“Voice of patient” in publications: Trends and perspectives

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BACKGROUND

- Integrating the “**voice of the patient**” (VoP)[1,2] in medical publications marks a shift in healthcare communication and research towards patient-centric care[3,4]
- Patient narratives provide holistic insights beyond clinical endpoints, supporting informed decisions and better treatments
- Key gaps regarding VoP authorships include lack of awareness, unclear authorship guidelines, and challenges in searching for and retrieving VoP-related literature

The objectives of our study were to

① Analyze trends in patient-authored publications over time using a literature search on **PubMed**

② Assess the awareness among and gather insights from medical communication professionals regarding the involvement of patients as authors in medical publications using a survey on **SurveyMonkey®**

CONCLUSIONS AND FUTURE DIRECTIONS

- VoP involvement in published literature has evolved over time, with a **notable increase observed in the past 5 years**. Largely, the western countries appear to have identified the value of VoP and integrated it into their publication ecosystems. However, broader global adoption is needed
- Across the publications analyzed, VoP affiliation terminologies used were inconsistent, **suggesting the need for standardized guidance**
- Awareness of GRIPP2 guidelines remains low among medical communication professionals, calling for greater education to ensure **ethical and authentic patient involvement**

RESEARCH DESIGN AND METHODS

1 **Literature evaluation on PubMed**

Search string

No filter

(Patient author[Affiliation]) OR (Advocacy group[Affiliation]) OR (Patient advocate[Affiliation]) OR (Patient partner[Affiliation]) OR (Caregiver[Affiliation]) OR (Patient representative[Affiliation]) OR (Carer[Affiliation]) OR (Patient group[Affiliation]) OR (Patient panel[Affiliation]) OR (Patient relative[Affiliation])

Articles retrieved and screened for VoP[a] affiliation

Articles with no VoP[a] affiliation excluded

Articles with VoP[a] affiliation evaluated for trends and representation

2 **Survey on SurveyMonkey®** (targeted at medical publication professionals)

Online survey
14-question survey in multiple-choice format, with a free-text response option to some questions

Survey invitations posted
(Oct 29, 2024-Nov 30, 2024)
- ISMPP, LinkedIn, and Connect forums
- Cactus Life Sciences employees
- Authors’ professional networks

