

ABSTRACT

POSTER TITLE: Patient engagement in the development and implementation of an online coaching intervention for parents of children with suspected development delays: Strategies and perceived benefits

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Background: Patient-oriented research strategies are becoming central to the way clinical research is being conducted at all its stages. A multi-site randomized clinical trial evaluating the effectiveness of a health coaching intervention, *BRIGHT Coaching*, for parents of children with suspected developmental delay(s) was launched. We aim to demonstrate the implementation of patient engagement strategies in that undertaking and to evaluate the patient-engagement processes and their impacts according to researchers' and patient-partners' perspectives.

Methods: In a cross-sectional, snapshot study design, a mixed approach of qualitative and quantitative methods was used. The study population included researchers (RES, n=18) and a parent-advisory group (PAG, n=9) who are members of the *BRIGHT Coaching* research project and who are mostly connected virtually given the multi-site nature of the trial. Modified versions (1. for RES; and 2. for PAG) of a standardized questionnaire, the Public and Patient Engagement Evaluation Tool (PPEET), were administered. The PPEET included 18 (for RES) and 21 (for PAG) questions (rated using a 5-point Likert Scale and open-ended) in four categories: Communication and Supports for Participation; Sharing Views and Perspectives; Impacts and Influence of Engagement Initiative; and Final Thoughts/Satisfaction. Data analysis consisted of descriptive statistics and thematic summaries.

Results: Responses from RES (n=11; 61% response rate) and PAG (n=6; 67% response rate) were shown to be similar in most PPEET sections. Mainly, high agreement was noted, with responses ranging between "Agree" to "Strongly Agree". Qualitative reports reflected that patient engagement was important, meaningful and had a significant impact on the quality of the project and on the professional development of researchers in their understanding and use of patient-oriented methodology. From the PAG's perspectives, challenges exist related to having realistic deadlines in providing feedback and a lack of a broader range of representation amongst members.

Conclusions: Several benefits and challenges of applying patient-oriented research methods to a multi-center randomized trial, where members are virtually connected, were highlighted. Those will be used to improve engagement processes, impacts and evaluations of this work. This project can also inform engagement and evaluation efforts of other patient-oriented research teams.