Can access and accessibility rebuild public trust in research?

Alison Chisholm
Oxford PharmaGenesis, Oxford, UK

doi: 10.56012/wzoz4567

Correspondence to:
Alison Chisholm
alison.chisholm@pharmagenesis.com

Abstract

Trust is built gradually, and it is easily threatened, particularly in relation to pharmaceutical research. The potential for open access publishing and plain language summaries to contribute to improved trust in pharmaceutical research was discussed by experts at the Open Pharma Satellite Symposium, held at the Association of Learned and Professional Society Publishers Annual Conference and Awards 2022 in Manchester, UK. No single endeavour will win public trust overnight, but removing paywall barriers between all readers and sources of trusted information, and publishing research summaries that are written in accessible, plain English are important steps towards fostering greater trust in research. Both endeavours also have the potential to help the public make informed decisions about their health.

Photo: Freepik

How can we improve trust in pharmaceutical research?

This question was the challenge posed to speakers at the Open Pharma Satellite Symposium, held at the Association of Learned and Professional Society Publishers Annual Conference and Awards 2022, held in Manchester, UK.

Despite the unprecedented successes of the COVID-19 vaccines, public trust in scientific research fell during the pandemic. Richard Smith (Symposium Chair and former editor of the *BMJ*) kicked off the symposium with a quote from Dr K. "Vish" Viswanath (Professor of Health Communication at Harvard University): "[During the pandemic], people saw the sausage being made, and they [didn't] like what they [saw]." Scepticism in research, he noted, is further fuelled by hyperbolic tabloid headlines, such as the *Mail on Sunday*'s splash "exposé", "The plague of fake medical trials putting lives in danger", which claimed that "…the medical world is rife with research fraud".[1]

Whether the antidote to such poisonous proclamations lies in improved systems of publishing, better public education, or something else is not yet clear. Recognising two clear opportunities for positive change, the Open Pharma Symposium focused on the role of open access publishing and plain language summaries in improving public trust in science.

Why open access matters

Richard Stephens (patient advocate and Co-Editor-in-Chief of *Research Involvement and Engagement*) explained that a preponderance of medical buzzwords has led to patients being increasingly aware that their treatment should somehow involve "precision", "personalisation", and "stratification". Many patients also now expect that decisions around their care are shared and know that, beyond all else, treatment decisions should be based on evidence.

Open access publishing is the avenue through which patients can read the very evidence on which their treatment decisions are based. Open access publishing removes an important barrier between patients and sources of trusted information. It enables peer-reviewed medical literature to sit alongside traditional patient information sources, such as the knowledge and opinions of friends and family, the information provided by patient groups, and that espoused by social media influencers.

> Open access publishing removes an important barrier between patients and sources of trusted information.

On a more fundamental level, there is an inherent fairness in allowing patients to read the results of research to which they may have contributed data. Removing paywalls to peer-reviewed evidence not only resonates with fundamental matters of fairness to research participants, but it also enables improved patient education, negates accusations of hiding data, and improves article impact. According to Leila Moore (Director of Open Access Policy at academic publisher Wiley), although only a small proportion of articles in Wiley journals are currently published open access, those that are receive approximately 50% more citations and three times more downloads and Altmetric attention scores than their pay-per-view counterparts.

If open access publishing improves timely communication of the latest health literature to all interested stakeholders, improves levels of

Box 1. Implementing an open access mandate within a pharmaceutical company

Appropriateness to act

- Recognise that pharmaceutical companies are a major funder of medical research.
- Recognise that researchers are used to restrictions/requirements from funding sources; an open access requirement is no different.

Consider strategic benefits

- Consider open access benefits in the context of core company principles (e.g., transparency; rapid access to literature for healthcare professionals and patients; potential impact on diagnostic journeys).
- Challenge attitudinal barriers and legacy thinking that associate open access publishing with inferior journal quality.

Pragmatics and implementation

- Garner broad alignment with senior leadership (medical, R&D, legal, and compliance business units).
- Incorporate open access requirement into policies, standard operating procedures, and agreements (research, author, etc.).
- Budget for open access fees, if required, with Medical Affairs.
- Conduct internal training and alignment post launch.
- Take a pragmatic approach to the definition of open access, recognising that open access publishing without embargo (a CC BY licence) may be the goal, but that it is necessary to work within the reality that currently exists in publishing until such licences are widely available.