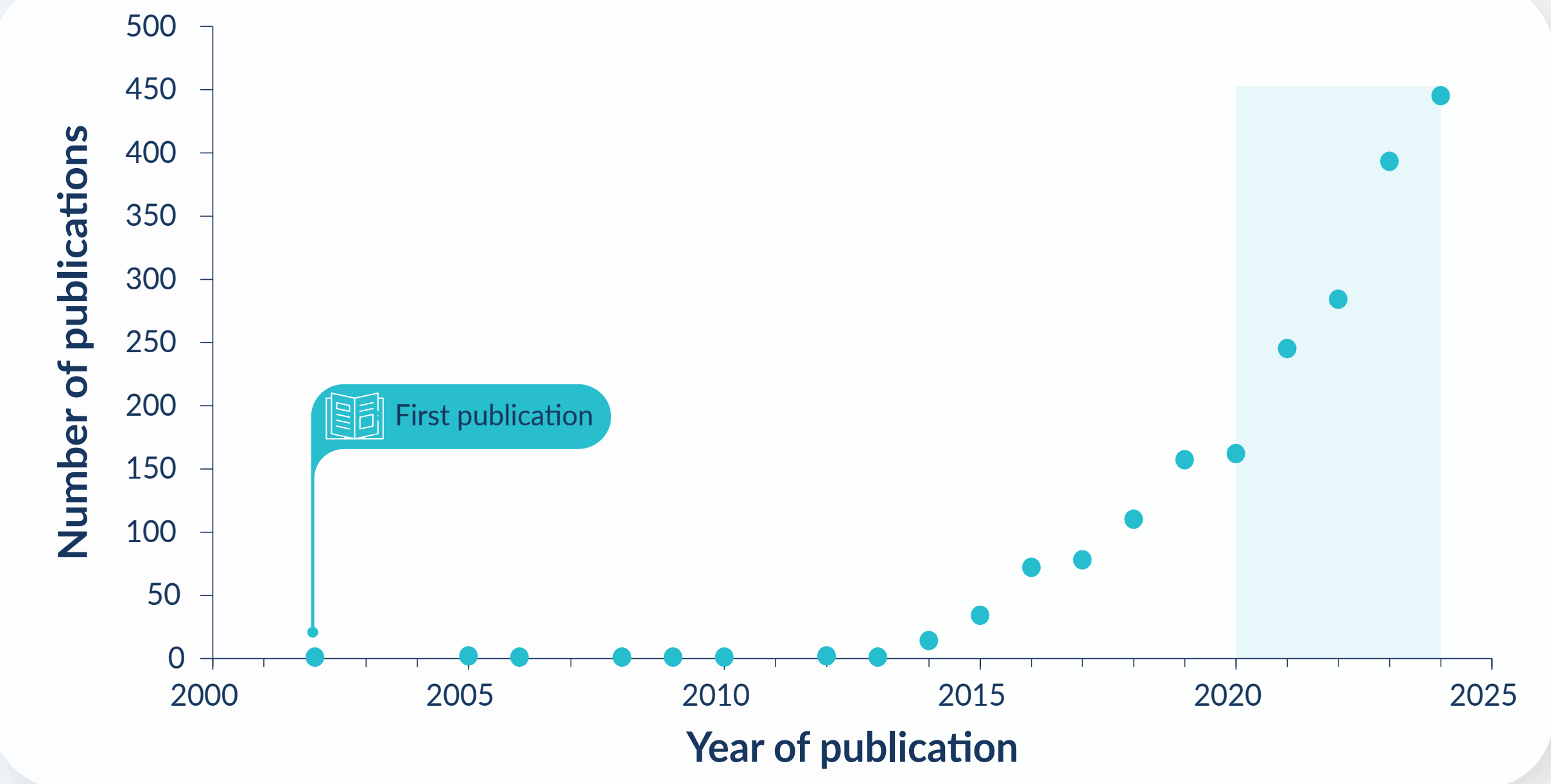
Survey responses analyzed

[a] VoP affiliation was manually confirmed by reviewing the affiliations listed in the publications.
VoP, voice of the patient

RESULTS

① *Literature evaluation (N=2004)*

- Of the 2456 publications retrieved from PubMed by using the search string, manual screening identified 2004 publications with a VoP affiliation
- The distribution of VoP-authored publications showed an increasing trend over the years, with a steep increase between 2015 and 2024
- More than half (76.3% [1529/2004]) of the VoP-authored publications were published between 2020 and 2024



