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COMMENTARY

Patients at the Heart of the Scientific Dialogue: An Industry Perspective

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PLAIN LANGUAGE SUMMARY

Pharmaceutical companies need to regularly communicate to patients all essential information about their medicines, especially data from the research studies that were conducted to evaluate the medicine's benefits and risks. To do that, companies will need to make sure patients have access to and awareness of relevant information. This can be achieved by ensuring medical information is freely available to the reader, and working with publishers to facilitate open access (free) publications. Companies should also help improve patients' understanding of medical terminology, offer simplified versions of scientific content, and deliver information through various formats (print versus digital, text versus audio versus video) to address different learning styles and literacy levels. This will empower patients with knowledge and improve shared decision-making. It will also be essential for pharmaceutical companies to involve patients in various stages of medicine development, such as getting their input on how the research studies for investigating these medicines are designed and reported to ensure relevant information to patients are well-captured and clear. This should also go in parallel with providing opportunities to elevate the patient voice through patient-partnered research and authorship on topics particularly relevant to them.

Keywords: Patient centricity; Open access; Plain language summary; Health literacy

Key Summary Points

Scientific communications are a key pillar for dissemination of clinical trial and product data to multiple stakeholders including patients.

Tailoring communications to the appropriate level of a patient's health and digital literacy are essential to ensure optimal information delivery.

Ensuring access to and readability of scientific publications can be achieved through open access publication, plain language summaries, and enhanced publication content.

Patients can be directly engaged to communicate their voice throughout a product's lifecycle by providing input on clinical trial design and conduct during development, as well as education programs and materials post launch.

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Patients can also act as co-authors on scientific publications, journal peer-reviewers, and partners in research studies as appropriate.

INTRODUCTION

There is no doubt that new drug development is undertaken to improve patient outcomes. Historically, patients have mostly taken part in this complex process as clinical trial participants and/or eventual medicine users, by primarily getting their disease and therapy education through their healthcare providers. Patient centricity, per se, was focused on devising appropriate methods to be utilized by the pharmaceutical industry and healthcare providers that ensure patient safety, benefit, and data protection [1, 2]. In the past few years, however, the concept of patient centricity has evolved to reflect a transition in mindset from conducting research "on" or "for" patients, towards an aim of conducting research "with" patients [1]. The core principle has become for the industry to "partner" with patients throughout development of, education on, and access to medicines to ensure best outcomes that are meaningful to them and their families [1, 2].

Patient-centric relationships have gradually become increasingly common between patients, industry, regulators, and healthcare professionals [1, 3–6]. The definition and principles of patient centricity in healthcare and drug development also continue to evolve; with the latter essentially revolving around education and information, co-creation, access, and transparency [1]. In this work, we provide an industry perspective on key concepts and engagements that align with patient centricity in scientific communications throughout the development lifecycle of new cancer treatments. Where relevant, we also provide examples and lessons learned from our own initiatives as the oncology medical team at Pfizer.

COMMUNICATING SCIENCE TO PATIENTS

Establishing Health and Digital Literacy

Scientific data are at the core of patient communications and patient education in various clinical, research, and community settings. Thus, it remains imperative for patients and their caregivers to have the appropriate level of health literacy for such information sharing to be effective and meet intended goals. In fact, health literacy among cancer patients is associated with better care experiences and quality of life [7]. We cannot simply assume that patients know the various components of scientific/educational materials, even those developed for lay readership. Additional resources need to be developed and disseminated that educate patients on how to read scientific content prior to approaching the data. This could include tailored information on the clinical trial and drug development process; how to navigate and interpret study abstracts, manuscripts, and other scientific materials; what constitutes misinformation about scientific data; what to expect during the course of disease and treatment; why and how comorbidities are managed; and how to manage and escalate side effects, among others. Educational level and cultural differences should also be taken into consideration upon assessing patients' health literacy, as these would help tailor information delivery in terms of content and context.

