Where *are* biomedical research plain-language summaries (PLS)?

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OBJECTIVE

How best to embed and value the patient voice in all stages of drug development is a topic currently being debated across disciplines

Plain-language summaries (PLS) are increasingly being heralded as a tool to improve communication of research to patients, other lay audiences (eg carers), non-specialist healthcare professionals and time-poor specialists, but this will only be achieved if PLS are intuitively located and accessible

We investigated how this PLS 'findability' is being handled by biomedical journals

METHODS

As the large majority of biomedical journals do not request PLS,[1] it was challenging to determine a systematic and robust sampling methodology. After exploring different options, journals were ultimately identified based on the eLIFE list of journals/ organisations that produce PLS.[2] Note that, while this provided a cross-section, it is possible that some journals were not captured (eg Adis journals publish key points in non-technical language, but were not included in the eLIFE list)

> On 12 July 2018, the eLIFE list included 23 biomedical journals
>
> Some publishers had multiple journals in the list that handled PLS in a largely similar way
>
> PLOS, n=6   National Institute for Health Research, n=5
> American Chemical Society, n=3   Elsevier, n=2
>
> To avoid potentially skewing the results, the journal with the highest impact factor was selected from each publisher
>
> This left a sample of 10 journals from distinct publishers, plus *eLIFE* itself
>
> Internet research explored how these journals generate and share PLS
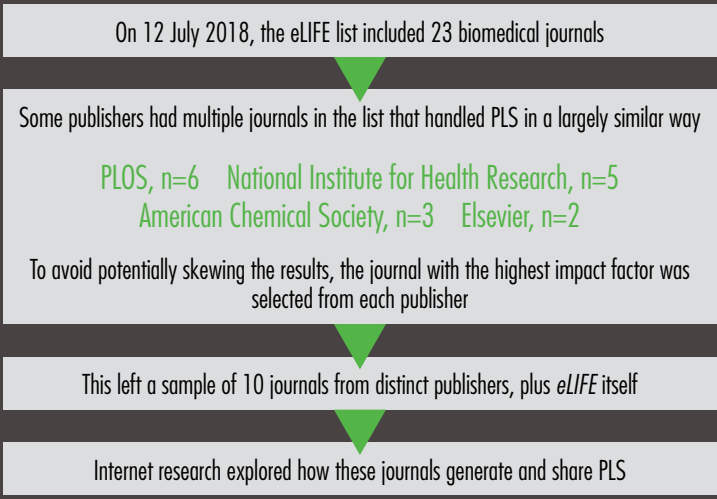
ABSTRACT

Objective

How best to embed and value the patient voice in all stages of drug development is a topic currently being debated across disciplines. Plain-language summaries (PLS) are increasingly being heralded as a tool to improve communication of research to lay audiences and time-poor healthcare professionals, but this will only be achieved if PLS are intuitively located and accessible. We investigated how this 'findability' is being handled by biomedical journals.

Research design and methods

As the large majority of biomedical journals do not request PLS[1] it was challenging to determine a systematic and robust sampling methodology. The eLIFE list of journals/organisations that produce PLS[2] was consulted on 12 July 2018; where multiple journals were from the same publisher, the journal with the highest impact factor was selected. Internet research explored how these journals share PLS.

Results

Our methodology identified a sample of 10 journals from distinct publishers, plus *eLIFE* itself. Nine different terms were used to describe PLS. Authors wrote them in 9/11 cases; seven journals required PLS on article submission (one at revision; three on acceptance). The location/sharing mechanism varied: within articles, alongside articles (separate tab/link), and/or on separate platforms (eg social media, dedicated website). Where PLS were published with articles, they were still freely accessible, even when the main article sat behind a paywall. PLS were only included with conventional abstracts on PubMed for 2/11 journals.

Conclusions

Among a subset of the few biomedical journals producing PLS, there is wide variation in terminology, location, sharing mechanisms and PubMed visibility. We advocate a more consistent approach to ensure that PLS have appropriate prominence and can be found by their intended audiences.

