Involving Patients, Carers and Patient Organisations in European Medical Congresses

POSTER #11

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Background

- Patients (including carers and patient organisations) are interested in attending and contributing to medical congresses[1]
- There is also increasing attention being paid to patient-led congresses, such as the PxP Conference[2]

Objective

- Our objective was to understand how patients are involved in European medical congresses

Methods

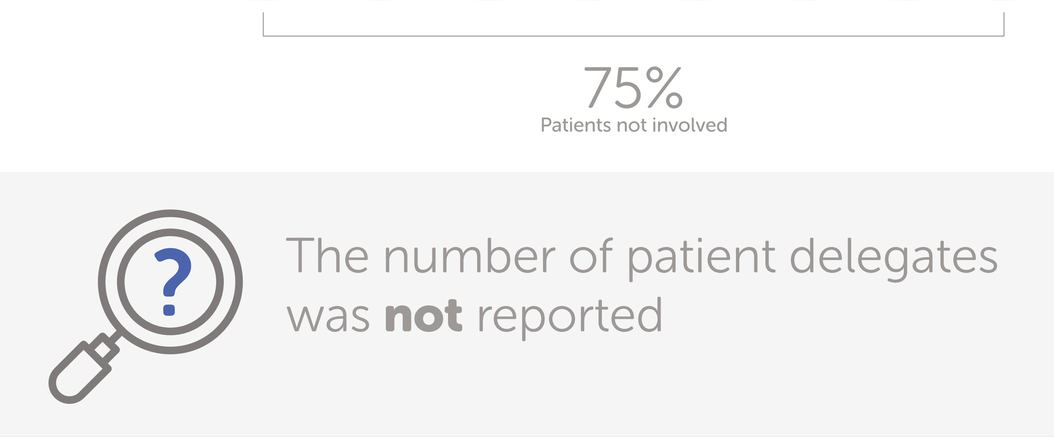
- We identified European medical congresses using an internet search engine (Google), according to the 43 specialties outlined by the European Union of Medical Specialists (EUMS)[3]
- We manually extracted information available on congress websites in September 2024 that pertained to patient involvement across 8 a priori activities identified by the authors
- The terms 'engagement', 'involvement' and 'participation' are often used interchangeably in the literature, with considerable differences among the definitions that do exist. For this analysis, the authors drew on the National Institute for Health and Care Research's (NIHR) definition of patient involvement[4]

> "Involvement is research done with or by patients and the public, not to, about or for them. It is an active partnership between patients, carers and members of the public and researchers that influences and shapes research."
>
> NIHR - Briefing notes for researchers - public involvement in NHS, health and social care research