Abbreviation: CC BY, Creative Commons Attribution [licence]

Adapted from: Rains C. Open access commitment for Takeda-supported research. *Who can we trust? Open science and pharma research*. Presented at the Open Pharma Satellite Symposium at the Association of Learned and Professional Society Publishers Annual Conference and Awards, Manchester, UK, September 14, 2022 (oral presentation).[3]

research impact and engagement, and diminishes data distrust, research funders should be its staunch champions. This very realisation was what Christopher Rains (Vice President of Global Medical Affairs, Global Portfolio at biopharma company Takeda) described as his "lightbulb moment". Recognising that up to two-thirds of medical research is funded by the pharmaceutical industry, he decided that pharmaceutical companies have an important role to play in advocating wider adoption of open access publishing. In January 2018, Shire (his then employer) became the first pharmaceutical company to mandate open access publishing of their funded research.[2] Two years later, Takeda, which had by then acquired Shire, adopted the Shire policy and became the first top 10 pharmaceutical company to mandate open access for all globally funded research.

Global mandates of the kind adopted by Shire, later Takeda, do not happen overnight, especially in large pharmaceutical companies. Not only are there many minds to align, but there is also legacy thinking to contend with, a legacy that is permeated with conservatism in the pharmaceutical sector. Yet Takeda overcame these challenges because an open access mandate made strategic sense (Box 1).[3]

The company had already made a commitment to clinical trial transparency; a similar commitment to open access publishing was a continuation of the same principle. It also made sense from a business performance and reputational perspective, as well as from the perspective of building trust in Takeda-funded research. Importantly, it also embodied the company's commitment to patient centricity.

Other pharmaceutical companies, including Ipsen, have since followed suit. A wide range of non-profit and publicly funded research organisations have also voiced their support of open access publishing for medical research, including the Wellcome Trust, the Bill & Melinda Gates Foundation, National Institutes of Health, and the European Commission. If there were any lingering doubts that open access is the direction of travel for medical publishing, these were likely eradicated by the right-to-read proclamation that came from the White House this summer. On August 25, 2022, President Joe Biden's administration announced that, beginning in 2026, federal agencies must make papers that describe taxpayer-funded work freely available to the public as soon as the final peer-reviewed manuscript is published.[4]

Access alone does not ensure accessibility

Removing the paywall barrier between interested stakeholders and medical evidence is a positive step towards improving access to timely novel evidence, but open access is not synonymous with accessibility.

Borrowing a description coined by the highly reputed medical writer Michael O'Donnell, Symposium Chair Richard Smith questioned whether scientific writing is still written in the style of "decorated municipal gothic".[5] O'Donnell's elaboration of this description is that academic writing is frequently "long, tortuous, opaque, uninteresting, and possess[es] a 'built-in quality of unreadability'". Its main purpose, he argued, is to ennoble the writer rather than to inform the reader.[5] Yet writer ennoblement is not a solid foundation for reader trust. Step forward the plain language (or plain English) campaigners.

As medicine strives to move away from paternalistic approaches to patient care and didactic prescribing, the patient voice can and should be factored into clinical decision-making. If that voice is to be intelligent and informed, patients need to have access to intelligible information. Quoting David Schley (Deputy Director of Sense about Science), Adeline Rosenberg (Senior Medical Writer at Oxford PharmaGenesis and Open Pharma) explained that "we have a better chance of having a well-informed public making critical decisions if they've got access to plain language summaries".[6]

As an advocate for plain language summaries, Adeline also shared the view of Brian Southwell, an expert in communication and human behaviour, who explained that during the pandemic, "Part of the reason people turn[ed] to convenient, accessible, and ubiquitous information sources [was] because they [were] convenient, accessible, and ubiquitous … We need to worry less about stamping out misinformation and worry more about providing people with a steady diet of information that serves their needs".[7]