In the era of digital transformation in general, and within the pharmaceutical industry specifically, it is equally essential for patients and caregivers to have access to digital sources, and more importantly, an adequate knowledge of using technology. Recent surveys highlighted that even in the USA and UK, around a quarter of cancer patients do not have access to internet or technology [8, 9]. Digital platforms are becoming the prime resource for patient-oriented education and scientific information developed by the industry. Thus, the formats by which the industry shares information to different types of audiences need to be tailored to patients' access to technology and eHealth

Literacy. To determine the most effective communication pathways, dedicated patient surveys can be conducted for industry to better understand preferences and access privileges to multiple formats and channels, for the various audiences of interest. The expanding interest in using technology should thus be carefully balanced with patient preferences, capabilities, and access privileges (e.g., resource-limited countries, older patients). The downside of the ease of digital information delivery, "information overload," should also be taken into consideration as it may complicate rather than facilitate patient education.

At Pfizer, we have joined other industry partners in the Center for Information and Study on Clinical Research Participation (CISCRP, www.ciscrp.com), with a core mission to provide accessible, relevant, useful, high-quality educational resources, programs, and services that increase patient awareness and understanding of the clinical research process [10–12]. Pfizer Oncology's Patient Centricity Ecosystem (POPCE) was also launched in 2019, with 40+ advocacy organizations having regular discussions with Pfizer leadership. This program generated over 40 ideas for Pfizer to consider, and these were prioritized to focus on three core areas: health literacy, health equity, and increasing patient engagement in clinical trials [10–12]. Our teams have regular touch points with patient advocates to assess unmet need, co-create with them, gain feedback on newly deployed resources, and brainstorm new educational opportunities for the future.

The success of all such initiatives also relies on designing programs focused on educating healthcare professionals (physicians, advanced practitioners, nurses, and care coordinators) about the availability and appropriate use of various materials developed by the industry to educate patients about their treatment journey and expand the reach of scientific data to patients. Educating healthcare providers about patient centricity as a concept may also be needed, since it is not necessarily part of their medical education and training.

Ensuring Access to and Readability of Scientific Publications

Peer-reviewed manuscripts and congress presentations are the common language for scientific data communication between healthcare stakeholders. Across some publishers and industry, several tactics have been maturing over the past few years to allow these direct sources of scientific knowledge to be readily available and comprehensible to patients, primarily through open access publishing of scientific articles and plain language summaries (PLS) published alongside. Access to PLS with peer-reviewed articles and conference presentations helps overcome the risk of receiving complex or overwhelming information from healthcare providers through other sources; or incomplete, outdated, or inaccurate information from web-sources. It will also address the right of patients to receive accurate information and fulfill their desire to be part of the decision-making process for their treatment pathway [13, 14]. In fact, the recent 4th edition of the Good Publication Practice (GPP 2022) Guidelines, which are commonly used by the industry to set publication policy, recommends PLS for any clinical trial and other biomedical publications [15].

Open access (i.e., free readership) of journal articles remains key for patients to be able to read scientific publications. Over the past decade, there have been several initiatives to increase the uptake of open access by publishers, government and/or research sponsors, and the pharmaceutical industry [13, 15–25]. On one hand, several calls and support initiatives have been made by major funding agencies to publish research results in open access journals [13, 26–30]. On the other hand, open access fees remain largely unaffordable for unfunded research and the "obligatory" open access option in many emerging journals is being met with skepticism of commercial bias and reduced academic quality [13, 19, 31]. In collaboration with industry sponsors, it is essential for professional societies and journal publishers to offer free open access publishing as widely as possible, at least for articles reporting clinical trials likely to impact clinical practice; or to

make access to such articles free of charge for nonprofit patient organizations [13, 15]. Only a few of the first quartile impact factor journals in oncology are fully open access, and these are where most key clinical trials of novel therapies are usually published [13]. A few journals, such as Annals of Oncology, have moved to having policies to make articles freely available to patients and caregivers [32].

Efforts to provide open access to publications should also go in parallel with strategies that help patients identify relevant publications for their disease and treatment. Authors may wish to use simple titles for their publications and make use of social media sharing techniques currently offered by many journals. This would ensure awareness to new and relevant publications by patient organization, and subsequently, patients [13]. Unfortunately, publishers are still inconsistent on allowing PLS to have a digital object identifier (DOI), which makes discoverability of those without a DOI more difficult for the patient if not shared on social media. At Pfizer, we prioritize open access publishing, strategize broader dissemination of PLS to address accessibility issues, and consistently share tweets on the Pfizer Oncology Medical Twitter handle that raise awareness of new data and plain language content available across disease states.

