Where are North American Medical Congresses at With Involving Patient Voices?

Poster 17

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Key Takeaway

Only **1 in 5** North American medical congresses appear to involve patients in their activities.

Background

- Patients (including caregivers and patient organizations) are interested in attending and contributing to medical congresses.[1]
- There is also increasing attention paid to patient-led congresses, such as the PxP Conference.[2]
- Recently published research indicated that only 25% of European medical congresses appear to involve patients in their activities in some capacity.[3]

Objective

- To understand how patients are involved in North American medical congresses.

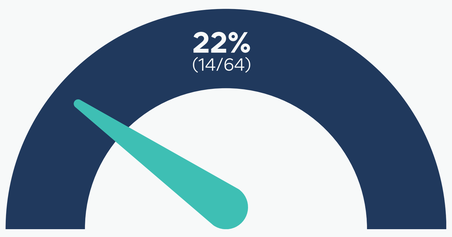
Methods

- We identified North American (American and Canadian) medical congresses using an internet search engine (Google), according to specialties outlined by the American Board of Medical Specialties (ABMS).[4]
- We manually extracted information available on congress websites in January 2025 that pertained to patient involvement across 8 a priori activities identified by the authors (**Supplementary Methods**).
- 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 UK National Institute for Health and Care Research's (NIHR) definition of patient involvement.[5]

> "Involvement is research done with or by patients and the public, not to, about or for them. It is an active partnership between patients, [caregivers] and members of the public with researchers that influences and shapes research."
>
> NIHR – Briefing notes for researchers – public involvement in NHS, health and social care research (2021)[5]

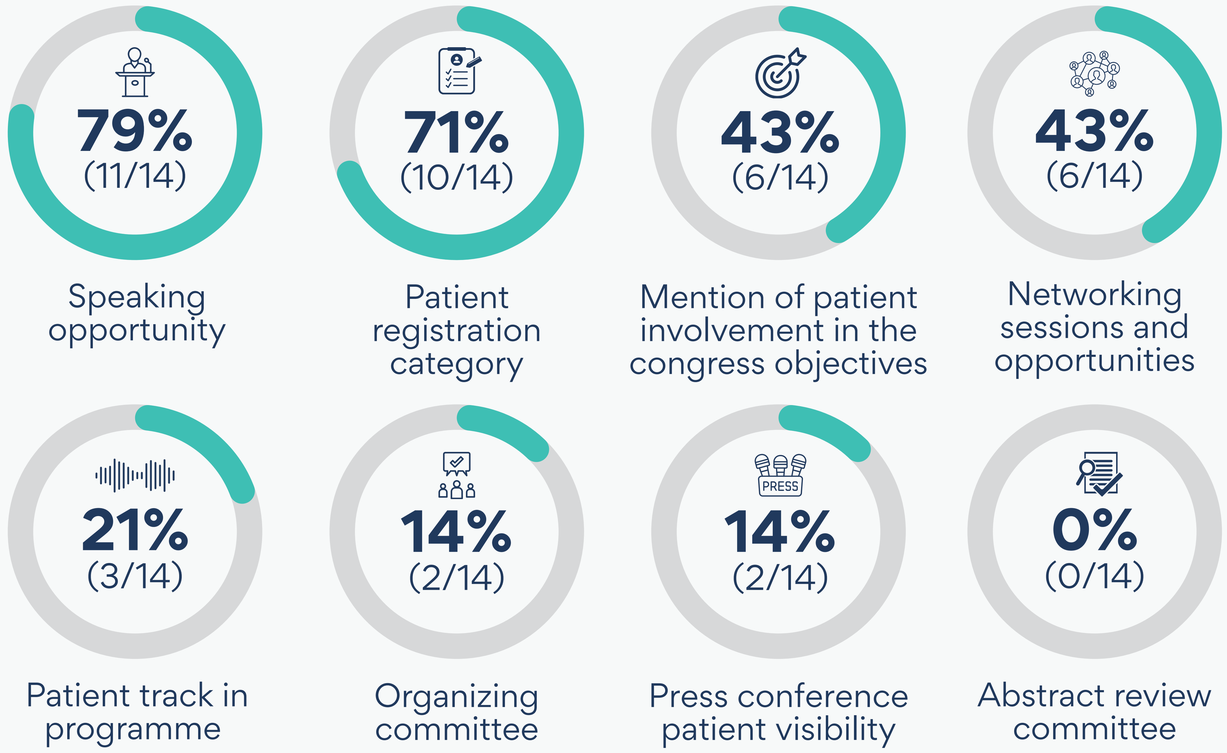
Results

1. Patient involvement metrics at congresses



- Only **22%** (14/64) of congresses appeared to involve patients (**Supplementary Table**).
- Documentation of patient involvement was poor.
- The number of patient delegates was reported for 2 congresses (**1–2%** of attendees).

2.Patient involvement activities at congresses



- **None** of the medical congresses appeared to include patients across all 8 activities.

3. Quality marks of patient involvement at congresses

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

Not used | Patients Included™ charter[6] | Everyone Included™ Stanford Framework for Convenings[7]

Limitations

- We used a pragmatic search using the ABMS as a framework to identify North American 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

- It is encouraging to see speaking opportunities and patient registration at the majority of North American medical congresses identified; however, few demonstrate true patient involvement by including patients in all aspects of congress planning and delivery.
- Greater efforts toward meaningful patient involvement and consistent reporting of involvement are required.
- Despite some differences (e.g., fewer patient tracks in North America), patient involvement in medical congresses is consistent between North America and Europe.[3]

Scan for digital poster, supplementary material, and disclosures

Scan for poster presented at the 2025 European Meeting of ISMPP on involving patient voices at European medical congresses[3]

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References

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