

Searching for information about stem cells online in an age of artificial intelligence: How should the stem cell community respond?

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Patients and their families routinely use the Internet to learn about stem cell research. What they find, is increasingly influenced by ongoing changes in how information is filtered and presented online. This article reflects on recent developments in generative artificial intelligence and how the stem cell community should respond.

INTRODUCTION

These are exciting times for those interested in stem cell research. After decades of hard laboratory labor, next-generation stem cell-based products have entered or are about to enter clinical trials for Parkinson disease and other conditions (Gravitz, 2021; Yamana, 2020). For researchers, patients, and the public, the promise of regenerative medicine has never been more tangible. However, with unabated growth in direct-to-consumer marketing of unauthorized stem cell treatments across the globe, it is likely that research participants, patients, interested members of the public, journalists, policy-makers, and health professionals struggle to obtain accurate information about scientifically validated stem cell therapies (Master et al., 2021). While many are likely to search for answers online, how can individuals discern what information to believe in such a landscape? What determines the information they find? Although what is found will be partly determined by the search engine used, few will understand the economic and technical logics behind the search engine. Indeed, there have been cases in which patients mistake commercial clinics for legitimate trials and have faced serious risks (Kuriyan et al., 2017).

In parallel to the developments toward cell-based therapies, the technology platforms that facilitate how information is presented and found online are undergoing major transformations. The widely used search engine, Google, continuously changes its algorithms, as well as its business models, in ways that are mostly opaque to the individual user (Mager et al., 2023). Average users may not understand the mechanisms that determine which advertisements they see, which search results appear first, and with which adjacent links. With large language models (LLMs), such as ChatGPT, Bard, or Bing Chat, the challenges proliferate. Here, users are offered synthesized information through so-called generative artificial intelligence (AI) based on the statistical likelihood of sentences answering their questions. Although LLMs may produce highly accessible answers quickly, these answers will also be error prone and could simply be wrong. Errors do not have the same significance when you ask an LLM for help in, for example, correcting your grammar, but they are very worrying in the context of healthcare decision making.

This forum article delves into the intersection between the progression toward stem cell therapies and the

rapidly evolving landscape of online search technology. To identify the relevant implications of this intersection, we convened a group of researchers specializing in online search technology and representatives from the international stem cell community with interests in patient advocacy and communication for a structured workshop. The article is the result of that workshop. We suggest that the stem cell community needs to pay attention to the new online mediation of information and consider how it is shaped by changing technology as well as political and economic forces. The stem cell community needs to care because it affects trial recruitment, information exchange, and, ultimately, trust in gene and stem cell technology and those involved in its development and delivery.

HOW “Dr. GOOGLE” HAS INFLUENCED THE INFORMATION LANDSCAPE

Online direct-to-consumer advertising has been pivotal in facilitating and expanding various marketplaces for putative stem cell therapies for decades (Berger et al., 2016; Chavez et al., 2021). As people ask what is colloquially called “Dr. Google,” they





are finding not just what they are looking for but also what others pay to show them. This is seen across platforms such as Google, YouTube, Facebook, TikTok, and Instagram. Indeed, a fundamental part of Google's business mandate is to provide commercial entities with audiences and let advertisers pay per click. This payment for "contact," rather than just exposure, is facilitated also through the personalization of search results based on tracking user behavior and interests. Because stem cell researchers and their institutes rarely direct precious resources toward online marketing, scientifically valid information may not be promoted online.

Although here we adopt the term Dr. Google, digital search operates across a number of platforms and interfaces. Some are connected and even owned by the same company, such as Alphabet, which owns and operates both Google Search and YouTube, as well as the advertising sales and deployment platform Google Ads, which facilitates commercial advertisements across Google platforms and beyond. The near-monopoly status of Alphabet in the online search market has raised concerns and is currently being challenged by the European Commission (Nicoli and Iosifidis, 2023). However, people also use social media platforms to find information, not only search engines. During the Coronavirus disease 2019 pandemic, Telegram and BitChute, for example, created a niche market for controversial health information (Islam et al., 2020). Such markets know no clear boundaries and are difficult to regulate.

Through these online interfaces, private providers and clinics selling reputed stem cell treatments can reach a global audience, irrespective of their physical location (Berger et al., 2016). Conversely, search engines enhance their customization of results by using geolocation because it is correlated to certain purchasing preferences (Zook

and Graham, 2007). Information is thus both bounded by place and impossible to tie down to one place. Search technologies thereby mediate knowledge about stem cell research in ways that simultaneously cross borders and establish local and fragmented information landscapes that are complex to regulate.

How do people find out who and what to trust in such a complex information setting? Information scholar Claudia Egger has described how many patients come to learn about medical issues through the people they follow online (Egger, 2022). Such mediators may include celebrities and can be influencers or podcast hosts, or self-appointed specialists (Du et al., 2016; Sipp et al., 2017). This also means that just because a stem cell researcher or websites of official scientific societies make information available, it is not certain that it will be found—or found credible. With LLMs, things get even more complicated.

LLMs ENTERING THE SEARCH MARKET

LLMs have been trained on vast amounts of data to be able to generate new texts that resemble human language. They affect information search in ways that require our attention. Texts are assembled based on a statistical propensity to be an answer that matches the question posed, but with some LLMs, the sources used to generate responses remain unknown to the user. It implies that they cannot assess, or want to assess, the trustworthiness of the source. With other LLMs, training sets and software are made open source, but while that helps specialists to understand how an answer is created, the average user will typically just read the AI-generated text as any other piece of information available online.

