

Do patient-authored publications vary by format and metrics?

– Review of literature

Uma Kundu^a, Vatsal Shah^b and Madhavi Patil^a

^aSIRO Clinpharm Pvt. Ltd, Mumbai, India; ^bSIRO Clinpharm USA LLC, Princeton, NJ, USA



Introduction and Objective

- Patients are increasingly adopting technological advancements and becoming more informed about healthcare.
- Both regulators and pharmaceutical industry have recognized the importance of patient perspective in development of therapies. Certain medical journals also encourage the involvement of patients and empower them as authors, editors, peer reviewers and readers.
- Good Publication Practice (GPP) 2022 emphasizes the importance of patient inclusivity in publications planning and authoring.¹
- Cognizant of this all-round greater awareness of patient involvement in medical research, we aimed to explore the inclusion of patients as authors in publications along with the format and outreach.

Methods

- A PubMed search using “Patient author [Affiliation]” search term was conducted to identify peer-reviewed, indexed, patient-authored publications.
- Freely available full-text publications were analyzed for characteristic features such as number of patient-authors involved, therapeutic area, research/publication type, format, content, and style of data/information representation. We further assessed the impact of patient-authored publications using Altmetric Attention score.

Conclusions

- A surge in patient-authored publications was observed in the past few years and a greater proportion were open access.
- Patients are empowered by involvement as authors in medical publications; sections dedicated to 'patient perspective/experience' resonate with the patient's voice.
- Our findings indicate that patient-authored articles have more impact via social media platforms, which can serve as useful tools for improving patient engagement in research.

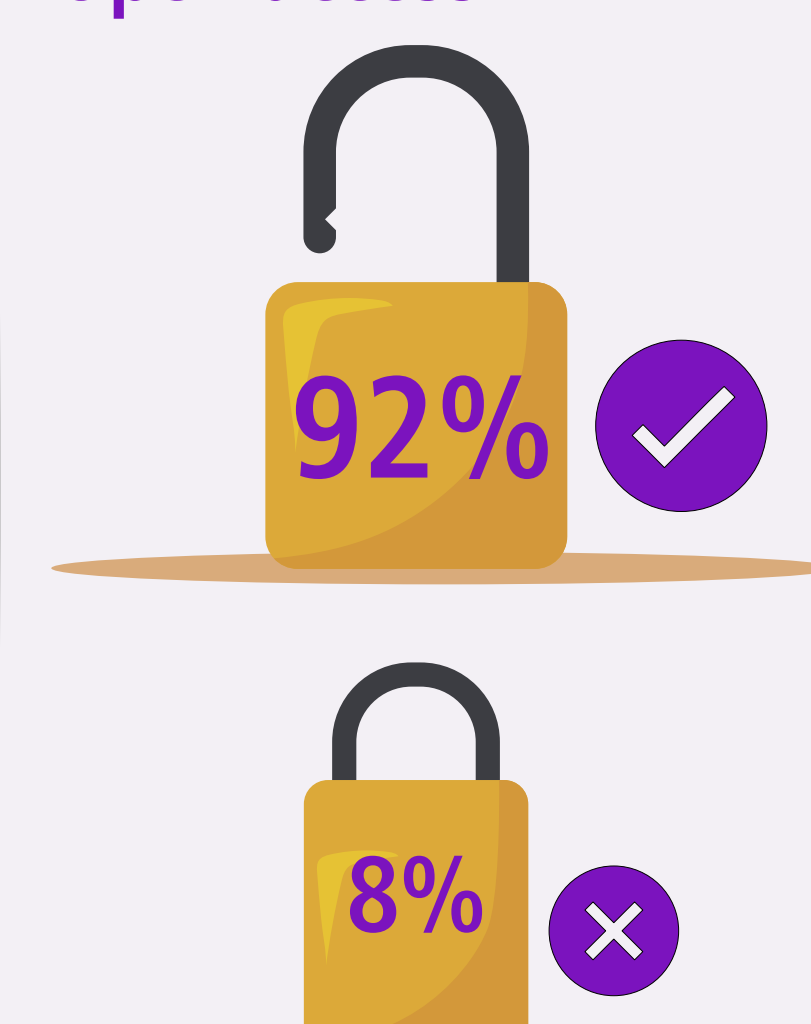
Results

As of January 17, 2024, the PubMed search yielded 83 patient-authored publications, of which 18 were standalone plain language summaries (PLS) of publications.

