

Improving access to oncology publications for advocates and people with cancer

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- Journal articles provide reliable and current information about cancer research.
- This can offer hope to people with cancer and help them make decisions about their care.
- Here, the authors suggest ways in which different groups may help people with cancer to find, view, and understand articles.
- For example, journals should make articles free to view if they describe research that could change patient care.
- Also, clear titles and easy-to-follow summaries or videos may help people to find relevant articles and understand the main findings.
- It is important to explore ways to best share research with all those whose lives it may affect. **Cancer 2022;128:3757-3763.** © 2022 Pfizer Inc and The Authors. *Cancer* published by Wiley Periodicals LLC on behalf of American Cancer Society. This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](#) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

KEYWORDS: cancer, caregivers, communication, health equity, patient education, patients.

THE VALUE OF SHARED DECISION MAKING AND THE ROLE OF INFORMATION SOURCES

Increasingly, studies are establishing that many people with cancer want to be involved in shared decision making with their health care providers.¹⁻³ This approach may be associated with positive effects on a person's quality of life, improved emotional outcomes, reduced health care use, and better treatment satisfaction.⁴⁻⁷ Conversely, a passive role in decision making may be associated with more unmet expectations and decisional regret.^{8,9} The value of shared decision making has been recognized by the European Cancer Patient's Bill of Rights, which acknowledges the right of European citizens to receive the most accurate information and to be proactively involved in their care¹⁰; similarly, the European Code of Cancer Practice states that people with cancer have the right to participate in shared decision making with their health care team about all aspects of their treatment and care.¹¹

But where do people with cancer find information upon which to base their decisions? Surveys suggest that they often consult written materials from physicians or from the internet.^{12,13} However, the volume of written materials from physicians can be overwhelming or too detailed,³ whereas online information about cancer can be incomplete, outdated, and/or inaccurate.¹⁴⁻¹⁶ Oncology publications offer a valuable source of information about the latest research developments, but only if people with cancer are able to find, view, and understand them.

BARRIERS TO ACCESSING ONCOLOGY PUBLICATIONS

In terms of finding oncology publications, a barrier for some people could be limited access to journal articles online. This may be because of poor access to broadband or online devices: a survey reported in 2020 suggested that approximately one in four people with cancer at a US center did not have daily internet access,¹⁷ whereas a survey reported in 2021 suggested that approximately one in five breast cancer survivors in the United Kingdom did not have access to a tablet or smartphone.¹⁸ An additional factor for some people may be their level of eHealth literacy,^{18,19} defined as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.²⁰

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The last two authors contributed equally to this work as co-senior authors.

Additional supporting information may be found in the online version of this article.

DOI: 10.1002/cncr.34447, **Received:** November 12, 2021; **Revised:** May 3, 2022; **Accepted:** May 19, 2022, **Published online** September 13, 2022 in Wiley Online Library(wileyonlinelibrary.com)

For those with access to online information, a more important barrier may be that many journal articles sit behind a paywall.²¹ To address this, there have been drives to encourage open access publishing, which allows readers to view content free of charge and may be associated with greater numbers of citations and social media attention.^{22–24} Such drives include the publication of position statements on this topic,^{25,26} the introduction of open access policies by some research funders,^{27,28} and the Plan S initiative, which requires that applicable research is published in compliant open access journals or platforms.²⁹ The proportion of oncology journals that are open access has increased²⁴; however, considering the top 10 oncology journals by impact factor in 2021, only the journal *Molecular Cancer* is fully open access, with all articles made freely and permanently accessible online immediately upon publication. In addition, cancer researchers can be hesitant to submit to open access journals because of article processing charges and a perceived lack of journal quality.³⁰

