

Plain-Language Summaries (PLSs): Evolving Tools to Make Medical Research Accessible and Understandable for People Affected by Cancer

Joel Nowak¹, Len Sierra², Elliot Abramowitz³, Ian Blue⁴

¹CEO and Co-Founder, Cancer ABCs, Inc., Brooklyn, USA; ²Answer Cancer Foundation d/b/a AnCan; UsTOO International, Danbury, CT, USA; ³Prostate Cancer Foundation Volunteer Patient Advocate, Long Beach, NY, USA; ⁴Patient and patient advocate, Murray Bridge, SA, Australia

INTRODUCTION

To participate in informed shared decision-making about their health care, patients and their caregivers need to understand what a cancer diagnosis means and how different treatment options may affect them.



- As patient advocates, we have been collaborating with Bayer HealthCare and Future Medicine to develop peer-reviewed, patient-oriented, and patient-authored publications, including *Future Oncology's* first "PLS of Publications"¹
- The concepts that we discuss in this poster are based on our experiences communicating with cancer patients and their caregivers but can be applied to other therapy areas and audiences, including community oncologists, family practitioners, nurses, caregivers, and the general public

WHAT IS A PLS?

PLSs are new and credible educational resources for sharing research findings with patients and others involved in treatment decision-making.

- A PLS conveys complex information in a simple, easy-to-understand fashion for use by a general audience without a medical or research background and for nonspecialist healthcare providers and researchers²
- In the pharmaceutical and healthcare industries, PLSs are typically categorized into two types: clinical trial PLSs and publications PLSs—in this poster, we focus on Publications PLSs^{2,3}



Mandated by regulatory authorities in the US, Europe, and other countries and regions
Summarizes the specific details and results of a clinical trial in a templated format



Summarizes the results of a scientific study in a citable peer-reviewed publication
Potentially covers a broader range of information than a clinical trial PLS

WHAT MAKES A GOOD PUBLICATIONS PLS?

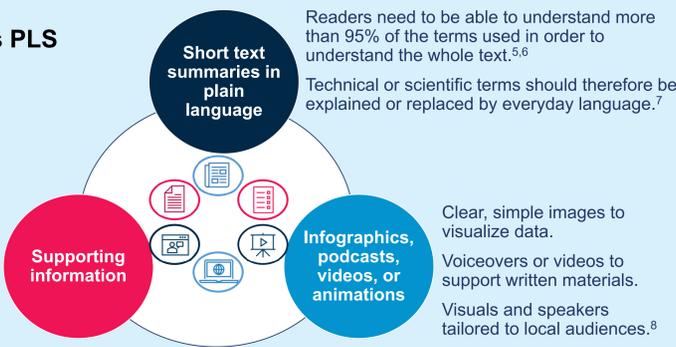
What Does a Good Publications PLS Look Like?

Different readers respond to different formats. In our experience, lay and nonspecialist audiences will appreciate information being presented in a variety of ways.

- Some readers may prefer information in print format, rather than web-based resources⁴

Good Publications PLS Formats

A glossary, providing short, clear explanations of the technical terms that lay or nonspecialist readers need to understand.
The original scientific article reporting the study results.
Relevant websites or patient organizations.



What Does a Good Publications PLS Say?

A good publications PLS must contain information that is relevant to the reader.

- Content should be selected according to what the reader needs to know. Too many detailed analyses can be overwhelming for patients and caregivers
- Readers need to be able to understand how the study findings might apply to them:
 - Does the study reflect their situation?
 - Who took part?
 - Where was the study done?
 - What are the benefits and risks of treatment?
 - What is the demonstrated survival advantage?
 - Can the treatment reduce symptoms?
 - What side effects are likely?
 - What impact will treatment have on their quality of life?
 - Will the treatment or its side effects prevent them from receiving other treatments or taking part in other studies?
- Incorporating patient perspectives (e.g., from trial participants) into the publications PLS helps readers to understand the relevance and context of the study results

“Patients who took part in the study had prostate cancer that had spread to other parts of the body, such as their bones or their liver”

“On average, patients treated with the study drug lived for xx months longer than patients being treated with the comparator drug”

“Among patients treated with the study drug, 6 in every 10 patients had a sore arm after the injection, and 1 in 10 patients felt dizzy”

Accessible and Easy to Find

- To best serve their purpose, publications PLSs and supporting content should be freely available and easy for lay readers and nonspecialists to find. Various methods of disseminating PLSs should be considered:
 - Ideally, readers should be able to find all of the information that they need in one place
 - We encourage publishers, the pharmaceutical industry, healthcare professionals, and patient advocacy groups to work together to create an accessible online repository or library of PLSs of medical research and other patient educational materials
 - The PLS needs to be recognized as a reputable source of information for patients, caregivers, and nonspecialist healthcare professionals (HCPs) about the disease, its treatment, and the potential impact on patients' lives
 - This resource should be peer reviewed, regularly updated, and searchable