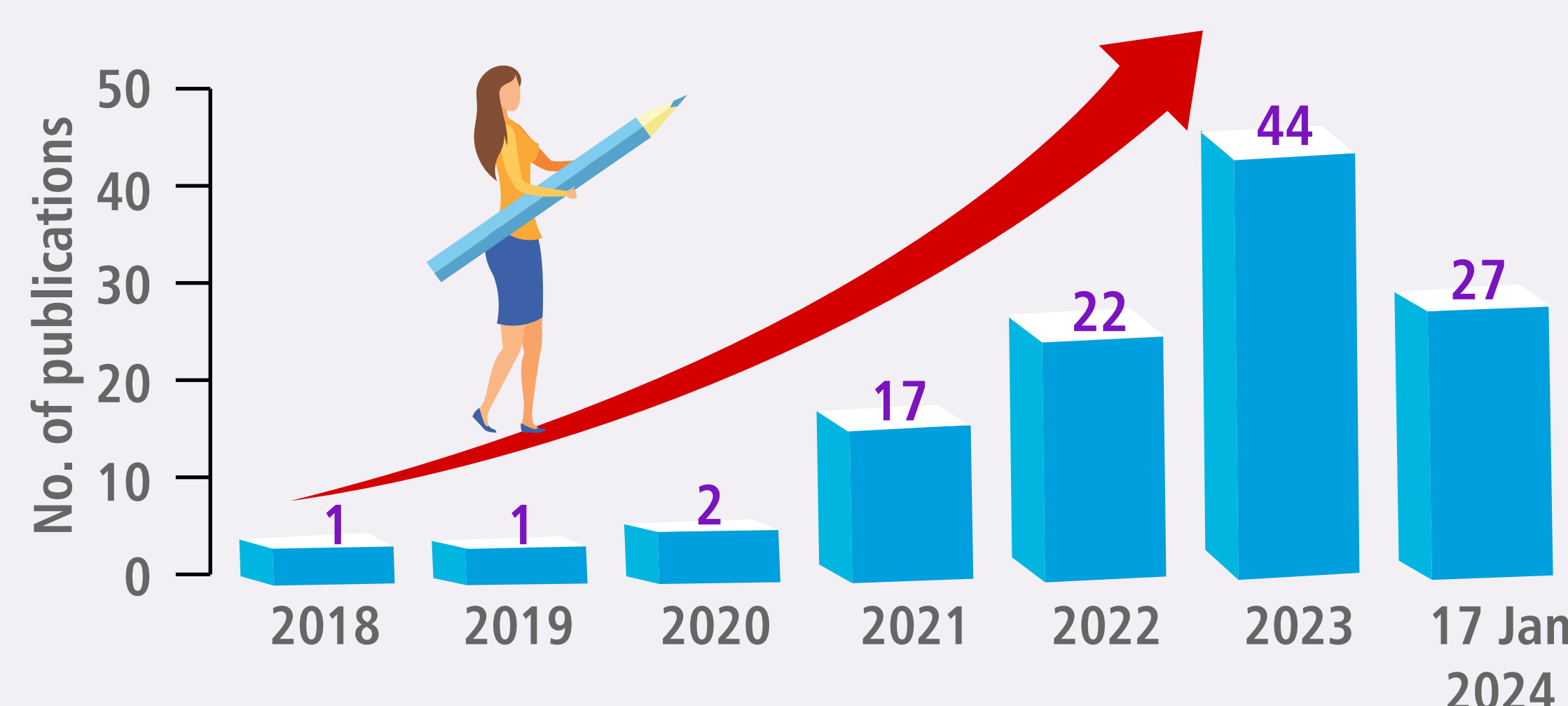
Type of Publication



Open access

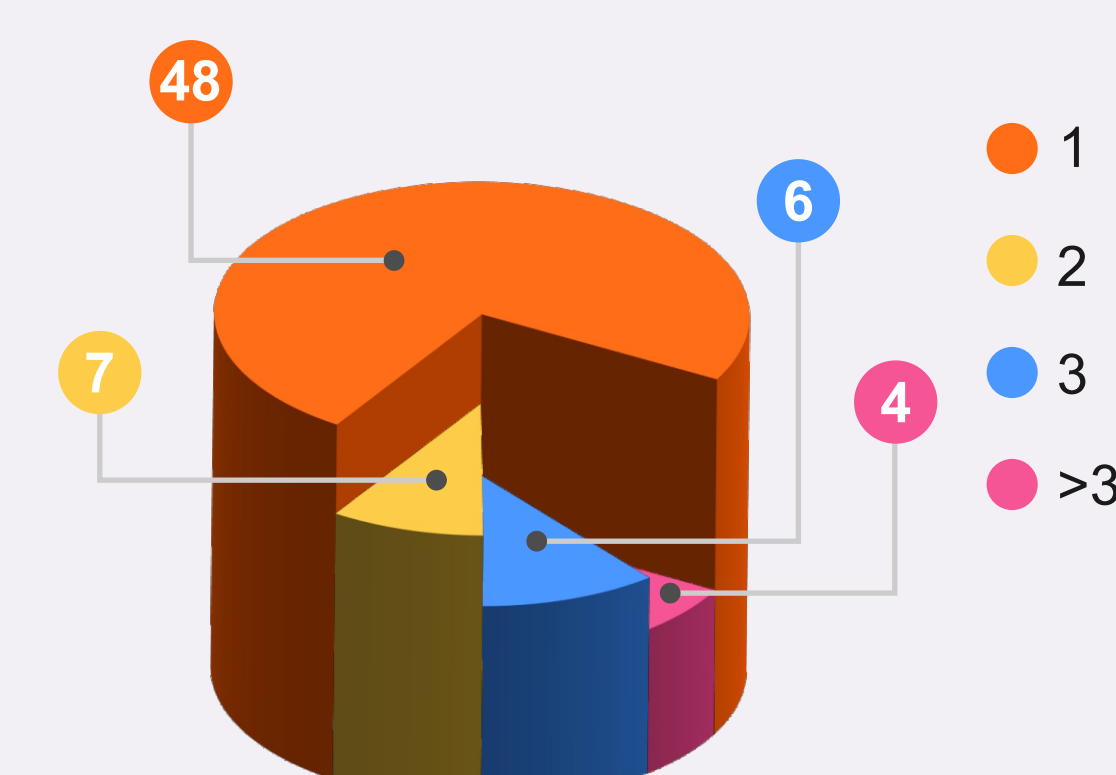


