date?
- Are the writing and grammar poor?

CONCLUSION

Social media platforms provide a powerful means for patients to connect, share tips, and voice their concerns, which is especially useful for those with rare and ultrarare

conditions. Still, the credibility of the medical information provided leaves much to be desired. Physicians should consider asking their patients about any sites they use to access additional information and direct them to reputable sources as needed. ■

1. Glaucoma discussion. Reddit. Accessed March 28, 2023. www.reddit.com/r/glaucoma

2. Schmuter G, North VS, Kazim M, Tran AQ. Medical accuracy of patient discussions in oculoplastic surgery on social media. *Ophthalmic Plast Reconstr Surg*. 2023;39(2):132-135.

3. Evaluating health information. UCSF Health. Accessed March 28, 2023. www.ucsfhealth.org/education/evaluating-health-information

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