Equity in access to information on newly approved drugs: How readily available are plain language summaries?

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This poster summarises key points from the accompanying oral presentation and follows plain language best practices. Although written in a plain language summary (PLS) style, we recognise that the ISMPP audience comprises publication professionals and have adapted the content accordingly.

Most (80%) key clinical study articles for new medicines approved between 2021-2024 do not have easy-to-understand summaries

See definitions of terms used in this poster here:

See oral presentation here:

Setting the scene

Patients, families, and their **caregivers** seek to play a bigger role in the decisions about their healthcare.

But **peer-reviewed scientific articles** sharing research findings often use complicated language. This creates a barrier to communicating research to patients and the public.

Easy-to-understand summaries of these articles, called **plain language summaries (PLS'),** help increase the reach and understanding of the research. They can also help patients make decisions together with their doctors.[1]

PLS are a recent development (starting around 2010), but since 2022 guidelines (**Good Publication Practice 2022**) have officially recommended PLS be made for clinical study articles be easy to find and free for everyone to read.[2]

What's the difference between a PLS and a PLSP?

A **plain language summary (PLS)** is a short summary of a scientific article, written in simple language so that anyone can understand the main points. **It's included as part of the main article.**

A standalone peer-reviewed PLS publication (PLSP): is a summary of the scientific article, written in simple language and **published in a different journal**.

What did we want to find out?

We wanted to find out how common it was for easy-to-understand PLS or PSLP to be made for peer-reviewed scientific articles of important clinical studies that have helped get new medicines approved between 2021 and 2024.

How did we do it?

Searched the FDA website to find new medicines approved between 2021-2024

Searched PubMed to find peer-reviewed scientific articles – about key ('pivotal') clinical studies that helped get these new medicines approved

Searched each article to see if it included a PLS – We looked within the main body of the article itself and in any extra online files (known as supplemental material)

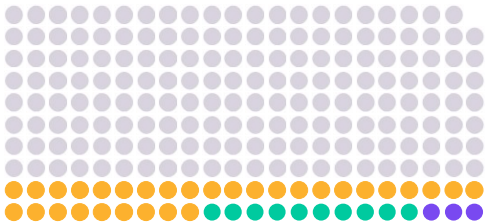
Searched PubMed and Google for standalone PLSP – We used the medicine name or ClinicalTrials.gov registration number, along with the phrase "plain language summary"

What did we find?

- Between 2021 and 2024, there were 192 new medicines to treat health conditions approved by the FDA.
- We found 219 peer-reviewed scientific articles for the key clinical studies that were the basis for FDA approval

How many scientific articles had PLS or PLSP and could people read these PLS or PLSP for free?

Total = 219 scientific articles



13 (6%) had a PLS that was linked on the journal website

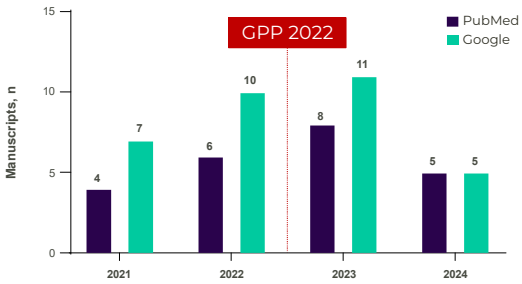
10 PLS were freely available (Open Access)

3 PLS were not freely accessible

31 (14%) had standalone PLSP

All 31 PLSP were freely available (Open Access)

PLSPs for scientific articles from 2021-2024



How long did it take for PLSPs to be published after a medicine was approved?

- The average (median) time from medicine approval to publication of a PLSP was 9 months.
- But there was a wide range: from 7 months before the medicine was approved to 35 months (nearly 3 years) after.
- The wait time for medicines approved between 2021 and 2024 and the publication of a PLSP was often 1 to 3 years.

Which journals most commonly included a PLS in key scientific articles?

- While most (65%) of the 219 key scientific articles were published in top-tier journals, the 13 articles that included a PLS were more often found in less widely known journals with a lower average impact factor (20.0).

What do these results mean?

- Most (80%) key clinical study articles for medicines approved between 2021-2024 did not include an easy-to-understand summary — either as a PLS or standalone PLSP
  - **What this means for patients:** It's often difficult to find clear, trustworthy information about new medicines.
- Articles with a PLS were usually freely available. All PLSPs were free to access.
  - **What this means for patients:** This matters because paywalls can be a major barrier for patients trying to find trusted information.
- Most key articles were published in top-tier journals, but those with a PLS were more often in lower-tier journals.
  - **What this means for patients:** Important research may be less accessible to patients if PLS aren't included in high-profile journals.
- When a PLSP was available, it often appeared well after the medicine was approved.
  - **What this means for patients:** it can take years to access clear, trustworthy information about the research behind new medicines — making it harder for patients to make informed decisions.
- Impact of the 2022 GPP guidance on PLS/PLSP development is still unclear, although trends may become more apparent over time. Further research is warranted
  - **What this means for the industry**: a push towards gain consensus, improved clarity, and commitment to publication integrity is critical

What Comes Next? A Call to Action

Insights: do we understand what is preventing key stakeholders (pharma, publishers, and agencies) from publishing PLS/PLSP?

Diversity: are we considering the diversity of the audience and readers as we develop these summaries?

Accessibility: How can we improve the opportunity to read these summaries?

Consistency: How can we work together to harmonize these summaries?

Availability: How can we break down barriers to those who need to access these summaries?

Innovation: How can we use technology to improve development and access?

References

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Disclosures

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