

Pediatric Parent Advisory Group (P-PAG): Involving parents in a research program

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Background

The Pediatric Parent Advisory Group (P-PAG) was developed in response to the growing shift towards patient-centred care that actively engages patients and their families in healthcare decision-making. The overarching purpose of the P-PAG is to provide advice, guidance and knowledge from a parent perspective to inform and improve research activities and initiatives in child health research in Alberta.



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Dr. Shannon Scott holds a Canada Research Chair (Tier II) for knowledge translation in child health. Find ECHO Research @ www.echo.ualberta.ca or on Twitter @echoKTresearch

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Methods

Recruitment of P-PAG members started in June, 2016, targeting caregivers from within the catchment area of the Stollery Children's Hospital. The recruitment process involves 1) the research team posting a brief advertisement via various avenues, both online and offline; 2) parents who are interested to join P-PAG contact the research team for in-person meetings to further determine eligibility and fit. Recruited parents undergo a brief orientation and introduction to become familiar with the operations of the P-PAG. Supported by ECHO Research (Faculty of Nursing), ARCHE and Cochrane Child Health (Department of Pediatrics), P-PAG members volunteer their time and meet 5-6 times a year undertaking one or several of the following activities:

- Evaluating digital information tools on common pediatric conditions for parents/families;
- Providing input on research processes to develop resources and decision-making tools for parents/families, physicians, and nurses;
- Providing input on how to involve parents/families in the research process;
- Contributing to building the framework for a sustainable P-PAG.

We are also conducting a concurrent evaluation of the P-PAG involving regular, short, anonymous questionnaires, to ensure that the group meets the expectations of its members and that each member's voice is heard.



Results

So far, 14 members joined the group and 5 meetings have been held bimonthly. P-PAG has been actively contributing to various child health initiatives mentioned above. For example, P-PAG was instrumental in the creation and evaluation of several knowledge translation (KT) tools (videos and infographics) on pediatric procedural pain, acute otitis media, and fever. P-PAG members evaluated the KT tools based on a set of questions. The tools were then modified and adapted based on the feedback received from P-PAG and other key stakeholders. Additionally, P-PAG has been accessed by other researchers to take on roles such as collaborators on grant applications and advisors on research instrument development.



Significance

Family engagement is integral to children's health care. P-PAG's advice and direction to the research team are instrumental to ensure the application of research evidence is appropriate, relevant, and accessible by parents and families in Alberta.