Results

1. Patient involvement metrics at congresses

- Only **25%** (13/52) of congresses appeared to involve patients **(Table)**



The number of patient delegates was **not** reported

Table. Patient involvement at congresses

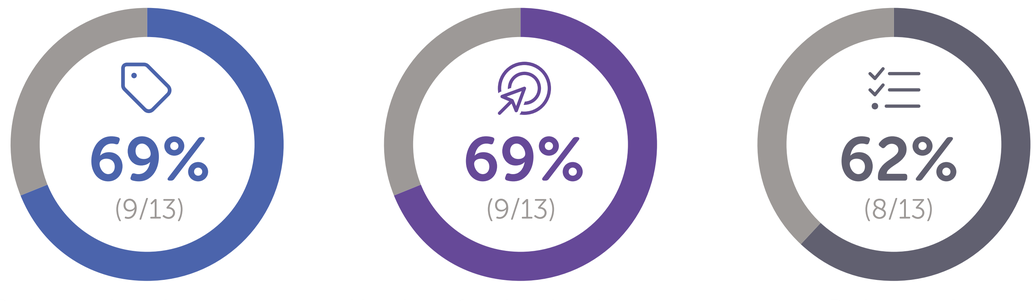
Congress	Specialty	Patient involvement activities (N = 13)							
		Congress objectives	Organising committee[a]	Abstract review committee	Patient track[b]	Registration category	Speaking opportunities	Press conference	Networking
ESC	Cardiology	No	No	No	No	No	Yes	No	No
ESCAP	Child and adolescent psychiatry	Yes	No	No	No	No	No	No	No
EADV	Dermatology and venerology	Yes	No	No	No	Yes	No	No	Yes
ECE	Endocrinology	No	No	No	Yes	No	Yes	No	Yes
ESMO	Medical oncology	Yes	Yes – patient committee	No	Yes	Yes	Yes	No	Unclear
ECTRIMS	Neurology	Yes	No	No	Yes	Yes	Unclear	No	Yes
ERS	Pneumology	No	No	No	No	Yes	Unclear	No	Unclear
EULAR	Rheumatology	Yes	Yes – scientific programme committee with patients	Yes	Yes	Yes	Yes	Yes	Yes
EAU	Urology	Yes	No	No	Yes	Yes	Yes	No	Yes
EMUC	Urology	No	No	No	No	Yes	Unclear	No	No
ECRD	Other: rare disease	Yes	Yes – scientific programme committee with patients	Unclear	Yes	Yes	Yes	Yes	Yes
EHA	Other: haematology	Yes	Yes – patient committee	No	Yes	Unclear	Yes	No	Unclear
EBMT	Other: haematology	Yes	No	No	Yes	Yes	Unclear	No	Unclear
Total yes, n (%)		**9 (69)**	**4 (31)**	**1 (8)**	**8 (62)**	**9 (69)**	**7 (54)**	**2 (15)**	**6 (46)**

EADV, European Academy of Dermatology and Venereology; EAU, European Association of Urology; EBMT, European Society for Blood and Marrow Transplantation; ECE, European Congress of Endocrinology; ECRD, European Conference on Rare Diseases; ECTRIMS, European Committee for Treatment and Research in Multiple Sclerosis; EHA, European Hematology Association; EMUC, European Multidisciplinary Congress on Urological Cancers; ERS, European Respiratory Society; ESC, European Society of Cardiology; ESCAP, European Society for Child and Adolescent Psychiatry; ESMO, European Society For Medical Oncology; EULAR, European Alliance of Associations for Rheumatology.

[a]Includes scientific programme committees composed of different professionals including patients, as well as separate patient committees with responsibility for patient-focused sessions at the congress.

[b]Activities and research of interest to patients or sessions designed by patients that are part of the main congress.

2. Patient involvement activities at congresses



Patient registration category

Mention of patient involvement in the congress objectives

Patient track
Activities and research of interest to patients or sessions designed by patients

eular EUROPEAN CONGRESS OF RHEUMATOLOGY

Only the **EULAR Annual European Congress of Rheumatology**[5] included patients across all **8 activities**

3. Quality marks of patient involvement at congresses

- None of the congresses identified used quality marks that could be used to easily assess patient involvement at medical congresses

Not used

Patients Included™ charter[6]

Not used

Everyone Included™ Stanford Framework for Convenings[7]

Limitations

- We used a pragmatic search using the EUMS specialties as a framework to identify European medical congresses
- There are no existing frameworks to identify and assess the level of patient involvement at medical congresses; therefore, the authors used a de novo 8-item framework

Conclusions

- Medical congress organising committees need to evolve to meaningfully include patients
- Organisers also need to improve external visibility and reporting of patient involvement at medical congresses
- More research needs to be done to see if these findings are generalisable to medical congresses outside of Europe

References

1. Utengen A, et al. *J Med Internet Res*. 2017;19(8):e280. 2. Ajayi O, et al. *BMJ*. 2024;385:q1411. 3. European Union of Medical Specialists. https://www.uems.eu/our-structure. Accessed 8 January 2025. 4. National Institute of Health and Care Research. https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research#tab-256881. Accessed 8 January 2025. 5. EULAR 2025 Congress. https://congress.eular.org/. Accessed 8 January 2025. 6. Patients Included™. https://patientsincluded.org/. Accessed 8 January 2025. 7. Everyone Included™. https://everyoneincluded.org/. Accessed 8 January 2025.

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