

Attendance of People with Lived Experience at Canadian Oncology Conferences

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Background

- People with lived experience (PWLE) are individuals who can provide insights about a system, based on prior or ongoing experiences, also referred to as patient partners
- There is a growing push to involve PWLE in varied academic spaces, and studies have shown their involvement to accelerate information flow between researchers and the community, strengthen relationships bidirectionally, and shape policy and research perspectives [1-3]
- In literature, patient partner involvement at conferences is described by 4 domains: physical accommodation, co-design, engagement in programming, and education (connecting PWLE to researchers, clinicians, and stakeholders to guide research and policy) [1]
- There is a paucity of literature on PWLE attendance at healthcare conferences in Canada and the depth and breadth of information publicized by conferences online

Objective

This study seeks to explore PWLE attendance and engagement at Canadian oncology conferences through grey literature (website) review.

Study Design

Methodology

- **Search strategy:** Grey literature search on Google
- **Inclusion criteria:** English- or French-language Oncology conferences in Canada
- Screenshots and timestamps for each website will be documented, and data will be coded based on predetermined variables of interest

Data

- **Qualitative:** Conference programming, financial provisions, travel and lodging expenses, additional resources for patients, discussions with patient partners
- **Quantitative:** Information visibility and accessibility metrics

Analysis

Qualitative

Content analysis

Predetermined categories (financial provisions, involvement in programming, etc.)

Thematic analysis

Identifying patterns of information after content analysis is completed

Quantitative

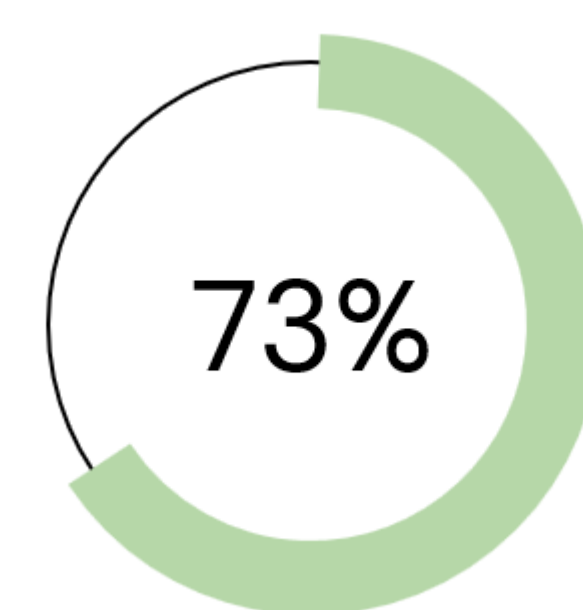
Information visibility

Metrics to determine information visibility, e.g. number of clicks to access attendance cost, readability scores (Flesch-Kincaid)

Comparative analysis

Data will be compared across conferences

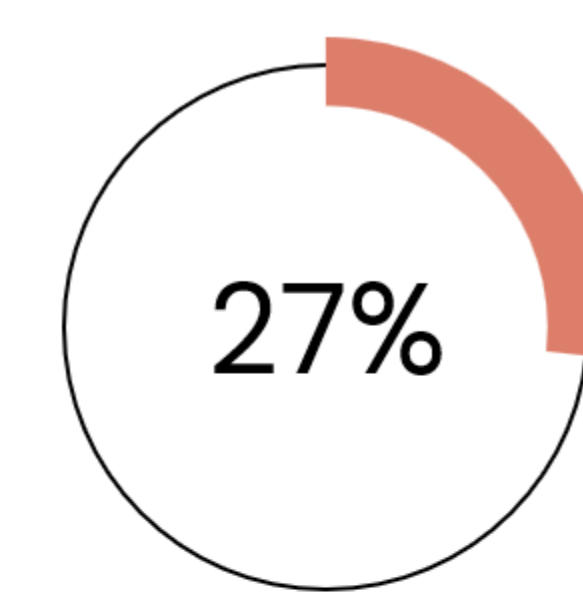
Preliminary Results (n = 15)