As mentioned earlier, to ensure scientific manuscripts and their data are comprehensible to patients, PLS have emerged as a tool that offers a suitable reading level for patients, especially as it comes to complex content such as statistics, which eventually saves time and burden of reading advanced scientific data [13, 16, 33, 34]. PLS should be peer-reviewed, not be oversimplified to avoid patronizing, and should rely on standard terminology to avoid confusion [35]. Enhanced content such as infographics and video abstracts are also increasingly used to optimize engagement [33, 36]. It is still somewhat uncommon for PLS of published articles to be offered by oncology journals; however, each year more journals are becoming amenable to inclusion either with its own DOI or as part of the Supplement (e.g., Annals of Oncology, Cancer, Adis Springer Nature Journals, Future Oncology) and hopefully the recommendation of GPP 2022 will encourage more journals to allow PLS [37]. We hope that this trend continues and that more journals would start mandating PLS, especially for late-stage clinical trials and real-world evidence studies that directly impact patient care [38] on their direct journal website with a DOI. Until then, if allowed by the journal, industry sponsors and authors could provide such PLS on platforms such as figshare (www.figshare.com), which is being utilized by Pfizer, if the journal does not publish PLS on their website [13]. The Future Science Group journals also allow submissions of PLS for publications from other journals, to progress the concept altogether and address its underutilization; this is also coupled with high search engine optimization and wide dissemination through social media platforms and patient societies [13, 39]. Information on enhanced content, social media sharing, and PLS has been extensively expanded in the recent GPP 2022 to reflect advances in biomedical publishing [15].

PLS can also be relevant to congress abstracts. In our experience to date at Pfizer, PLS have generated substantial views for abstracts based on Pfizer-funded research at oncology congresses. Cancer patients or their advocates often attend congresses to attain knowledge on scientific developments, and some societies such as the American Society of Clinical Oncology (ASCO), the American Society of Hematology, the European Society of Medical Oncology (ESMO), and the European Association of Urology (EAU) now offer free congress registration for nonprofit patient advocacy organization representatives [13].

We have several ongoing plans to create multiple PLS templates, translations, and interactive elements to adapt to different learning styles (auditory, visual, linguistic) and to offer a data visualization map to help patients better understand how each PLS in their disease area relates to each other to increase transparency and understanding. We are also working on a single resource that shares all such patient-centric content.

Customizing Educational Content and Optimizing Reach

Creative approaches to scientific communications and patient education should focus not only on reaching all patients but by meeting patients where they are and in the format they prefer. Omnichannel approaches have been at the core of digital transformation within pharmaceutical companies. While taking into consideration the limitations of digital access and literacy for some geographies and patient subgroups, dynamic and interactive online portals offer endless opportunities for customizing information and its passive or active delivery. Information for patients could expand beyond PLS and focus on other important topics in research and clinical trials to empower patients to speak with their healthcare provider. Industry needs to engage with patients to identify these unmet needs, rather than assume what information they desire. Such understanding, for example, will allow development of tailored support materials and programs that could help patients better cope with their surrounding environment. The information should also equally address family and caregiver concerns. The Global Status of Advanced/Metastatic Breast Cancer Report, supported by Pfizer, highlighted different biases against cancer in some countries, and how these make patients feel lonely, excluded, and shamed by their family or society for having cancer [40]. While this metastatic breast cancer report was not directly aimed at patients, it played an important role in raising awareness among healthcare providers about patient and cultural issues around breast cancer diagnoses. Addressing such barriers to quality of life in patient communications is equally important to sharing scientific data on disease and therapy. We have recently supported the first medical education series on "This is Living with Cancer" (www.thisislivingwithcancer.com), specifically, the development of the "Understanding Cancer" subsection of the site for the scientific topics: how clinical trials have changed during COVID-19, how to find reliable medical information online, understanding the clinical trial process, how to read an abstract for a clinical trial publication, and common terms used in abstracts and research articles for publications. We also have several ongoing plans to expand nontraditional, educational publication of scientific topics to various online channels (e.g., WebMD Education).

