

# Facilitating concussion research participation: A qualitative study exploring the patient perspective

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## PURPOSE / OBJECTIVES

To explore the perspective of the adult concussion patients on the recruitment, retention, and results dissemination elements of research studies, and how they can be positive experiences. There is a research gap in this space.

The ultimate goal is to use this knowledge to improve the recruitment and retention of adult concussion patients, to support concussion research and care. Handouts aimed at researchers and participants were created to support this aim.

## METHODS

- A qualitative description<sup>1</sup> study was conducted using semi-structured interviews
- Questions were developed using appreciative inquiry<sup>2</sup> to focus on elements contributing to a positive experience
- A purposeful sample of adult patients with persistent post-concussion symptoms were recruited from three tertiary care concussion clinics within Ontario
- All participants had experienced a concussion over three months prior to their interview, and were associated with Concussion Ontario Network: Neuroinformatics to Enhance Clinical-care and Translation (CONNECT)
- Reflexive thematic analysis was used to analyse transcripts and develop the themes<sup>3</sup>

## RESULTS

- 23 participants were interviewed
- Meaning saturation<sup>4</sup> guided the decision that saturation was reached at interview 19

## KEY POINTS

To improve the recruitment and retention of adult concussion patients in research studies, a qualitative description study was conducted to collect their perspectives on how to make it a positive experience.

Participants are motivated by the possibility of effecting positive change in concussion care and the chance to learn more about their condition.

Researchers should create patient-centred studies which consider necessary concussion-related accommodations and the patient experience of participation.

## RESULTS

### 1<sup>st</sup> Theme: **Positive Change**

Factors which motivated participation are captured within the sub-themes. Core related content is listed below.

**Study Impact** – Institutional reputation, and the potential impact of the study on patient care

**Personal Contribution** – A desire to help others along with themselves

**Information & Reassurance** – Wanting to learn more about concussion and their individual health

### 2<sup>nd</sup> Theme: **Patient-Centred Study Design**

Factors impacting a positive experience are captured within the sub-themes. Core related content is listed below.

**Accommodation** – Concussion-related considerations, such as limiting screen time and difficulties with memory

**Convenience** – Time commitment, and financial costs of participation

**Feeling Valued** - Receiving study results, and being treated with respect

## DISCUSSION

- Many factors discussed by participants aligned with issues impacting study participation previously reported elsewhere<sup>5</sup>
- The desire for information featured heavily, and may be more specific to concussion patients due to knowledge gaps in the field of concussion care
- Researchers should make clear what to expect as a participant, so as to reduce misconceptions about the care received in the study
- A one-pager highlighting key takeaways for researchers to use as a guide, and a checklist tool for concussion patients considering research study participation, has been created to support knowledge translation

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#### REFERENCES:

1. Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23(4), 334–340. [https://doi.org/10.1002/1098-240X\(200008\)23:4<334::AID-NUR9>3.0.CO;2-G](https://doi.org/10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G)
2. Preskill, H., & Catsambas, T. T. (2006). *Reframing Evaluation Through Appreciative Inquiry* (1st ed.). Sage Publications, Inc.
3. Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18(3), 328–352. <https://doi.org/10.1080/14780887.2020.1769238>
4. Hennink, M. M., Kaiser, B. N., & Marconi, V. C. (2017). Code Saturation Versus Meaning Saturation. *Qualitative Health Research*, 27(4), 591–608. <https://doi.org/10.1177/1049732316665344>
5. Houghton, C., Dowling, M., Meskell, P., Hunter, A., Gardner, H., Conway, A., Treweek, S., Sutcliffe, K., Noyes, J., Devane, D., Nicholas, J. R., & Biesty, L. M. (2020). Factors that impact on recruitment to randomised trials in health care: a qualitative evidence synthesis. *Cochrane Database of Systematic Reviews*, 2020(10). <https://doi.org/10.1002/14651858.MR000045.pub2>