73%

Registration Fee

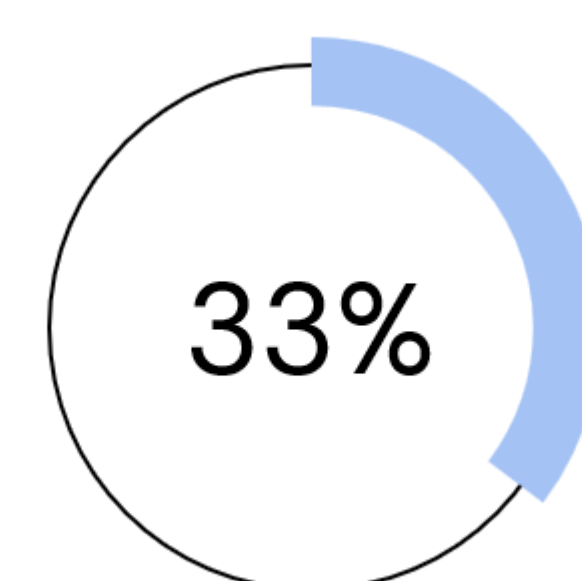
11/15 conferences publicized attendance costs



27%

Travel/Lodging Expenses

4/15 conferences publicized travel and/or lodging expenses



33%

Engagement Initiatives and Resources

5/15 conferences publicized patient engagement in programming and/or community resources

Information Accessibility

Mean number of clicks to access registration cost was **1.8**; mean number of clicks to access conference agenda was **1.5**

Information Visibility

Mean WCAG 2.0 Colour Ratio was **7.6:1** (above the threshold of 3.5-4:1)

Discussion

- Despite the growing push to involve PWLE in academic settings, there is a lack of literature that exists on their attendance and engagement at Canadian oncology conferences
- While most conferences publicized registration fees (73%), only a minority reported engagement initiatives and additional resources for patient partners (33%), and even fewer reported travel and lodging expenses (27%)
- Raw quantitative metrics were examined to assess information accessibility and visibility; across the 15 conference websites, the mean number of clicks to access registration cost was 1.8, while the mean number of clicks to access the conference agenda was 1.5
- Information visibility analysis using the WCAG 2.0 Colour Ratio as a comparative metric was done, with the mean ratio being 7.6:1, well above the passing threshold of 3.5-4:1

My ESAP Experience

Immersing myself in Education Scholarship and patient engagement

Learning how to conduct grey literature analysis

Discussions with patient partners to better understand patient engagement landscape

Patient Partner Discussions

Domain					
Background	Conference Engagement	Support and Resources	Outcomes and Gain	Feedback and Suggestions	Open-ended / Broad
How many oncology conferences have you attended?	What motivated you to attend oncology conferences?	Were there any financial aids available to you for attendance?	What did you gain from attending the conferences?	What improvements would you suggest for future conferences?	If you could design your ideal conference for patient partners, what would it look like?
What roles have you taken on at these conferences (e.g., speaker, panelist, attendee)?	How would you describe your level of engagement at these conferences, and did you experience any barriers to attending or participating?	Were conferences accessible?	How did your participation impact your advocacy or professional work?	What aspects of the conferences did you find most valuable/rewarding?	Can you share any memorable moments or insights from your past conference experiences that highlight the importance of patient partner involvement?

References

- [1] Utengen A, Rouholiman D, Gamble JG, Iii FJG, Pradhan N, Staley AC, et al. Patient Participation at Health Care Conferences: Engaged Patients Increase Information Flow, Expand Propagation, and Deepen Engagement in the Conversation of Tweets Compared to Physicians or Researchers. *Journal of Medical Internet Research*. 2017 Aug 17;19(8):e8049.
- [2] DASH — Data Across Sectors for Health [Internet]. [cited 2024 Jul 2]. Including People with Lived Experience (PWLE) — Thoughtfully. Available from: <https://www.dashconnect.org/blog/2024/04/16/including-people-with-lived-experience-pwle-thoughtfully>
- [3] Tips for Engaging Lived Experience | RNAO [Internet]. [cited 2024 Jul 2]. Available from: <https://mharesource.rnao.ca/tips-engaging-lived-experience>