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PLS for this poster

Simple summaries of medical research should be easier for patients to find

It seems hard to find the short, easy-to-read 'plain-language summaries' (PLS) of medical research. PLS are meant to be helpful to patients, but they will not help if patients can't find them.

We found that a range of names is used for PLS, which could make them hard to find with an internet search. Some names do not make it clear to patients that the PLS are for them to use. Also, PLS are not available for all research, and when they are available they are shared in different ways, like on journal websites or via social media.

Overall, we were pleased to find that PLS are free to read, but ways of naming and sharing should be standardised so that PLS are easier for patients to find.

RESULTS

Journal, Publisher	Terminology: What are PLS called?	Requirements: Are PLS developed by authors?	When are PLS required?	Are PLS required for all research articles?	Location: Where are PLS housed?	Accessibility: Are PLS freely accessible?	PubMed visibility: Are PLS noted on PubMed?
ACS Infectious Diseases, American Chemical Society	Lay summaries		Submission	✓	Not publicly available	Not publicly available	X
Annals of the Rheumatic Diseases, BMJ Publishing	Lay summaries/patient summaries	X[a]	Acceptance	X[b]	Archived on separate website	✓	X
Autism, Sage Publishing	Lay abstracts	✓	Acceptance	✓	Supplemental material and via social media (Facebook)	✓	X
Autism Research, Wiley	Lay summaries (formerly 'lay abstracts' and 'scientific summaries for families with ASD')	✓	Submission	✓	Within article and archived in separate section of journal website	✓	✓
European Urology, Elsevier	Patient summaries	✓	Submission	✓	Within article and archived in separate section of journal website	✓	✓
Health Technology Assessment, National Institute for Health Research Journals Library	Plain English summaries	✓	Submission	✓	Within article and via separate navigation from article page	✓	X
PLOS Medicine, PLOS	Author summaries	✓	Revision	✓	Within article and via separate navigation from article page	✓	X
Proceedings of the National Academy of Sciences, National Academy of Sciences	Significance statements	✓	Submission	✓	Within article and in separate section of issue table of contents	✓	X
Cochrane Database of Systematic Reviews, Cochrane Library/Wiley	Plain language summaries	✓[c]	Submission	✓	Within article and via separate navigation from article page	✓	X
FACETS, Canadian Science Publishing	Plain language summaries	✓	Submission	X[d]	Social media (Medium)	✓	X
eLIFE, eLIFE Sciences Publications	eLIFE digests	X[e]	Acceptance	X[c]	Within article and via social media (Medium)	✓	X