Assuming that people can find and view journal articles, another challenge can be readability²¹; again, this may relate to an individual's eHealth literacy. Plain-language summaries (PLS) of journal articles can improve understanding and facilitate patient–physician dialog^{31,32}; they can save time and effort on the part of the reader, help to explain statistics, and offer an alternative reading level, thereby improving accessibility.²¹ Research has suggested that visual approaches, including infographic-style PLS and video abstracts, may enhance engagement^{31,33} and that PLS and video abstracts offer better understanding than traditional abstracts, regardless of the reader's scientific background.³¹ However, few oncology journals invite PLS: research presented in 2019 found that none of the top five oncology journals (by impact factor) were publishing publicly accessible PLS, and scores for *patient-friendly content* were generally lower than for the top five journals in all other fields investigated (cardiovascular, diabetes, gastroenterology and hepatology, and general medicine).³⁴ Nonetheless, PLS are offered by some oncology journals, including *Cancer* and the Adis journals *Targeted Oncology* and *Oncology and Therapy*. Furthermore, a mechanism that may help to combat the apparent lack of PLS options in the field is the introduction of plain-language summaries of publications by the Future Science Group journals, allowing the publication of freely downloadable, peer-reviewed, standalone PLS of any article (including articles previously published in other journals), with dissemination through social media and patient organizations.³⁵

Patient involvement in publication development may also help to improve the clarity of content as well as

relevance to people with cancer.³⁶ *The BMJ* advocates such an approach as part of its innovative *patient and public partnership strategy*, which was adopted in 2014 to promote the co-production of content with patients and to help advance the global debate on patient and public involvement in health care and health research.³⁷ The initiative requires authors to state how patients were involved in the work and invites patients to review articles under consideration and write articles from the patient perspective.

AUTHOR PERSPECTIVES AND RECOMMENDATIONS

Our author group comprises people diagnosed with cancer, as well as health care professionals and representation from the pharmaceutical industry, to offer a broad perspective on the topic of access to oncology publications. We have summarized our key recommendations as part of the following text, in a visual PLS (Fig. 1) and in a video short (see Video S1).

Our case for improving access to oncology publications

Access to oncology publications is crucial for people with cancer and their caregivers, particularly when research could have real-time impacts on their treatment decisions and direct effects on their lives. An understanding of the research pipeline can also be empowering and offer insights into treatments that may become available in future. The importance of being able to access and understand information has been highlighted by a recent systematic review, which reported that health literacy among people with cancer has been correlated with care experiences and quality of life.³⁸ Evidence was noted to suggest that conflicting advice or lack of understanding of information could be associated with decision dilemmas, fear, or more unanticipated side effects.³⁸ Meanwhile, those with greater health literacy were able to play a more active role in managing their own health.³⁸ Clearly, it is not enough for information to simply be available: it also needs to be understandable and usable by all, irrespective of health literacy. Therefore, our recommendations below not only consider ways to help people find and view publications but also consider ways to support their understanding, e.g., through the development of PLS.

There has been increasing recognition of the need to communicate research to people with cancer and other health conditions. For example, [ClinicalTrials.gov](https://www.clinicaltrials.gov) is a website maintained by the US National Library of Medicine that provides information about clinical trials and associated publications and was made available to

People with cancer should have access to journal articles

Journal articles describe the latest cancer research. They are detailed and accurate. They can help people make treatment decisions and offer hope about new treatments.

What might stop people accessing journal articles?



"I can't find any that are relevant to me"

"I can't view them without paying a fee"

"I can't understand them"

How can we improve access to journal articles?

These actions have been recommended by a group of doctors, pharmaceutical company employees, and people with cancer

Recommended actions are for:



Pharmaceutical companies, and other research funders, who plan and fund research into new treatments



The **authors** who do the research, write the articles, and choose the journals where they would like their articles to be published



The **professional societies, and other publishers**, who publish articles in journals



Patient organizations who provide support and information to people with cancer

Authors should give their articles clear titles. For example, the titles should say if the research involved patients.

Some **professional societies, and other publishers**, publish articles in a way that means there is no fee to read them – all publishers should consider this. Another approach could be for them to make important journal articles free to view on patient organization websites.

Some **publishers** ask authors to produce easy-to-follow materials that can help people to understand their research. These can include short plain-language summaries (PLS) or video summaries. Publishers should do this wherever possible.

