Benchmarking the current state of patient involvement and patient-relevant content in oncology congresses in 2024. Where are we now?

Poster: 16

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Background

- The importance of involving patients in research and publications is well recognized[1–4]
  - The patient perspective adds meaning and value and can result in improved study design, quality, and increased applicability of research to the real-world, and better dissemination of findings and engagement with research[1–4]
- The importance of involving patients in publications extends to congresses, where there are multiple opportunities for patients to have a role, from organization through development and presentation of content[1,3–5]
- We sought to benchmark the current extent of patient involvement and patient-relevant content in oncology congresses as a first step towards enhancing patient engagement and outcomes

Research design and methods

- We selected 10 highly attended (≥1000 attendees) congresses from 2024 and searched the online programs for patient-focused content
- Patient-focused content was defined by the following criteria:
  - Content featured within patient-focused tracks, **OR**
  - Content with patient or patient-advocate authors/speakers/panelists/chairs, **OR**
  - Content within sessions/tracks focused on patient perspectives, or patient involvement in research, **OR**
  - Content within sessions/tracks focused on patient-reported outcomes (PROs) that also met any of the previous criteria
    - This was to distinguish from content that was not specifically patient focused, for example an abstract reporting a clinical trial that had a PRO endpoint was excluded
- Information reported includes what was publicly available online as of March 31, 2025

Results

2/10 Congresses (**WCLC** and **ESMO**) offered patient involvement in all categories assessed

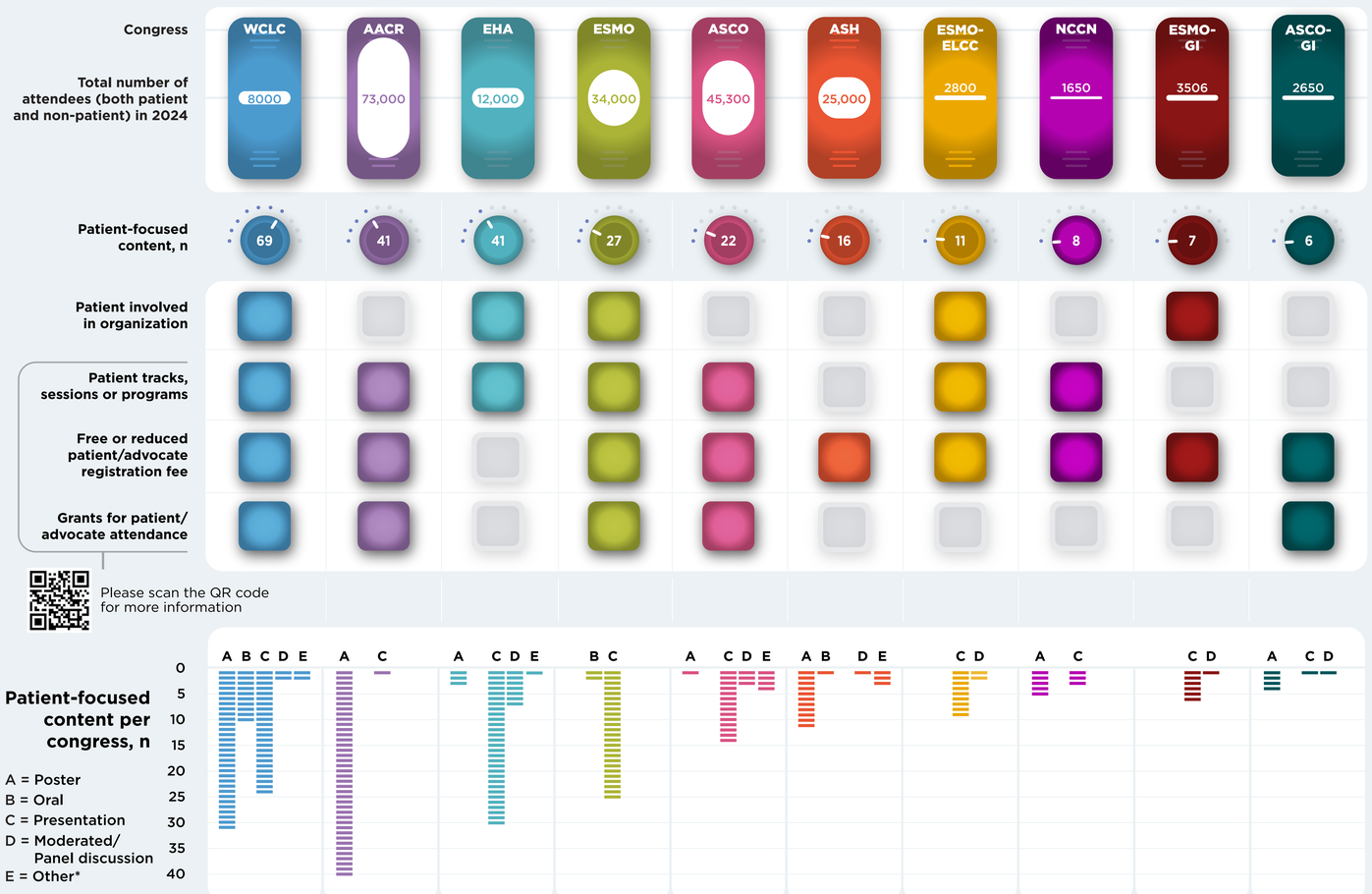
208/248 Of patient-focused content was posters and presentations

