

The Science of Nourishing the Next Generation

# **CHRD 2021: Abstract & Poster Submission Form**

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#### **Research Category:**

O Basic Science

- Clinical
- O Community Health / Policy

### What was your role in the project?

Design

- Perform Experiments
- ☑ Analyze Data
- Write Abstract

#### Presenter Status:

Undergraduate Students

- O Masters Student
- O PhD Student
- O Post-Doctoral Fellows
- O Residents
- O Non-Trainee

#### Title

Determining the benefits and drawbacks of parents using personal and social networks for recruitment in research projects: A qualitative study

#### Background

Patient-Oriented Research refers to the involvement of patients, parents/caregivers, and community members in the research process to improve research relevance and impact. Patient-partners often support research by sharing recruitment materials through their personal and social networks.

#### Objective

We aim to understand the perspectives of parent research partners regarding the use of their personal networks for research recruitment, to inform best practice recommendations.

#### Methods

We performed a qualitative study of Canadian parents with children with additional medical needs who have participated in research partnership. Participants were recruited through research network communications or social media and participated in a semi-structured interview or focus group. Interviews/focus groups were audio-recorded and transcribed verbatim. Transcripts were analyzed thematically.

#### Results

Eight parents participated in an interview or focus group. Three preliminary themes were identified: a) "What will I endorse?": sharing recruitment information can be viewed as endorsing a study or a research team and parents described both broad and specific approaches when choosing what to share; b) "How will I share?": many parents reported designating specific social media platforms for "personal" versus "professional" use; and c) "Whose story is it?": decisions regarding what personal information to share in a research context are complex and evolve over time. In general, relationship building, clear communication, learning through experience, and appropriate compensation were important recurring topics related to positive experiences in research.

#### Conclusion

Parents described a range of perspectives and approaches regarding the use of their personal networks for recruitment, which they refined with experience. Findings can be used to support decision making for parents who are new to research partnership. Emphasis on relationships, communication, and compensation by participants reinforce the importance of authentic support of patients as equal members of the research team.

## Authors

• For each author, please click "[+] Add Item" and provide the author's information

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