[a]PLS developed by the editors based on author responses to questions; [b]PLS may be developed by the authors themselves, or by the editorial team; [c]PLS only developed for articles selected by the editors; [d]authors are encouraged to provide PLS - PLS only available for articles where they are volunteered by the authors; coloured fonts correspond to pie charts below
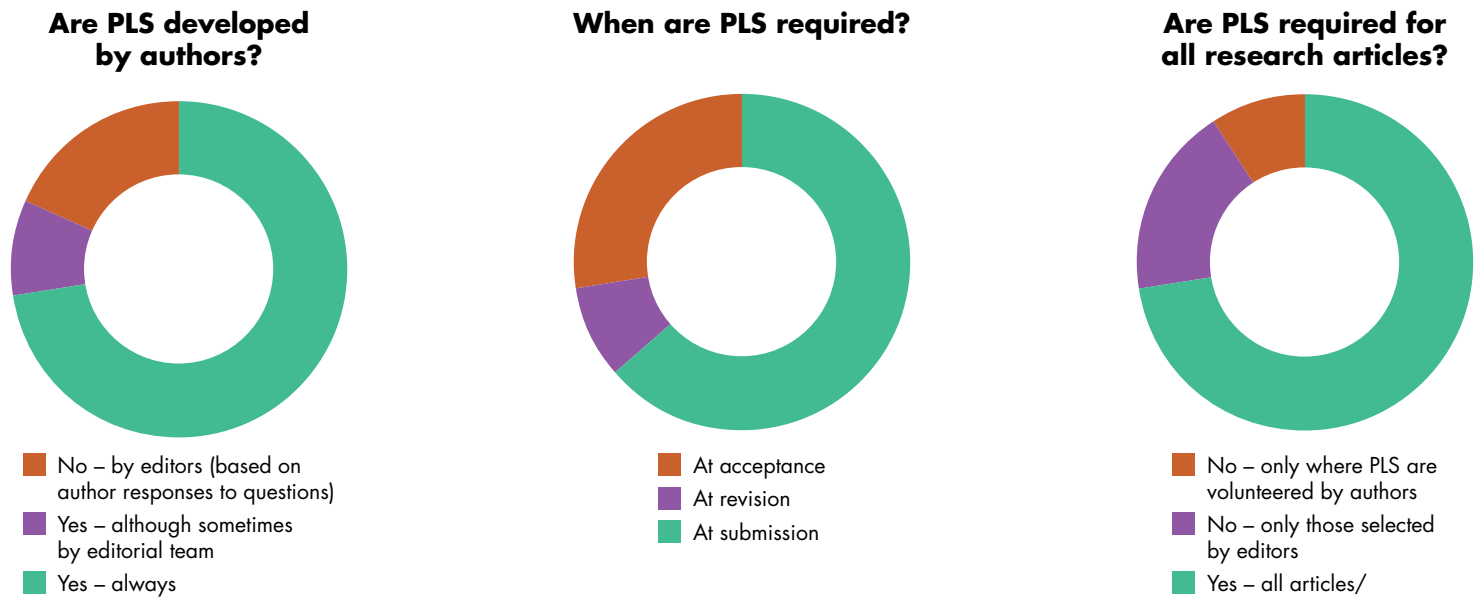
Terminology

9 different terms
for PLS were found

Annals of the Rheumatic Diseases refers to both 'patient summaries' and 'lay summaries'; *Autism Research* has changed from 'lay abstracts' to 'scientific summaries for families with ASD', and more recently to 'lay summaries'
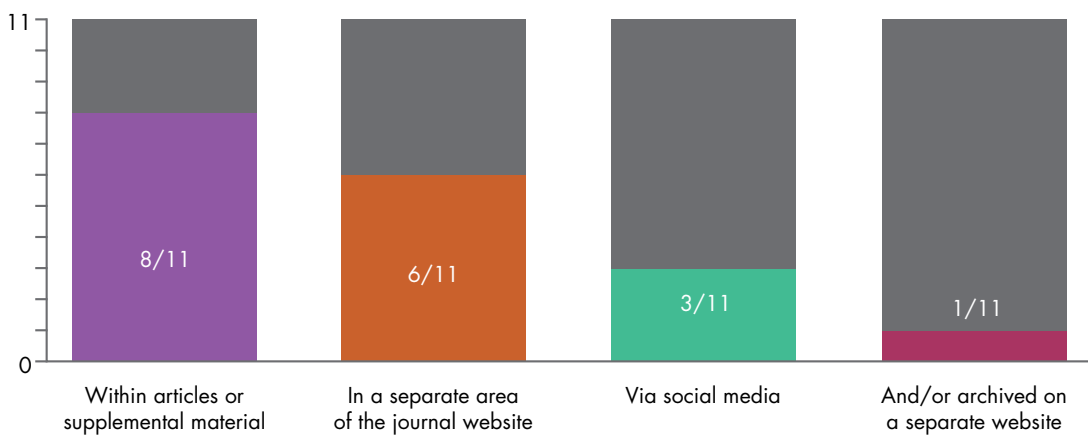
Some terms do not intuitively make the intended audience clear (eg 'significance statement', 'author summary'), meaning lay readers may overlook them

Requirements

Are PLS developed by authors?