Range, n=6–69 The volume of patient-focused content varied broadly across congresses

7/10 Congresses had ≥1 patient track (defined as an abstract submission category, a session, or a program within the schedule)

9/10 Congresses had reduced or free registration for patients and half offered grants for patient attendance

Figure 1: Analysis of patient inclusion and patient-focused content at oncology congresses



AACR, American Association for Cancer Research; ASCO, American Society of Clinical Oncology; ASCO-GI, American Society of Clinical Oncology Gastrointestinal Cancers Symposium; ASH, American Society of Hematology; EHA, European Hematology Association; ESMO, European Society for Medical Oncology; ESMO-ELCC, ESMO European Lung Cancer Congress; ESMO-GI, ESMO Gastrointestinal Cancers Congress; NCCN, National Comprehensive Cancer Network; WCLC, World Conference on Lung Cancer.

*Other: workshops, informational sessions, industry theatre, publication only.

Orals and posters had associated abstracts and had been peer reviewed; presentations included general/educational/meet-the-expert/plenary/special sessions and presentations within symposia, and were not associated with submitted abstracts.

- Only **WCLC** (patient advocacy) and **AACR** (survivorship) had specific patient-focused tracks that abstracts could be submitted to, resulting in a high number of patient-focused posters being presented at these congresses

The patient advocacy track at **WCLC** had sub-themes of:

- Financial toxicity
- Biomarkers
- Clinical communications
- Disparities
- Lung cancer education
- Needs of patients and caregivers
- Patient-researcher partnership
- Screening

- In the survivorship track at **AACR**, patient advocate members of the AACR Scientist↔Survivor Program® had the opportunity to present posters highlighting their advocacy efforts

- The majority (n=210/248; 85%) of patient-focused content included patients/advocates as authors/speakers/chairs (**Figure 2**)
- For content where patients or advocates were not included as authors/speakers/chairs, these were:
  - Meet and greet or informational sessions between congress representatives and patients/patient advocates in patient advocacy lounges
  - Talks given by health care providers where a patient perspective was provided as part of another presentation in the session
- Apart from **NCCN**, there was limited patient access to content post-congress (**Figure 3**) and in some cases this required membership or was paywalled

Figure 2: Patient involvement in patient-focused content

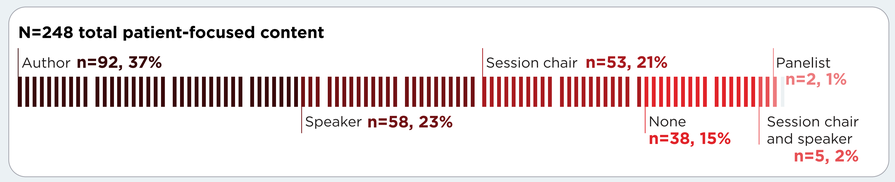
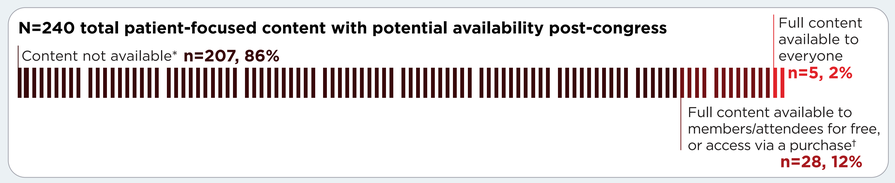


Figure 3: Availability of patient-focused content after the congress



Total N=240. n=8 records excluded as content not expected to be available (publication only abstracts, n=3; meet and greet/informational sessions in the patient lounge, n=4; health equity rounds lunch, n=1). *n=93 had an abstract available. †n=7 had an abstract available.