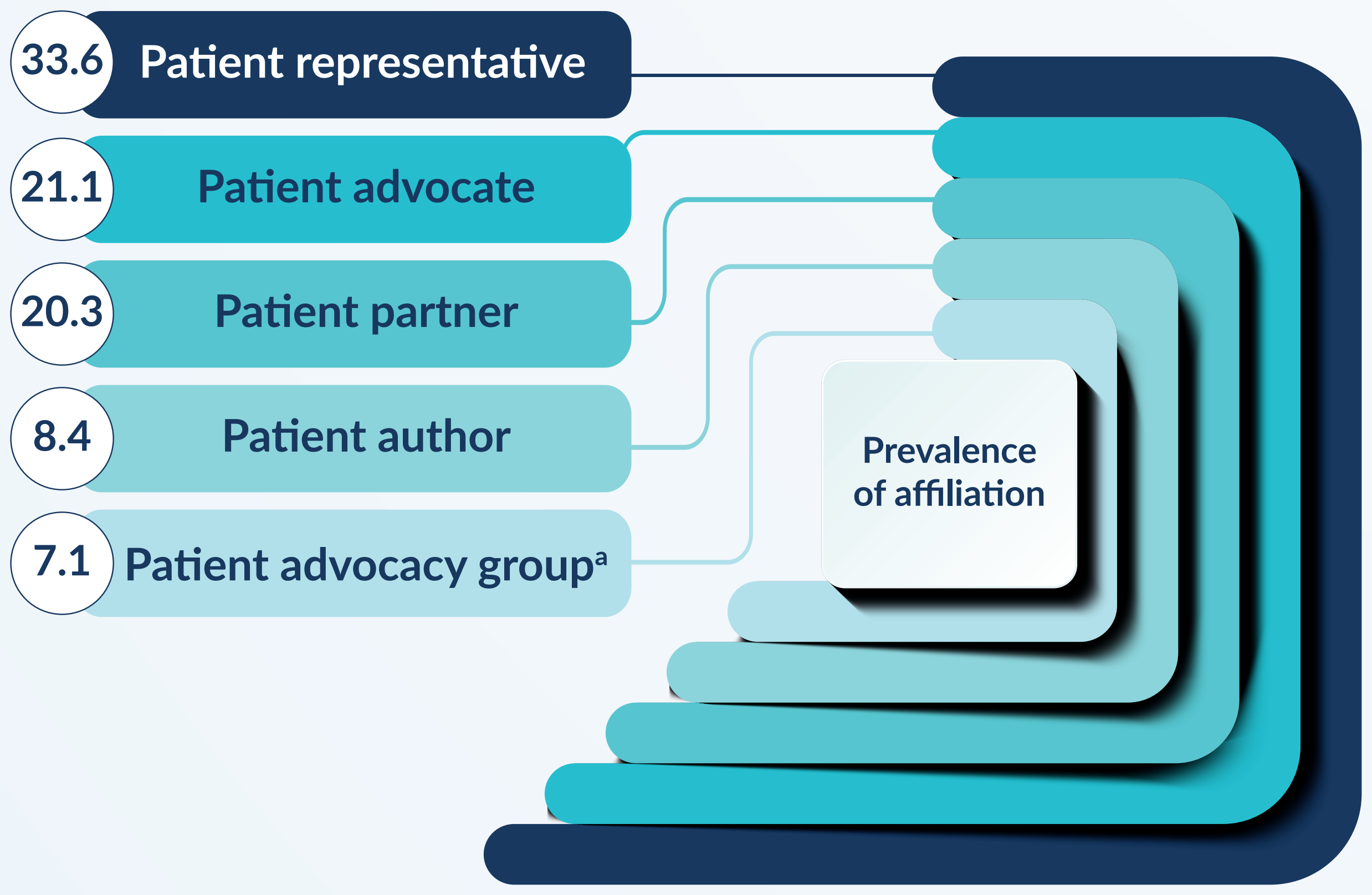
Number of VoP coauthors per publication

72.0%	17.4%	10.6%
1 VoP coauthor	2 VoP coauthors	≥3 VoP coauthors

Pharma involvement in publications with VoP

Non-pharma	Pharma
96.4%	3.6%

Top 5 affiliations used in medical literature to represent VoP involvement



%	Affiliation
33.6	Patient representative
21.1	Patient advocate
20.3	Patient partner
8.4	Patient author
7.1	Patient advocacy group[a]

[a] Alternative terminologies that were considered as patient advocacy group for the purpose of this analysis were patient advocate foundation, patient advocate group, patient advocate office, patient advocate coalition, patient foundation, patient committee, patient group, patient organization, and patient association.
Note: All values are expressed as percentages.

- The term carer or caregiver as affiliation was noted in **2.7%** of publications

Maximum representation of VoP by

Sex: Women (61.9%)

Top 3 countries: US (27.8%), UK (27.1%), and Canada (21.3%)

Therapeutic area: Oncology (23.0%)

Publication type: Observational studies (27.0%), guidelines (15.0%), interventional studies (11.0%), narrative reviews (11.0%), others[a] (36.0%)

[a] Others included systematic reviews/meta-analyses, plain language summaries/plain language publications, case reports/case studies/case series, commentaries/letters, protocols, and editorials.

② *Survey results (N=40)*

- A total of **77.5% (31/40)** of respondents were aware of patient/caregiver involvement in publications, whereas **37.5% (15/40)** had direct experience collaborating with them
- The Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist[5] was used by **20.0% (3/15)** of the survey respondents who had experience working with patient authors

Survey respondents (N=40)

Current role/work setting

Pharma/biotech company	17 (42.5%)
Academia/research	3 (7.5%)
Medical communications agency/CRO	12 (30.0%)
Patient/patient advocate	4 (10.0%)
Others[a]	4 (10.0%)

Experience in publication writing

>10 years	10 (32.5%)
4-10 years	21 (52.5%)
1-3 years	2 (5.0%)
<1 year	4 (10.0%)

Awareness and involvement

Are you aware of patient/caregiver involvement in publications?
✓ 31 (77.5%)

Were you involved in patient-authored publications?
✓ 15 (37.5%)

Guidelines and experience working with patient authors

Did you use the GRIPP2 checklist for reporting involvement of patient authors?
✓ 3/15 (20.0%)

Did you experience any challenges or were there advantages working with patient authors?

Challenges
✓ 5/15 (33.3%)

Advantages
✓ 12/15 (80.0%)

Publication types involving patient authors

What publication types that you worked on usually involved patient authors?

Review articles; PLS;Case reports & Case studies; Others[b]	17 (42.5%) each
Guidelines	14 (35.0%)

Which TA or disease state involved patient authors?

Rare diseases	21 (52.5%)
Oncology	17 (42.5%)
Others[c]	16 (40.0%)

[a] Others included medical institutions and societies.
[b] Others included articles on patient perspectives, grant proposals, meta-research on patient engagement practices, PROs, QoL studies, and commentaries.
[c] Others included metabolic disorders, neurology, and disease-agnostic topics (eg, meta-research).
CRO, contract research organization; GRIPP2, Guidance for Reporting Involvement of Patients and the Public; PLS, plain language summary; PRO, patient-reported outcome; QoL, quality of life; TA, therapeutic area.

Insights from medical communication professionals and patient groups on involving patient authors in publications

Advantages

> *“We were able to change a dogma in the field due to the patient voice”*

> *“It reflects real-world information on patient journey and disease burden”*

> *“… making content more accessible and relevant, making research more ethical”*

> *“… are often the most diligent when it comes to meeting deadlines and providing comprehensive reviews and feedback in my experience…”*

Challenges

> *“Getting input in a timely way …”*

> *“Article processing cost (APC) is very high…challenging to get sponsorship…”*

> *“Managing deteriorating health with publication commitments”*

> *“Sponsor not fully integrating/acting upon patient insights”*

> *“… patient authors unaware of what authorship involved, equitable opportunity..flexible working arrangements, …wasn’t possible to compensate patient authors…”*

> *“Emotional reporting leading to too many details”*

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