Patient organizations should share information about important journal articles on their websites. Community organizations may be able to help share the articles with people who have difficulty using the internet.

Authors should seek out journals that do not charge people a fee to read their articles.

Authors should seek out journals that publish easy-to-follow materials. They should produce materials that are clear and engaging.

Pharmaceutical companies should involve people with cancer in the research process and writing of articles. This could help to make information more relevant to people with cancer, and increase interest in articles.

Pharmaceutical companies, and other research funders, should encourage authors to do this.

Pharmaceutical companies, and other research funders, should encourage authors to do this.

Publishers should encourage this by asking authors to say how people with cancer were involved.

Some **professional societies** also organize cancer meetings. These can be the first place where research is shared, before a journal article is written. Meetings should be inclusive of people with cancer: for example, patient advocates should have free access to the full meeting programs.

Authors should try to use the same wording/language when talking about cancer and its treatment in journal articles. They should follow any established guidelines about this.

Publishers could also ask people with cancer to write their own articles and review those of others.

Publishers, pharmaceutical companies, and other research funders, should encourage authors to do this.

ONE-SENTENCE SUMMARY

The research described in journal articles can be of great value to people with cancer and their caregivers: here are some ways that the community could help people to find, view, and understand these articles.

FIGURE 1. Visual plain-language summary of this article summarizing key recommended actions to improve access to oncology publications for people with cancer.

the public in 2000³⁹; the US National Cancer Institute shares cancer information summaries written in lay language for patient audiences⁴⁰; and, in the European Union, there are requirements for clinical trial sponsors to develop lay summaries of clinical trials, with associated guidance provided by Good Lay Summary Practice, which was published in 2021.⁴¹ Such moves are aligned with drives by the American Society of Clinical Oncology (ASCO) toward achieving health care equity⁴² and the 2020–2021 ASCO President Dr Lori Pierce’s presidential theme of health care equity for everyone with cancer.⁴³ It is also part of the mission of the European Society for Medical Oncology (ESMO) to promote equal access to optimal cancer care for everyone with cancer, as well as disseminating knowledge to people with cancer and the public.⁴⁴ Against this background, it is only right that efforts are made to improve access to oncology publications for people with cancer.

Our recommendations to help people find publications

To help people with cancer and their caregivers find publications that are relevant to them, we encourage authors to provide clear titles that state whether research is preclinical or clinical. Short, tweetable abstracts may support sharing on social media, and some journals (for example, *Journal of Clinical Oncology*) suggest that authors use Twitter to announce the publication of their articles, although tweets can provide limited context and so should include a link to the full article. In addition, patient organizations should share information about key journal articles via their websites: such websites can offer valuable information for people with cancer, but content varies, and not all direct users to the primary sources. These approaches may all support community organizations in identifying relevant articles to share with people with various levels of eHealth literacy.

Our recommendations to help people view publications

Once relevant publications are found, open access publishing is key to ensuring that the full articles can be viewed freely. Abstracts alone rarely allow adequate assessment of the quality or relevance of research, yet full articles often sit behind paywalls, which can be a major barrier, particularly for people with cancer who have financial limitations (including those with a background of low socioeconomic status or those who have been unable to continue earning). Therefore, authors should preferentially submit articles to journals offering open

access options, with encouragement from pharmaceutical companies and other research funders. Equally, it is imperative that professional societies and other journal publishers offer open access publishing as widely as possible, particularly for articles reporting clinical trials likely to impact clinical practice.

One approach to address several of the challenges raised here could be for journal publishers to make key articles and supporting materials freely available on non-profit patient organization websites, such as METAvivor or Living Beyond Breast Cancer for those with metastatic breast cancer, or LUNGeivity or The GO2 Foundation for those with lung cancer. This could help bring oncology publications directly to the attention of people with cancer.

Our recommendations to help people understand publications

Once publications are viewed, the level of detail may be valued by some yet overwhelming to others; therefore, there is a rationale for complementing publications with PLS. Authors are advised to seek out journals that proactively engage with patient audiences and embrace opportunities to create patient-directed content. If PLS are not specifically invited by journals, authors should consider submitting a PLS as supplementary material or developing a separate plain-language summary of a publication (as offered by the Future Science Group journals; see above). This may drive more journal publishers to offer formal mechanisms for inviting, publishing, and sharing PLS.