Not only is outdated information a concern but also LLMs may be trained

on text that contain inherent biases or skewed information (Bender et al., 2021). The generated responses may lead to a range of consequences, from perpetuating or amplifying existing biases to misattribution and misinformation. Although ChatGPT (GPT-4), for example, seems to be instructed to warn users of known risks, it also can easily be prompted to generate incorrect or misleading information because of the disproportionate prominence that this information has online. Also, when trained on valid data, an LLM may "hallucinate"—in other words, fabricate information that does not exist. This presents a notable risk to patients, especially those who have few options for accessing expert medical advice, let alone stay informed about the characteristics of the datasets on which an LLM has been trained. Conversely, LLMs may in some instances be helpful for less resourceful patients as tools for making complex information more accessible. Often, people may not even notice that the information they read is generated by AI. As LLMs become more deeply integrated into the web infrastructure (both commercially through platforms such as Google and Bing and for civic software purposes), end users may not know, or pause to consider, how the information they access is generated.

A PROACTIVE APPROACH

As researchers and patient advocates, we can either ignore the seismic changes in search technology outlined above or take a proactive role in shaping how these technologies affect the informational environment into which gene and cell therapies interact with the public. To be proactive will mean embracing digital methods to audit public debates and to investigate how the public uses these technologies. It will also mean that the stem



cell community must find collaborators and allies within interdisciplinary fields of computer and social sciences.

The tools through which future research participants and patients acquire knowledge about stem cell therapies will become increasingly important as greater numbers of later-phase trials roll out across diverse therapeutic areas. Scientists, clinicians, and study sponsors need to ensure the accurate communication of their science to interested audiences. To do so, they will benefit from collaborating with experts in online search technology and social scientists studying public engagement.

To study search technologies and user engagement on social media platforms, however, researchers need to be able to access and audit data from the platforms. Unfortunately, gaining access to the platforms through application programming interfaces and documentation can be challenging. Despite attempts by the European Union through the introduction of the EU Digital Services Act and the coming AI Act, regulatory requirements to encourage search and social media companies to share data with researchers remain inadequate. Another notable challenge is the restrictive nature of "terms of use" licensing, which hampers researchers' rights to systematically test search engines and thereby decipher how they operate. Often, such experiments are prohibited in the agreements that users need to accept to access the search tools. To overcome this, proactive approaches to engagement and regulation are necessary. We as a community need to continue to lobby for changes to legal frameworks and need to insist on right of access when critical elements of the societal infrastructure is under the control of private companies. This includes calls to make the operation of online search technology more transparent. LLMs do not know facts, but they are good at creating intelligible language and

can be harnessed for this ability to serve communication goals, but only if the scientific community seeks to influence how they are instructed and used. Moreover, the academic auditing of LLMs can and must be enabled by platform providers as part of a commitment to transparency and user protections. However, the stem cell community also needs to align positions within our community if we wish to influence external actors.

THE WAY FORWARD

We believe it is important to acknowledge that these developments in online search technology offer not only challenges but also opportunities for the stem cell community. For over two decades, scholars in science communication have raised the alarm to move away from a model of one-way communication and education toward listening, learning, and even collaborating with diverse publics and their alternative forms of expertise (Davies and Horst, 2016). New online search tools offer opportunities for both research into and enhancement of practices of patient involvement and public engagement.

In research, it is possible to use the new technologies and the data available on these platforms to better investigate what different populations are already discussing, who they use as online expert mediators, and which search terms are trending. This can involve observing who bids on new key words on search platforms; what is being discussed where; how platforms mediate knowledge; how the knowledge produced by stem cell research is disseminated and to whom; and how LLMs generate new narratives about the intentions of stem cell research. This can then inform communication interventions and the development of educational material about stem cells, including the important work already

done by organizations such as the [International Society for Stem Cell Research](#) and [EuroGCT](#). However, it will also be necessary to do more to meet people where they are. The general public are diverse, have experiences of their own, and already trust particular online mediators, shaped by their own histories and beliefs. For members of the public to be willing to learn from stem cell researchers, they will typically need to first feel respected and heard. Top-down dissemination is not always conducive to this, but engagement on platforms they know and through mediators they trust may make a difference.

In practice, the new LLMs, if adequately trained, may add to these efforts and provide new dialogical ways of interacting with citizens. It could enable experimentation with collaborative communication whose premises are shaped more thoroughly by citizen interests and concerns, rather than the more traditional methods that often represent top-down dissemination in disguise.

Just as the stem cell community is not uniform, patients comprise diverse groups with distinct needs and perspectives. Using new technologies could enable researchers to better engage with diverse patient groups in approaches that suit their individual preferences. Furthermore, some stem cell scientists may also learn to communicate in more emotional registers that may better allow some patients to convey their values, needs, knowledge, and perceptions. Such a dialog can take place in alternative formats using, for example, arts- and narrative-based forms of communication. These dialogs may foster more socially robust communities around stem cell research and health innovation.

Welcome to the new world of information search. It has the potential to shape your everyday work and how your science is seen by patients, clinical trial participants, and the wider public. It is time to tune in.



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AUTHOR CONTRIBUTIONS

All of the authors participated in discussions that led to the initial manuscript. Preparation and finalization of the paper was led by K.H. and M.M., with comments and edits from all of the authors.

DECLARATION OF INTERESTS

M.M. is a board member of the International Society for Stem Cell Research (ISSCR); has been involved in the design and delivery of the ISSCR A Closer Look at Stem Cells website and ISSCR Guidelines, and is on the International Advisory Panel for EuroGCT. A.C. is a staff member of EuroGCT and serves on the Education Committee of the ISSCR.

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