- No – by editors (based on author responses to questions)
- Yes – although sometimes by editorial team
- Yes – always

When are PLS required?

- At acceptance
- At revision
- At submission

Are PLS required for all research articles?

- No – only where PLS are volunteered by authors
- No – only those selected by editors
- Yes – all articles/all research articles

Location

The sharing mechanism/location of PLS varies:

- Within articles or supplemental material: 8/11
- In a separate area of the journal website: 6/11
- Via social media: 3/11
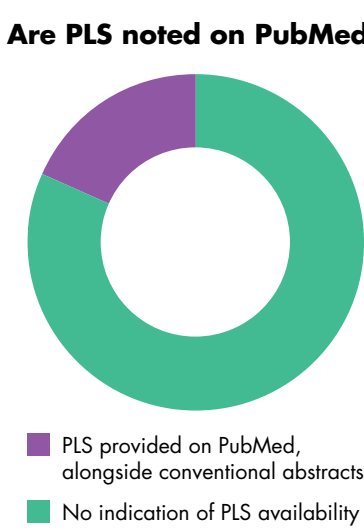- And/or archived on a separate website: 1/11

Accessibility

All PLS are freely accessible, with the exception of *ACS Infectious Diseases* – e-mail follow-up determined that these PLS are only for the press, and are not publicly available

PLS published within articles are freely accessible, even when the main article sits behind a paywall

PubMed visibility

Are PLS noted on PubMed?

- PLS provided on PubMed, alongside conventional abstracts
- No indication of PLS availability

CONCLUSIONS

- Among a subset of the few biomedical journals that produce PLS, all but one made PLS freely accessible to the public, and none housed PLS behind a paywall
- However, there was wide variation in terminology, requirements, location and PubMed visibility, meaning that there is no obvious or consistent approach for people to find PLS, a fact that was also evident from the challenges we had in identifying a robust sampling methodology for this research
  - Some journals housed PLS in a separate archive – we envisage that, once located, such archives could be accessed regularly to keep abreast of current research
- Other approaches may be less visible to lay audiences – for example, we speculate that summaries such as the 'significance statements' published in the body of articles in *Proceedings of the National Academy of Sciences* may currently be used more by healthcare professionals than by patients

RECOMMENDATIONS

In order to standardise approaches and optimise reach to the intended audiences we recommend that

- All journals refer to PLS by this consistent descriptor *(plain-language summaries, PLS)*, particularly to make them easier to search for using standard internet search engines
  - PLS are signposted with a recognisable icon to help readers locate them easily
  - PLS are developed by article authors, although support may be sought (eg from journal editorial staff and/or patient organisations) to ensure PLS are written appropriately for the intended audience

- PLS are required by journals at submission so they can be reviewed alongside all other elements of an article
- Journals publish PLS for all articles
- Like conventional manuscript abstracts, PLS are published outside any article paywall and displayed prominently with the article
- PLS are published alongside the associated article abstract on PubMed to give them equal prominence and extend their utility to other non-specialist readers
- Mechanisms to search across all PLS (by keyword or topic) are implemented via search engines or online databases – each PLS to include a hyperlink to the original full article location to avoid PLS being categorised as duplicate publications

- Journal databases flag journals that publish PLS so authors can make informed choices about target journal selection when wanting to reach lay audiences
- Good Publication Practice (GPP), and other publications initiatives, provide guidance to support consistent and appropriate approaches to PLS

References
1. Narayaran R, et al. Patient lay summaries in biomedical journals: what and how much is currently available? Presentation at the *14th Annual Meeting of ISMPP* (2018), National Harbor, MD, USA.
2. Plain-language Summaries: journals and other organizations that produce plain-language summaries. *INSIDE ELIFE* Mar 15, 2017. Available at: https://elifesciences.org/inside-elife/5ebd9a3f/plain-language-summaries-journals-and-other-organizations-that-produce-plain-language-summaries. Accessed 12 July 2018.

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