The content of PLS should be understandable and engaging for a broad audience, including people with cancer who have limited specialist knowledge of medical terminology; input from patient advocates may help with this. Data and statistical analyses should be explained clearly, without downplaying their complexity (over-simplified language can be viewed as patronizing)^{21,33} to support people in developing the skills and understanding to interpret data appropriately. Infographics can be an effective means to visualize data, especially to explain the design of clinical trials in progress or the results of trials reporting complex biomarker data. We also support efforts to reduce confusion by striving for consistent terminology, such as the recent recommendations for consistent plain-language terms for precision oncology testing, which have been proposed by a multistakeholder group of patient advocacy organizations, professional societies, and industry representatives.⁴⁵

Although people with cancer are exposed to information of vary quality across the internet and social media,

it is important that they are able to rely on the accuracy and validity of PLS and other easy-to-follow materials produced alongside oncology publications. We support previous calls for PLS to be provided at the point of article submission (as is the case for PLS submitted to *Cancer*) so that they can undergo peer review alongside the full journal article,⁴⁶ and we note that plain-language summaries of publications (as offered by the Future Science Group journals; see above) are subjected to their own peer-review process. We are encouraged to see that many journals are already implementing appropriate measures to safeguard the quality of these materials.

Broader considerations

In line with previous proposals,⁴⁷ we advocate that patient input into research and oncology publications in general may help to improve relevance and appropriate communication to others with cancer. However, this may require a shift in the mindsets of researchers, research funders and author groups, and patient authors would need to be supported in understanding publication processes. Nonetheless, progress is being made; for example, the Workgroup of European Cancer Patient Advocacy Networks offers an online course on how patient advocates can publish their own research and act as co-authors or peer reviewers, and the European Patients' Academy on Therapeutic Innovation provides training for patients on the process of medicines research and development. Other initiatives are connecting cancer researchers and patient advocates, including Guiding Researchers and Advocates to Scientific Partnerships.

Beyond journal articles, congress abstracts represent an important publication type because they report the latest research. As for journal articles, PLS of congress abstracts can support broader access; based on our experiences, when PLS were developed for 363 abstracts that reported Pfizer-funded research at oncology congresses, there were >6700 views of the PLS. We also note that people with cancer may attend congresses to *translate* information for others, and so encourage more societies to join ASCO, ESMO, and others in offering free congress registration for patient advocates. Oncology congresses could also follow the lead of other congresses aiming to better connect patients and physicians; for example, the meeting of the European Association of Urology expanded a previous Patient Information Session into a Patient Day, which included sessions focused on the patient perspective, and a Patient Poster Session (a summary of learnings from the 2021 Patient Poster Session on the theme of *disconnect between the physician and*

patient) has been shared online.⁴⁸ Patients can also present posters during the Patient Perspectives programs at the meetings of the American Urology Association and the American College of Rheumatology. Stanford University's Medicine X program is championing best practices via their model for creating meaningful patient partnerships at congresses, potentially through patient involvement in planning and speaking, financial support, educational support and mentorship, and endorsement of the Everyone Included vision.⁴⁹

Because oncology is a vast field, a key question may be to ask which oncology publications are most relevant to people with cancer and thus should be made more accessible. A multistakeholder working group has recently advocated that, ideally, all publications reporting industry-sponsored medical research should have a PLS mandated by the journal, while acknowledging that this may not be possible in practice because of cost and resource limitations.⁵⁰ The group was unable to reach a consensus on how publications should be prioritized for PLS, although it was suggested that PLS for journal articles should be prioritized above PLS for congress abstracts, because congress abstracts are not subject to rigorous peer-review processes (we suggest, however, that a counter-argument could be that congress abstracts should be prioritized because they report the latest research potentially much sooner than full publication in a peer-reviewed journal). Further evidence to help profile the journal articles that are of most value to patients may be informative, but ultimately we suggest a focus on the research that is most likely to impact clinical practice, such as phase 2 and 3 clinical trials and real-world studies of approaches to patient care.

