

Social media use by patient organisations in discovery and dissemination of medical research: pilot survey



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Objective

- To explore how patient organisations use social media to discover and share medical research with patient communities, including which aspects of research publications they consider valuable for increasing the capacity to share.

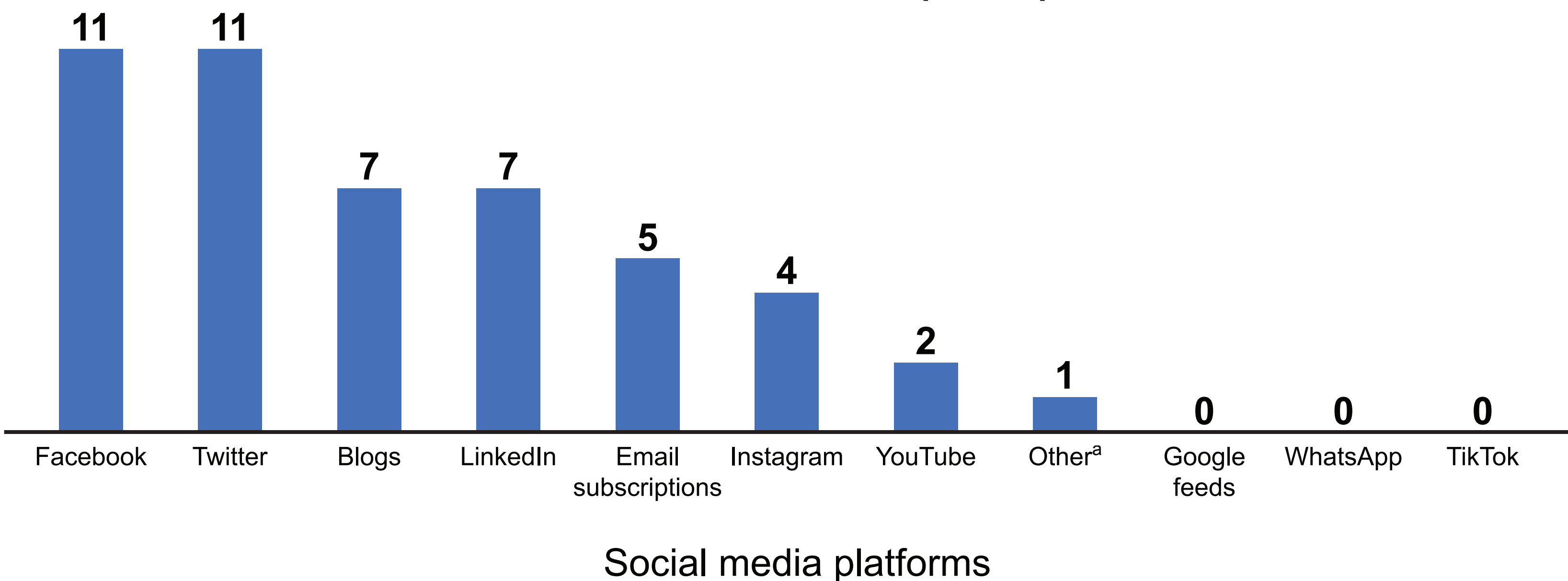
Methods

- We co-developed a 16-question Microsoft Forms survey – including multiple-choice and open-response questions – with patient representatives.
- A link to the pilot survey was distributed by the Patient Information Forum to patient group member organisations via a newsletter and social media posts (13–29 September 2022).