Steep increase in patient-authored publications since 2022.



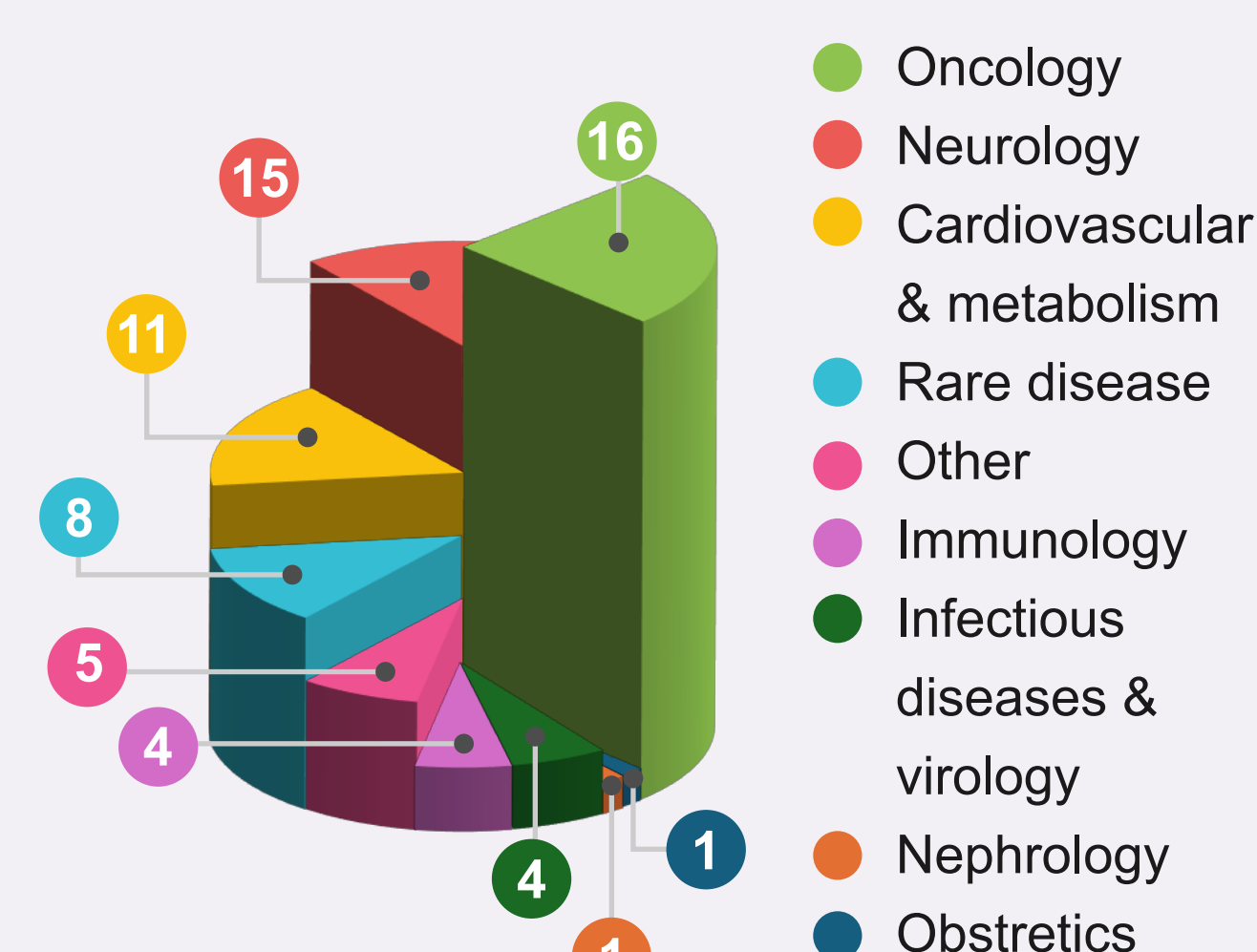
65 articles further analyzed:

Most articles (n=48/65, 74%) had a single patient-author.

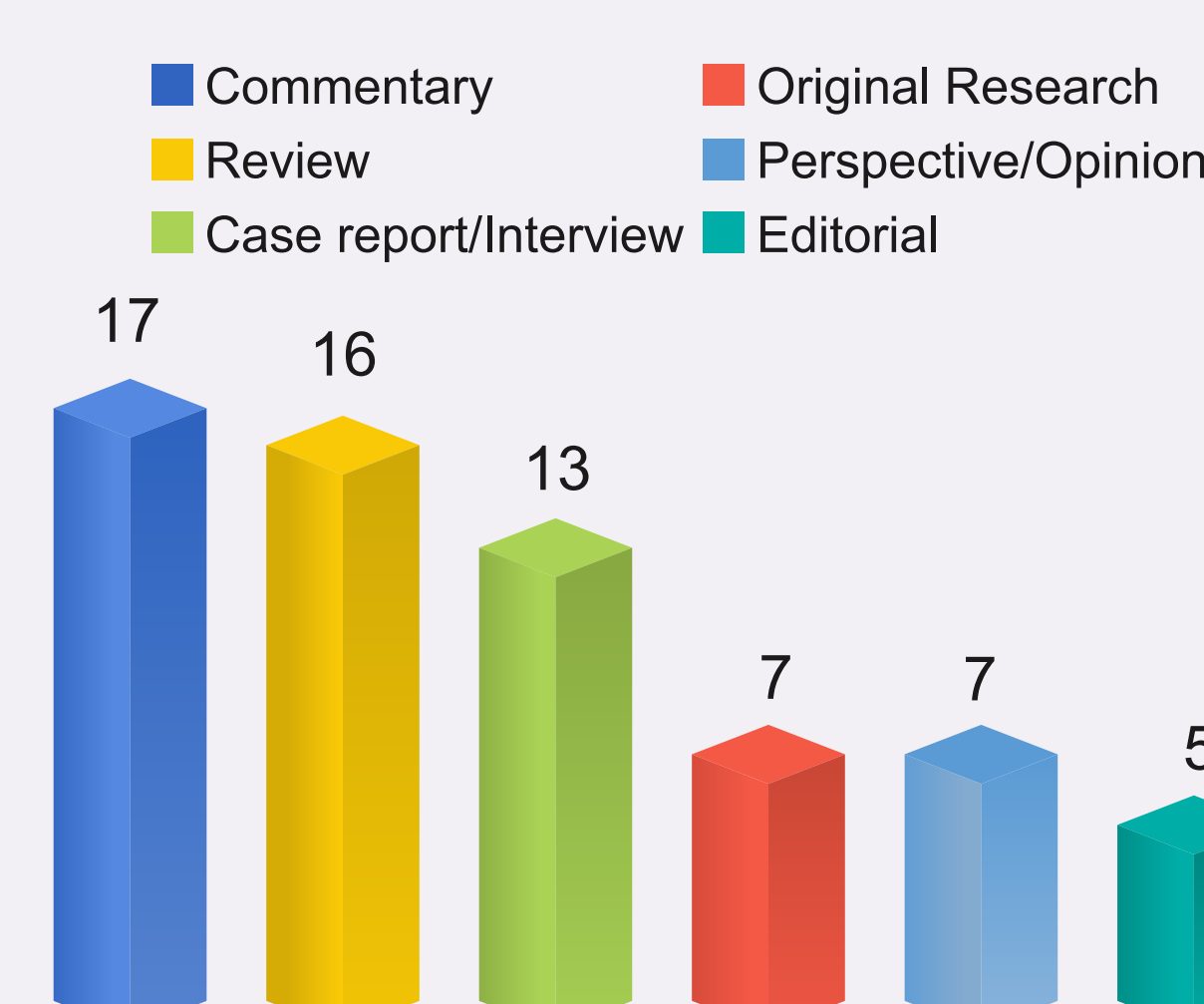


Top 3 therapeutic areas with patient authors:

- Oncology (25%)
- Neurology (23%)
- Cardiovascular & metabolism (17%)



Patient authors were predominantly involved in commentary (26%) and review articles (25%).



Certain features in patient authored publications:

- Verbatim quotes
- Patient narratives
- Publication enhancers (including digital features)

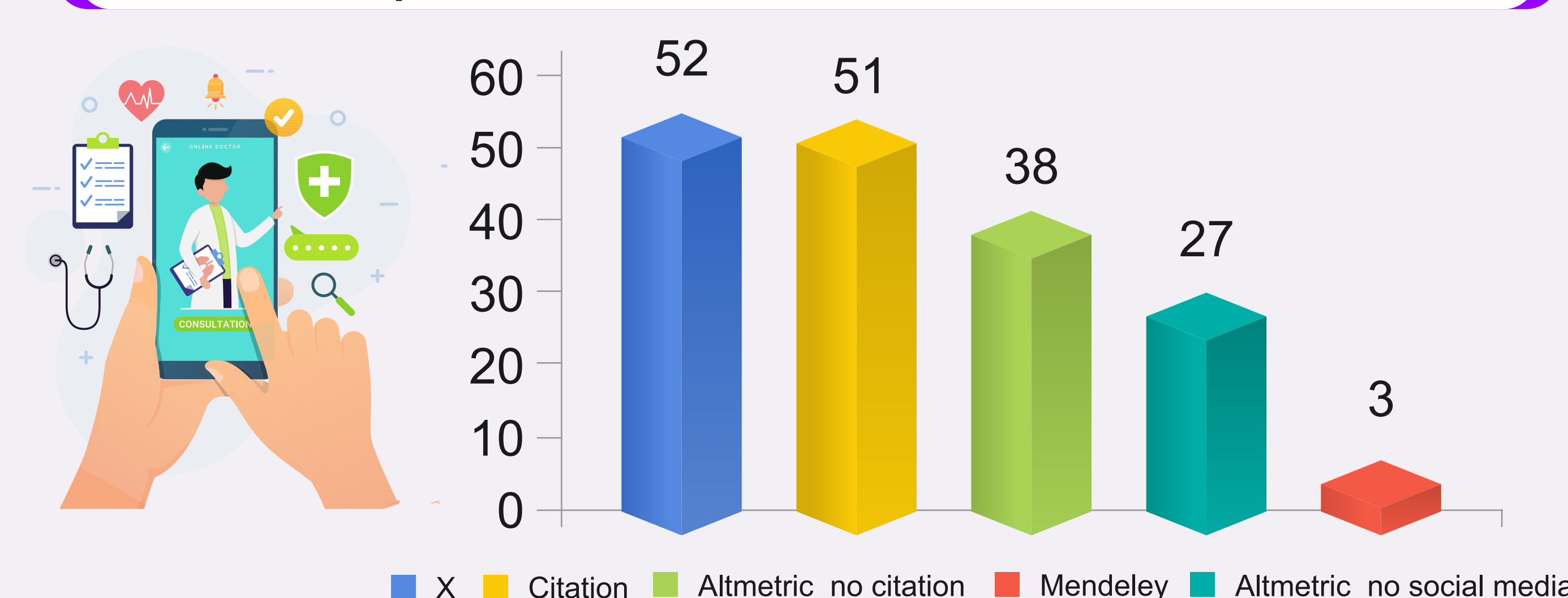
23 articles included patient perspective/live experience as 'verbatim quotes'

10 articles had features like patient narratives

8 articles had digital enhancements (audio/video slides/podcast)

15 Publication enhancers: (PLS: 15, and/or, graphical abstracts: 3)

Patient-authored publications garnered more attention via social media platforms than citations/cross reference



References

1. DeTora LM, Toroser D, Sykes A, et al. Good Publication Practice (GPP) Guidelines for Company-Sponsored Biomedical Research: 2022 Update. Ann Intern Med. 2022;175(9):1298-1304.

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