ENGAGING PATIENTS TO COMMUNICATE THEIR VOICE

Patient Engagement in Drug Development and Medical Affairs

Following optimized patient understanding of scientific information through the aforementioned channels, it becomes the industry's responsibility to empower patients to have a voice in the decision-making process throughout the product's lifecycle [14, 41]. Engagement of patients in key milestones of drug development and in strategic planning for medical affairs functions, would naturally warrant the associated scientific communications to be patient centric. The Medical Affairs Professional Society (MAPS) recent vision statement highlights that the specific structure to enable "patient-centricity," in terms of ways of working and personnel, will need to be clearly defined within pharmaceutical companies by 2030 [42]. The impact of such patient engagement should also be constantly measured [43].

For instance, patients and patient advocates can be involved and consulted during the development of informed consent, clinical trial materials, and recruitment strategies, to make these processes seamless and understandable for trial participants. Seeking input from patient representatives and caregivers earlier during study design can also help ensure appropriate and feasible trial eligibility and assessment criteria are in place. This would not only maximize participation in research but also ensures diversity and representation of ethnic minority groups and special populations such as the elderly [10–12]. Patients could help build directly relevant clinical trial education materials for their own peers and be part of implementation by acting as community educators. Including testimonials of patients who have

been in clinical trials would resonate with future participants from the same age, gender, or ethnic group who can relate and identify with such experiences [44]. We have taken things a step further at Pfizer, by creating the Blue Button Program that allows patients in our clinical trials to have access to their clinical trial data, thus helping them feel more involved in the research they are being part of [10–12].

Surrounding and after product launch, a continuous two-way dialogue with patient advocates and ambassadors is critical to ensuring that the industry is developing patient materials and education programs on disease and treatment in a way that tells the patient story, helps patients manage their own health, and empowers them to make their own decisions. Patient advocates play a critical role in data dissemination within patient communities and require access to scientific information in the appropriate formats for the patient audiences within their reach. The industry can organize cross-healthcare advisory groups including patients advocates and societies to help co-create patient awareness and education solutions, instead of just sponsoring them or developing them without their input [1].

Patient Engagement in Scientific Communications

Involving patients in the development of original scientific publications may help better clarify content and highlight relevance to cancer patients [45]. Some journals such as The BMJ have already adopted such an approach and advocate to have patients as co-authors on publications [46]. The journal also invites patients to review articles under consideration and to write perspective pieces. The fourth edition of Good Publication Practice Guidelines supports patient inclusivity and states that "patients and patient advocates may be included in publication planning and development, and included as authors or contributors to publications, as appropriate to the topic or therapeutic area" [15].

In fact, several calls have been made to involve patients as co-authors of clinical studies, authors of patient experience and perspective contributions, or as researchers and publication leads themselves. This applies to physician- and patient-facing journals and congress presentations [13, 47]. Several congresses have now transformed the conventional patient information session into sessions planned and designed by patients, dedicated to sharing their perspectives. These are also often coupled with patient poster sessions, and Pfizer has recently been the founding sponsor of three such Patient Perspectives Poster Tracks at the EAU, American Urology Association (AUA), and the Advanced Practitioner Society of Hematology and Oncology's JADPRO Live meeting. The latter remains essential given the significant one-on-one time that advanced practitioners have with their patients, and how they can take the learnings and directly apply them to their clinical practice. We have worked with relevant societies to implement other activities surrounding the patient track, such as patient training workshops and physician–patient roundtables. Lessons learned from some of these engagements were shared through a special report [48]. We have also supported peer-reviewed plain language podcasts featuring a dialogue between a patient advocacy leader and a physician on bladder and kidney cancer describing findings from ESMO 2021 [49], which also covered opportunities for patients to be involved in research or as a part of their care team.