Here, we have described multiple approaches that could improve access to the information in oncology publications for people with cancer and their caregivers, but can this be directly translated to improved patient-centered care? We call for further research efforts to clarify the relationship between access to information and the experiences of people with cancer, and we anticipate that more widespread adoption of approaches to improve access to oncology publications will facilitate research to better understand their impact.

SUMMARY

People with cancer are the ultimate beneficiaries of oncology research and must be supported in accessing and understanding research findings so that they can make informed decisions about their care with their health

care providers: research should be made available to all those whose lives it may impact. As such, the pharmaceutical industry and other research funders, authors, professional societies, journal publishers, and patient organizations have a duty to optimize access to oncology publications and strive for content that is relevant and clear.

ACKNOWLEDGMENTS

Medical writing support for article development, under the guidance of the authors, was provided by Hannah FitzGibbon, PhD, and Ajay Mirakhur, MPH, of CMC AFFINITY, a division of IPG Health Medical Communications, and was funded by Pfizer Inc. The final article was shared with Julia Maues from Guiding Researchers and Advocates to Scientific Partnerships (GRASP) for expert comment and confirmation of information relating to GRASP.

CONFLICTS OF INTEREST

Josep Taberero has held consultancy or advisory roles for Array Biopharma, AstraZeneca, Avvinity Therapeutics, Bayer, Boehringer Ingelheim, Chugai Pharmaceutical, Daiichi Sankyo, Eli Lilly and Company, EMD Serono, F. Hoffmann-La Roche Ltd, Genentech Inc., HaliDX SAS, Hutchison MediPharma International, Ikena Oncology, IQVIA, Menarini, Merck Sharp & Dohme, Merus, Mirati Therapeutics, NeoPhore, Novartis, Orion Biotechnology, Peptomyc, Pfizer, Pierre Fabre, Samsung Bioepis, Sanofi, Seattle Genetics, Servier, Taiho Pharmaceutical, Tessa Therapeutics, and TheraMyc; and has participated in educational collaborations with Imedex, Medscape Education, MJH Life Sciences, PeerView Institute for Medical Education, and Physicians Education Resource. Tami Eagle Bowling is a patient ambassador for Pfizer, received an honorarium from Pfizer for her participation as a patient author for this manuscript, and is a volunteer for METAvivor Research and Support. Jamil Rivers received an honorarium from Pfizer for her participation as a patient author for this manuscript, and reports leadership or fiduciary roles with METAvivor Research and Support, Living Beyond Breast Cancer, and The Chrysalis Initiative. Dheepa Chari, Jennifer Ghith, and Roxanne Ferdinand are employees and stockholders of Pfizer Inc. Kelly Shanahan has served as an advisory board member for Pfizer Inc, received an honorarium from Pfizer for her participation as a patient author for this manuscript, received an honorarium for participating in a Medscape virtual event on metastatic breast cancer, and serves as a member of the Board of Directors for METAvivor Research and Support. Neal D. Shore is the Director of Carolina Urologic Research Center, has received payment from Ferring for expert testimony, and has served as a consultant or advisory board member for Abbvie, Amgen, Asieris, Astellas, AstraZeneca, Bayer, BMS, Boston Scientific, Clarity, Clovis Oncology, Cold Genesys, Dendreon, Exact Imaging, Exact Sciences, FerGene, Foundation Medicine, GenesisCare, Invitae, Janssen, Lantheus, Lilly, MDxHealth, Merck, Myovant, Myriad, Nymox, Pacific Edge, Pfizer, Phosphorous, Photocure, PreView, Propella, Sanofi Genzyme, Sema4, Sesen Bio, Specialty Networks, Telix, Tempus, Tolmar, UroGen, and Vaxiion.

FUNDING INFORMATION

Medical writing support for article development was funded by Pfizer Inc.

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