Simple and Easy to Understand

- Simple statements and illustrations are easy for readers to understand
 - People looking for information about their disease and its treatment are likely to be under many emotional pressures
 - They may be unable to critically evaluate complex information^{9,10}
 - They may believe that they understand the information but, if it is too complex, they may in fact miss or misunderstand a key point
- Short sentences making clear points will reduce the risk of misinterpretation
 - The wording must not be vague or ambiguous
 - Rather than omitting technical details, PLSs should include explanations to help educate the reader
- Infographics reduce the cognitive load on lay readers¹¹

WHO BENEFITS FROM A PLS?

Patients and caregivers²

- Study participants appreciate finding out the study results^{3,12}
- Patients view PLSs as tools to facilitate knowledge sharing and accessibility¹³
- Patients feel empowered by the information conveyed by PLSs¹³

Healthcare professionals¹

- PLSs are also likely to be used by time-limited or nonspecialist HCPs and researchers, because they provide a quick summary of the most important or relevant findings from large volumes of literature

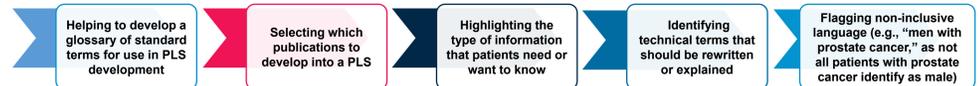
Study sponsors and investigators¹

- PLSs can enhance trust, transparency, and partnership between study sponsors, researchers, HCPs, and study participants
- PLSs can reduce the risk of information being misinterpreted or misrepresented, for example in the news or on social media

WHO SHOULD BE INVOLVED IN DEVELOPING A PLS?

PLS development should involve patients, patient advocates, caregivers, nonspecialist HCPs, and researchers as authors or reviewers to validate content readability for a lay audience.

- Lay authors or reviewers can help by reviewing and advising on content accuracy and readability:



- Lay authors or reviewers should represent the diverse range of patients and have different educational, socio-economic, and ethnic backgrounds
- In addition to contributing to or advising on the written or visual content, patients and patient advocates can take part in videos and podcasts to discuss their perspectives and what the information means to them

CONCLUSIONS

- PLSs summarize medical research findings for patients and anyone else involved in treatment decisions
- Different formats and methods of dissemination should be used to reach the widest audience
- Formats likely to be of most value to the diverse range of stakeholders involved in patient care and treatment decision-making are:
 - Short text summaries, supported by:
 - Glossaries
 - Links to additional information
 - Infographics, podcasts, videos, and animation
- Content should be developed with the involvement of patients or patient advocates as authors or reviewers
- PLSs need to be easy for lay readers and nonspecialists to find and should be available in print and digital formats

GLOSSARY

- Clinical trial:** A study to determine whether a treatment is safe and effective before it can be made available to all patients. Results from clinical trials are reported as medians or totals for a group of patients with a specific type of disease. This information can help people consider what treatment effects may be likely in individual patients with a similar diagnosis
- Medical journal:** A type of magazine that contains articles written by scientists and medical professionals, usually reporting the results of their research or providing expert opinions on how the research findings might improve the care of patients
- Original article:** The first publication of new research results in a peer-reviewed journal
- Peer review:** A process in which other experts critically assess a draft publication before it is published to ensure that the analysis and conclusions are robust
- Publication:** Sharing information publicly; in the case of medical publications, the information is typically research results or expert opinions on how best to treat patients. Publications can be in the form of short summaries, posters, or presentations at scientific congresses or articles in peer-reviewed journals

FIND OUT MORE

- Explaining science to nonspecialists**
 - Cochrane. Our Evidence. <https://www.cochrane.org/evidence>
 - MedlinePlus. Easy-to-Read Health Information. https://medlineplus.gov/all_easytoread.html
 - National Institutes of Health. Science, Health, and Public Trust. <https://www.nih.gov/about-nih/what-we-do/science-health-public-trust>
- Guidance on plain language writing**
 - National Institutes of Health. Clear Communication. <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication>
 - National Institutes of Health. Plain Language. <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language>
 - Plain Language Action and Information Network. Plain Language Guidelines. <https://www.plainlanguage.gov/guidelines/>
 - Plain Language Association International (PLAIN). Plain Language. <https://plainlanguageinternational.org/plain-language/what-is-plain-language/>
 - Rosenberg A, Baróniková S, Feighery L, et al. Open Pharma recommendations for plain language summaries of peer-reviewed medical journal publications. *Curr Res Med Opin* 2021;37:2015–2016. <https://www.tandfonline.com/doi/full/10.1080/03007995.2021.1971185>

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