Results

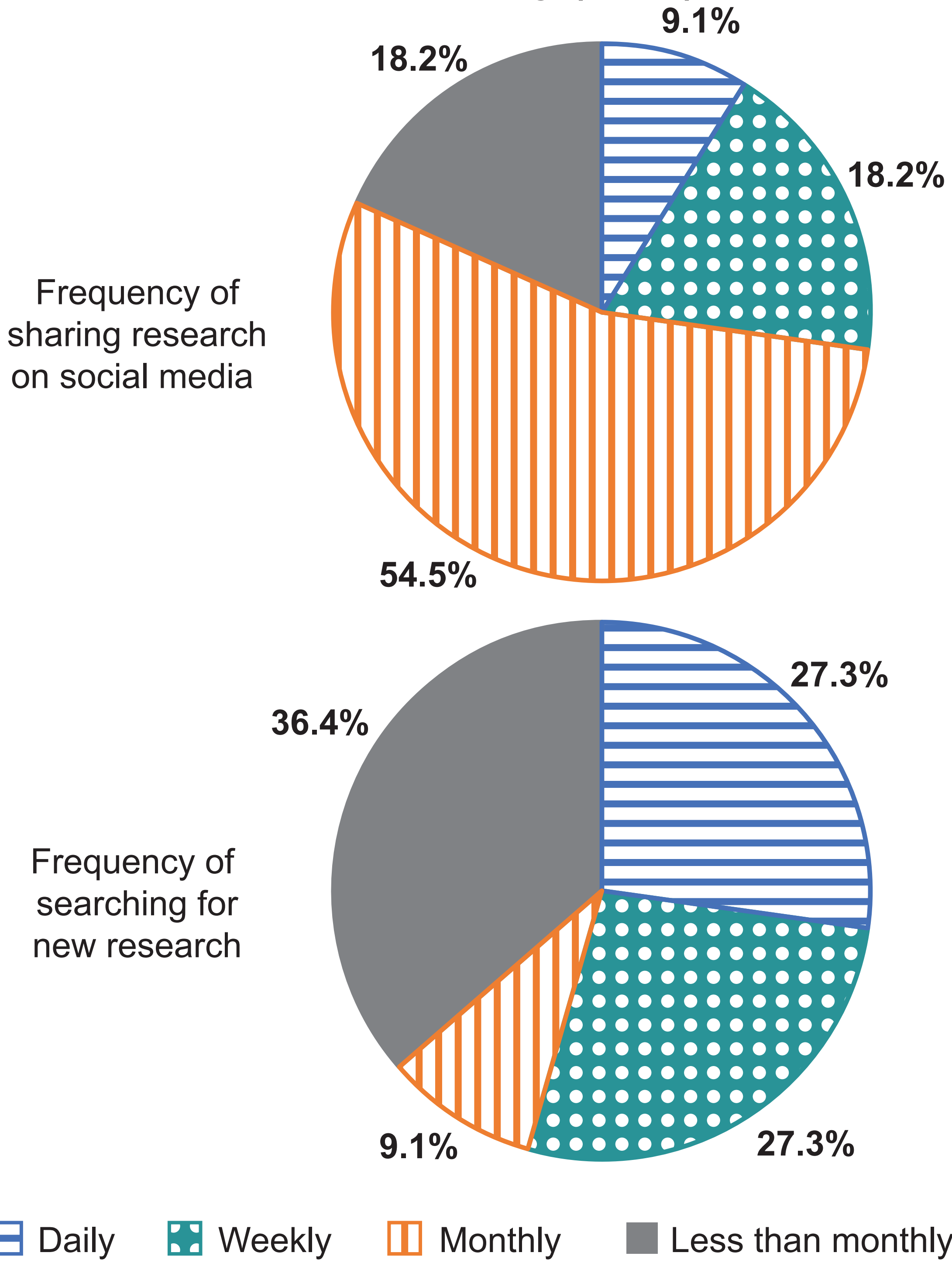
- Overall, 11 unique organisations in the UK and Ireland responded to the survey, representing a range of organisation sizes across the following therapeutic areas: dermatology, gastroenterology, infectious diseases, oncology, rare diseases and rheumatology.
- All respondents regularly shared research with their members and community, and 10 (90.9%) used social media to do so, either as the preferred medium or to supplement other communications; 1 (9.1%) used social media to share research infrequently.

Facebook and Twitter (now X) were the most frequently used platforms to share research (N=11)

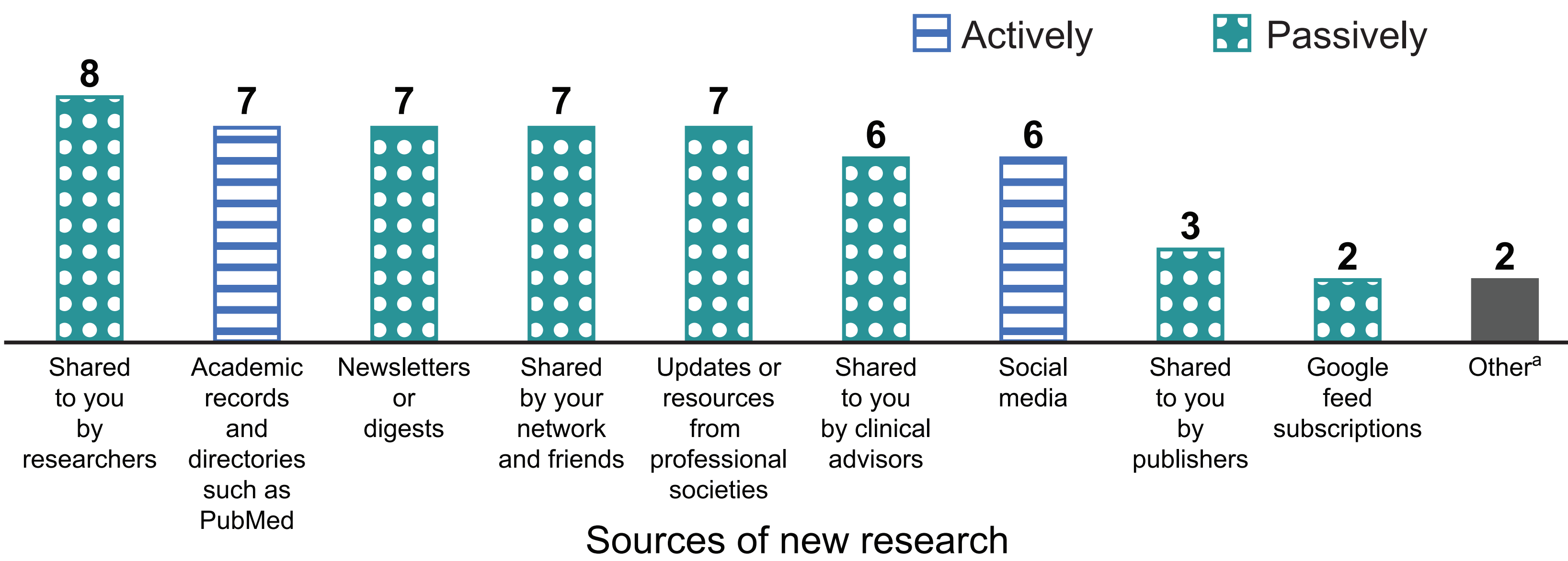


^aOther^a included an organisation-specific user platform

Most organisations shared research on social media and searched for new research at least monthly (N=11)