Note: Information reported includes what was publicly available as of March 31, 2025. Some congresses may have made content freely available for a limited time following the meeting, which will not have been captured here. Percentages may not add up to 100% due to rounding.

Themes and research methods

- Focusing on the posters and orals that had an associated abstract, and where patients/advocates were involved as authors (n=80), presented themes are shown in **Figure 4**

Figure 4: Themes presented in patient-focused content

Patient perspectives | Disparities | Patient advocacy | Risk factors | Screening | Early detection | Education and awareness | Impact of disease and treatment

- The majority of research methods used were descriptive/case-based (n=37; 46%) and qualitative (n=35; 44%)
  - Other methods used (n≤2) included mixed methods, genomic analysis, interventional, literature analysis, and trial protocol

Limitations

- Some congresses may have had time-limited availability of content and therefore may have not been captured when the searches were conducted
- Availability of some content post-congress is the decision of the content sponsor/owner and not the congress
- There was selection bias in the 10 congresses we chose in terms of size, location, and therapeutic area; all had at least one category of patient involvement or patient-focused content presented
- We did not assess for quality marks of patient involvement at congresses, such as the Patients Included™ charter[6] or the Everyone Included™ Stanford Framework for Convenings,[7] which have been proposed by others as a way to increase visibility and reporting of patient involvement[8]
- This was a manual search of online programs with the potential for human error
- All patient-focused content was weighted equally and therefore did not account for differences such as length of presentation or session
- It was not possible to calculate the proportion of patient-focused content to total content presented, making any comparisons between congresses challenging

Conclusions

- Patient involvement in congresses, from content to attendance, is integral in fostering collaboration and providing the patient perspective to further drive awareness, understanding, and inclusivity
- While some congresses are making efforts to include patient-focused content, comprehensive involvement (i.e. in all categories assessed here) is still limited
- When given the opportunity, patients and advocates are playing a role in shaping the content and discussions at oncology congresses
- The research methods employed in patient-focused content suggests a focus on understanding patient experiences and perspectives rather than quantitative measures, which may be crucial for capturing the nuanced aspects of patient involvement and advocacy

Call to action

- There is a need for standardized approaches to patient engagement to increase patient involvement in oncology congresses
- Dedicated tracks can enhance the visibility and involvement of patient-related content
- The limited access to patient-focused content post-congress, poses a barrier to ongoing patient engagement, suggesting a need for improved accessibility to congress materials for patients
- Further research is needed to:
  - Understand the impact of patient-focused content from the perspective of the patient
  - Understand how the level of patient involvement in congresses is changing over time

References

1. Oliver J, et al. *Res Involv Engagem*. 2022;8(1):12
2. Brett J, et al. *Health Expect*. 2014;17(5):637–50
3. Patients as Partners in Clinical Research. https://theconferenceforum.org/hub/patients-as-partners-in-clinical-research [Accessed April 2025]
4. Francisco R, et al. *Res Involv Engagem*. 2024;10(1):107
5. Stones S. *Ann Rheum Dis*. 2024;83:2222
6. Patients Included™. https://patientsincluded.org/ [Accessed April 2025]
7. Everyone Included™. https://everyoneincluded.org/ [Accessed April 2025]
8. Stones, S, et al. Involving Patients, Carers and Patient Organisations in European Medical Congresses. Poster 11 presented at the ISMPP EU meeting 2025. https://www.pathlms.com/ismpp/courses/94221/sections/104782 [Accessed April 2025]

Disclosures

LMo, **CC**, **RF**, **MM**, **RW**, and **SY**: employment with and ownership of stocks and shares of Takeda Pharmaceuticals U.S.A., Inc., Lexington, MA, USA. **PS**: employment with Takeda Pharmaceuticals U.S.A., Inc., Lexington, MA, USA. **EW**, **KL**, **LMa**, and **HW**: employment with Inizio Medical, Macclesfield, UK.

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