Pfizer has also recently organized the American Association of Cancer Research (AACR) Patient Partnership in Research Spotlight Theater, which focused on the spectrum and status of patient partnership in oncology research and what it can provide in terms of clinical value. We are also collaborating with Stanford University to support a grant program entitled Public Led Opportunity Trials and Training (PLOT). The intent is to develop a generation where research and publication co-production is the norm and where patients are fully trained, mentored, and funded as research partners, co-authors, and co-investigators. PLOT will offer preparation and grantsmanship, leadership skills, applied research opportunities, and collaboration strategies to support good clinical

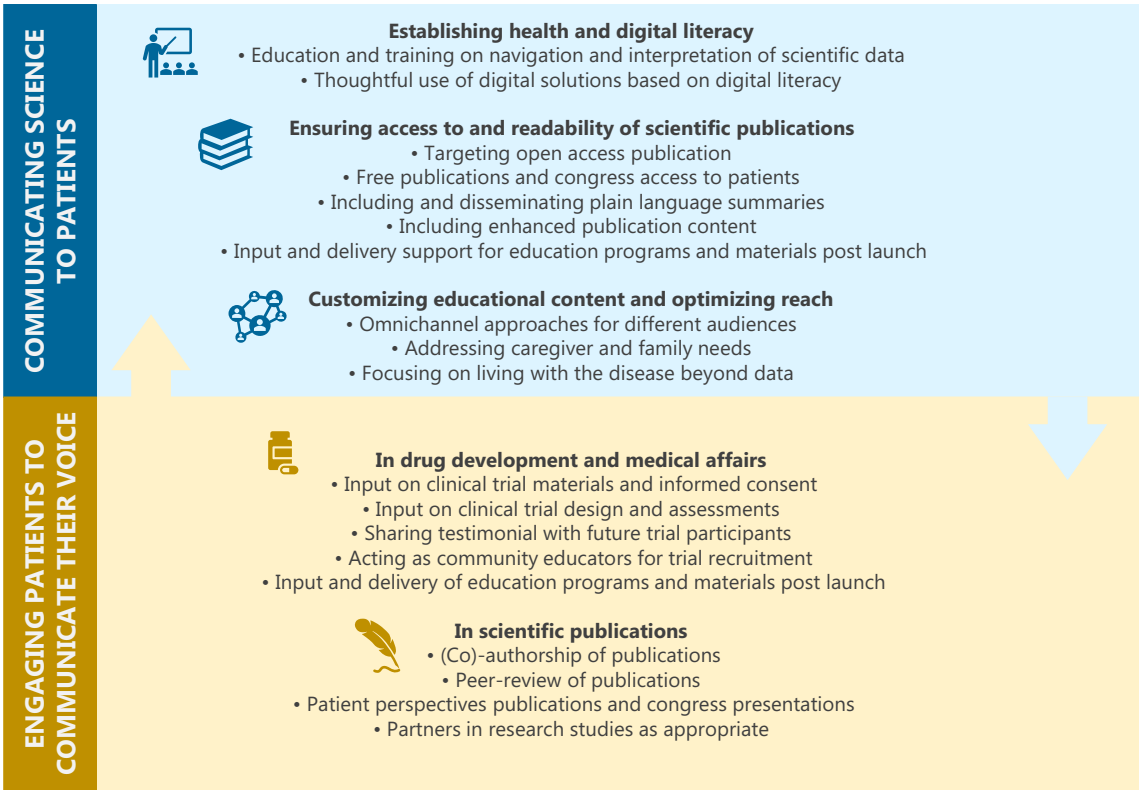

Fig. 1 Patient centricity in scientific communications

practice, excellence in research methodologies, and effective publication strategies. Patient and/or patient advocacy led teams will be mentored and supported to write their own proposals for quality improvement innovation and patient-reported outcome measures, among others. Our ongoing Representation in Scientific Engagement (RISE) project is using a behavioral science approach to understand why some physicians are reluctant to involve patients in medical affairs activities, especially co-authorship of publications, and to find solutions to address this challenge.

In summary, patient centricity in scientific communications requires an effective two-way dialogue between the industry and patients, with support and engagement of other key stakeholders who are involved in the patient journey (Fig. 1). We cannot achieve full patient inclusion in drug development and associated activities if they are not fully empowered and informed, not only about their rights and obligations, but about peculiarities of the science we co-create that are most meaningful to them. Beyond the examples shared in this article, we will continue evolving and prioritizing our strategy and engagements to address the patient gap. We also urgently call on other industry partners to take action and move patient-centricity forward.

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