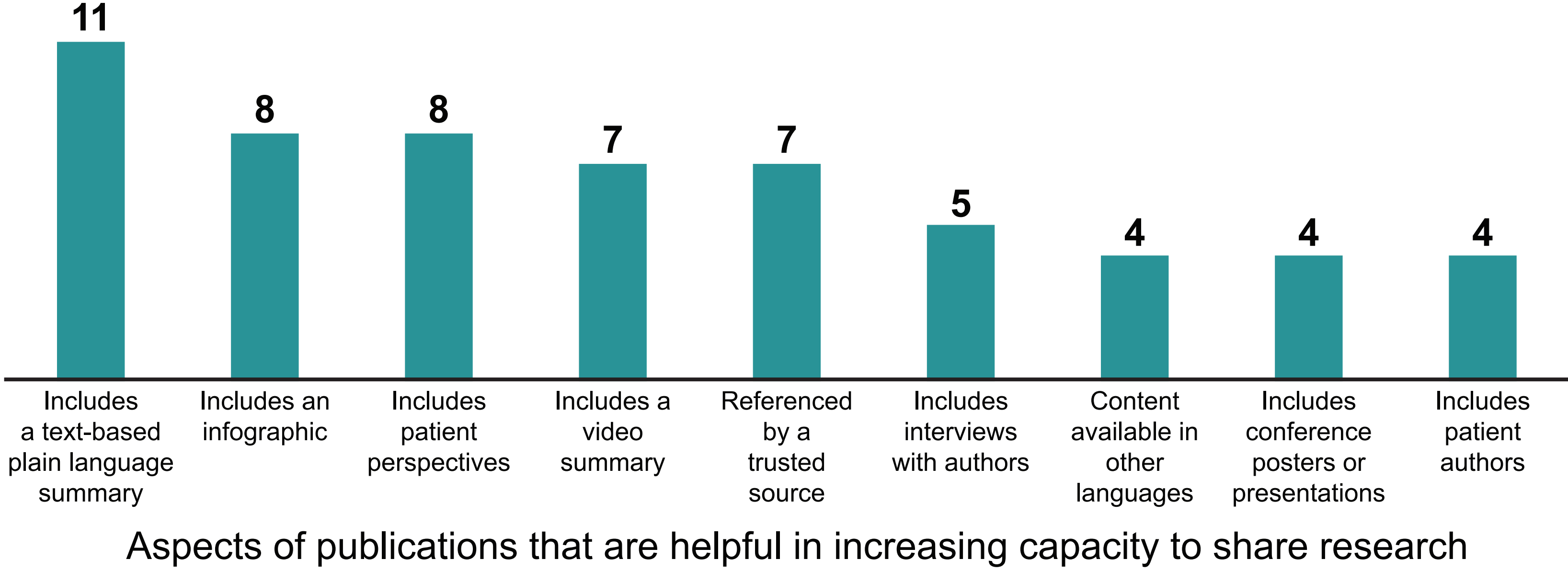


Organisations found new research actively through discovery and passively through recommendations from connections (N=11)



^aOther^a included new research found through responses to media stories and through requests for support from clinical and academic researchers

Text-based plain language summaries were the most popular aspect of research publications, followed by infographics and patient perspectives (N=11)



Conclusions

- While social media is an important method for patient organisations to discover and share research, active discovery of research through publication records and passive recommendations from connections are also notable routes.
- Plain language summaries and digital features remain valuable elements of research publications for patient organisations.
- Limitations of this pilot include the small sample size and limited geographical scope; the survey remains open for additional responses, to expand geographic coverage for further analysis.



Access the survey here

Disclosures and acknowledgements

This research was performed as part of the ISMPP Social Media and Web-based Metrics Working Group and the ISMPP Advocacy & Outreach Committee. AR, AS, CH, CJP, DT and RJC are employees of their affiliations; this work represents the opinions of the authors and not of their employers. JW is a co-owner and an employee of Becaris Publishing. TB is the owner of The Spark Global, a consultancy firm that works with multiple stakeholders within the life sciences and healthcare industry. Since the submission of the abstract for this poster, CH has taken on the role of Business Development Director for Springer Healthcare IME. The authors thank Durhane Wong-Rieger of the Canadian Organization for Rare Disorders, Anna Geraci of ISMPP, and Sophie Randall and Sheena Campbell of the Patient Information Forum for their assistance in developing and distributing the survey, as well as the respondents of the survey for sharing their time and insights.