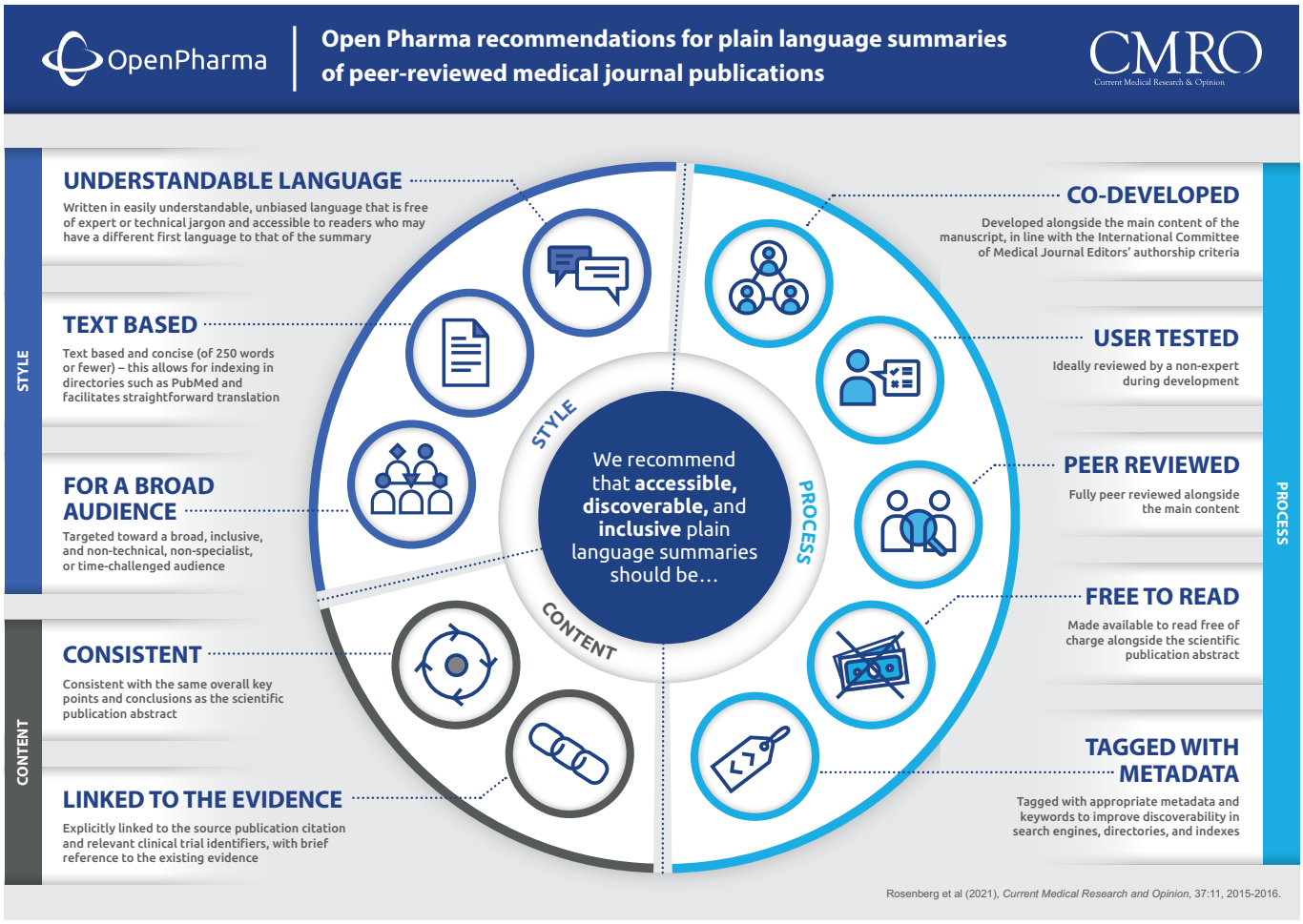

Figure 1. Open Pharma recommendations for plain language summaries of peer-reviewed medical journal publications

Reproduced from: Rosenberg A, Baróniková S, Feighery L, et al. Open Pharma recommendations for plain language summaries of peer-reviewed medical journal publications. Curr Med Res Opin. 2021;37(11):2015–16. Update in: Curr Med Res Opin. 2022;38(6):881–2. With permission from the authors and the publisher Informa UK Limited, trading as Taylor & Francis.[8]

Motivated by this principle, the Open Pharma collaboration brought together representatives from the medical communications and pharmaceutical sectors at an expert round-table event and focused public consultation in 2021 to discuss and develop key recommendations for plain language summaries. The resultant set of recommendations is not a formal guideline for plain language summary development; rather, it is a proposed foundational standard.[8] Appropriately, the recommendations were published open access (subject to an unrestricted Creative Commons Attribution licence) and included a plain language summary, an explanatory author video, and an accessible infographic summary of the 10 core tenets (Figure 1).[8]

Ipsen were represented among the stakeholders involved in the development of the Open Pharma plain language summary recommendations. In another clear break from pharmaceutical company legacy thinking, Ipsen subsequently announced a commitment (starting in July 2022) to publish a plain language summary for all company-sponsored journal publications that include data from human studies.[9] These publications will, as a minimum, be accompanied by a 250-word plain language summary. The mandate does not preclude other formats; it is a minimal commitment to ensuring content accessibility. Box 2 summarises some of the steps involved thus far in Ipsen's implementation of their mandate.[10]

> We have a better chance of having a well-informed public making critical decisions if they've got access to plain language summaries.

Journal publishers are also increasingly supportive of accessible summary article enhancements. Caroline Halford (Development Director for Medical Education at Springer Healthcare) spoke of the myriad accessible summary formats that are now on offer. These range from simple text summaries that can be indexed alongside the article abstract on PubMed to full-text plain language publications, more visual (infographic) formats, or multimedia (video, animation, and/or podcast) formats.

The inciting spark for the rapid growth in accessible summary formats may have come from author and reader demand, but it has been fuelled by regulatory mandates[11] and further accelerated by publisher analytics. According to Springer Healthcare data, accessible summaries not only improve article comprehension, but also bring new readers, increase article downloads, and facilitate content sharing (especially

Box 2. Implementing a plain language summary mandate within a pharmaceutical company

- Define a mandate with clear minimum requirements.
- Communicate the mandate internally and externally.
- Develop a plain language summary lexicon to facilitate consistent language use.
- Develop a plain language summary review process.
  - Develop briefing materials and checklists.
  - Identify non-expert reviewers and/or patient reviewers (the gold standard).
- Build plain language summary development into publication SOPs.

Abbreviation: SOP, standard operating procedure

Adapted from: Thomas S. Ipsen commitment on plain language summaries. *Who can we trust? Open science and pharma research.* Presented at the Open Pharma Satellite Symposium at the Association of Learned and Professional Society Publishers Annual Conference and Awards, Manchester, UK, September 14, 2022 (oral presentation).[10]

graphical summaries). Further, from a medical education perspective, Halford explained that accessible summaries can help to equip healthcare professionals with the correct language to discuss research data with their patients.

Embracing open access publishing and shunning decorated municipal gothic writing are clear and admirable breaks with legacy thinking, across the pharmaceutical, publishing, and medical communication sectors. Trust is built gradually, and it is easily threatened. No single endeavour will win public trust in research, but an important and achievable step towards improving public confidence in research is reporting it in a way that is both accessible and easier to understand.

Acknowledgements

The author thanks Joana Osório for critically reviewing a version of this article.

Disclosures and conflicts of interest

The author is an employee of Oxford PharmaGenesis, which co-funds and facilitates the Open Pharma collaboration. She has no other conflicts of interest to disclose.

References

1. Calman B. Exposed: The plague of fake medical trials putting lives in danger as experts reveal a FIFTH of studies published each year could contain invented or plagiarised results. The Mail on Sunday. 2021 [cited 2022 Oct 10]. Available from: https://www.dailymail.co.uk/health/article-10147503/Exposed-plague-fake-medical-trials-putting-lives-danger.html.
2. Takeda Pharmaceutical Company Ltd. Shire Press Release. Shire continues to uphold high standards of ethics and transparency with adoption of open access policy for publication of Shire-supported research. 2018 [cited 2022 Oct 10]. Available from: https://www.takeda.com/newsroom/shire-news-releases/2018/xajhds/.
3. Rains C. Open access commitment for Takeda-supported research. Who can we trust? Open science and pharma research. The Open Pharma Satellite Symposium at the Association of Learned and Professional Society Publishers Annual Conference and Awards. Manchester, UK. Oral presentation, September 14, 2022.
4. Brainard J, Kaiser J. White House requires immediate public access to all U.S.-funded research papers by 2025. 2022 [cited 2022 Oct 10]. Available from: https://www.science.org/content/article/white-house-requires-immediate-public-access-all-u-s—funded-research-papers-2025.
5. Conference report: Doctors in society. Br Med J. 1980 Jul 26;281(6235):282-3. PMID: 20793148; PMCID. PMC1713801. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1713801/
6. Edgell C, Rosenberg A. Putting plain language summaries into perspective. Curr Med Res Opin. 2022;38(6):871–4. doi:10.1080/03007995.2022.2058812
7. Southwell B. How to combat health misinformation: insights from a communication and human behaviour expert. The Publication Plan. 2021 [cited 2022 Oct 10]. Available from: https://thepublicationplan.com/2021/08/10/how-to-combat-health-misinformation-insights-from-a-communication-and-human-behaviour-expert/.
8. Rosenberg A, Baróniková S, Feighery L, et al. Open Pharma recommendations for plain language summaries of peer-reviewed medical journal publications. Curr Med Res Opin. 2021;37(11):2015–6. doi:10.1080/03007995.2021.1971185
9. Gattrell W. Ipsen press release. Our pledge: summaries in plain language for all journal publications. 2022 [cited 2022 Oct 10]. Available from: https://www.ipsen.com/our-pledge-summaries-in-plain-language-for-all-journal-publications/.
10. Thomas S. Ipsen commitment on plain language summaries. Who can we trust? Open science and pharma research. Open Pharma Satellite Symposium at the Association of Learned and Professional Society Publishers Annual Conference and Awards, Manchester, UK. Oral presentation, September 14, 2022.
11. US FDA. Plain writing: It's the law! 2022 [cited 2022 Oct 10]. Available from: https://www.fda.gov/about-fda/plain-writing-its-law.

Author information

Alison Chisholm is a communications team leader at Oxford PharmaGenesis. She has worked in healthcare communications for almost 20 years, within medical research, publishing, and medcomms. She has Masters degrees in Public Health, Journalism, and Creative Writing.