

Parent Engagement in a COVID-19 Cohort Study of Children and Families: Successes, Challenges and Next Steps

Shelley M. Vanderhout, Catherine S. Birken, Peter D. Wong, Shannon Weir^P, Jennifer Batten^P and Jonathon L. Maguire

Abstract

This article describes the methods, successes and challenges of engaging parents while studying the impacts of COVID-19 on healthy children and families. Parent partners in a Parent and Clinician Team (PACT) informed study aims, supported feasibility and recommended changes to enhance participation. PACT members stated that they felt a sense of connectedness and purpose by contributing to COVID-19 research. Engagement increased by parents acquiring new roles, attending more frequent meetings and co-creating alternative methods of engagement. Recruiting new PACT members was challenging, likely due to limited time and resources available to parents of young children during a pandemic.

Key Points

- Parents co-developed child and family COVID-19 research by informing study aims, supporting feasibility, recommending changes to enhance participation and helping researchers adapt to evolving family concerns, priorities and challenges.
- Researchers perceived parent engagement to increase among those who had partnered prior to the pandemic but recruiting new, diverse parent partners during COVID-19 was challenging.
- The next steps include increasing the diversity of parent partners, co-presenting findings alongside parents, recruiting youth partners and evaluating our patient engagement approach.

Background

Patient engagement in health research can increase the acceptability, relevance and reach of the evidence it produces (Domecq et al. 2014) while allowing patient communities to have an active voice in the planning, conduct and dissemination of research (Frank et al. 2015). Best practices for engaging patient partners in research suggest including patients as early as possible (Kirwan et al. 2017). During the COVID-19 pandemic, child health researchers developed new studies to understand the physical, social, emotional and developmental effects of COVID-19 on children's health and well-being,

creating an opportunity to partner with parents and families to conceptualize, design and conduct research.

Working alongside parent partners, we describe how support provided by an Ontario SPOR SUPPORT Unit (OSSU) EMPOWER award supported patient engagement in a study about the impacts of COVID-19 on healthy children and their families. Reflecting on the methods we used and the successes and challenges of engaging parents, we explore next steps for meaningfully engaging parents in child health research during the COVID-19 pandemic.

^P = Patient partner.

TARGet Kids! COVID-19 Study of Children and Families

In March 2020, the TARGet Kids! COVID-19 Study of Children and Families was developed within the TARGet Kids! (Carsley et al. 2015) primary care research network to prospectively follow healthy children and their families throughout the pandemic. The objectives of the study are to describe the key epidemiological characteristics, risk factors and short- and longer-term outcomes of both COVID-19 infection and the effect of the COVID-19 pandemic on healthy children and families in Toronto, ON. TARGet Kids! is a collaboration of applied health researchers at The Hospital for Sick Children and St. Michael's Hospital, primary care providers from the Departments of Paediatrics and Family and Community Medicine at the University of Toronto and families. Children participating in TARGet Kids! are recruited from multiple primary care practices; anthropometric, dietary, lifestyle, developmental and biochemical data are collected at well-child visits from birth to adolescence. Families participating in the TARGet Kids! COVID-19 Study of Children and Families completed brief biweekly online questionnaires about family routines, mental health, public health preventive behaviours, COVID-19 infection and overall well-being.

The PACT

The Parent and Clinician Team (PACT) (Vanderhout et al. 2021) was formed in 2018, with support from the OSSU and the Canadian Institutes of Health Research Strategy for Patient-Oriented Research (CIHR SPOR) and serves as the core patient engagement team for all TARGet Kids! research. Parents of children participating in TARGet Kids! were invited to partner in the planning, conducting and sharing of research results. E-mail invitations to join the PACT were sent to all parents of the study's participants who had agreed to be contacted by e-mail. Typically, 10 to 12 parent partners attended semi-annual meetings, which were held in person until March 2020, after which meetings switched to a virtual format on Zoom. Parent partners were provided training via the Patient-Oriented Research Curriculum in Child Health Research (PORCCH n.d.) modules and compensated for their time according to the CIHR SPOR considerations when paying patient partners in research (CIHR 2019). With the support of an OSSU EMPOWER award, a part-time patient engagement coordinator with expertise in working with patients and families in research was hired to provide structure and coordination for patient engagement activities in the PACT and education for patient partners. This coordinator oversaw communication between study investigators and PACT members, conducted ongoing needs assessments, matched PACT members to ongoing tasks based on skills and interests and managed administrative duties.

Outcomes of Parent Engagement

Our OSSU EMPOWER award enabled us to sustain patient engagement we had established through the PACT in the COVID-19 Study of Children and Families. PACT members were invited to help co-develop the study during the protocol design stage, inform the study aims by voicing their suggestions and research interests, support study feasibility and recommend changes to enhance participation. They co-developed questionnaires and reviewed outcome measurement instruments, indicating what was relevant and appropriate to them. PACT members also provided key logistical and technical feedback about online versus paper questionnaires, which had been used in TARGet Kids! before the COVID-19 pandemic. PACT members volunteered to serve as patient-partner co-investigators on research funding applications. The frequency of virtual PACT meetings was increased to every other month. It was essential to achieve a balance of maintaining consistent communication, not overburden parents and allow for feedback to be rapidly incorporated into the study procedures and materials. Parent partners provided input to questionnaires, such as adding questions about mask use and vaccination, and modified questions about school and child care to suit current restrictions and routines. At each meeting, members were briefed on how their input from the previous meeting was incorporated into the study, and available findings were shared.

Parent partners were consistently willing to participate, possibly because they were curious about how COVID-19 would affect their families ...

Successes

Parent engagement in TARGet Kids! created an opportunity for parents to share their lived experience in the production of children's health research and communication of COVID-19 research findings with their communities (Vanderhout et al. 2020). PACT members were enthusiastic and promoted team building over Zoom, which was more accessible to parents with small children and resulted in better attendance than pre-pandemic meetings. New ways of contributing to meetings were introduced using the chat function in Zoom. Online collaborative documents were used to obtain feedback on questionnaires between meetings, which parents found quick and easy to use. Active participation appeared to be the most effective mode of engagement (i.e., meetings), but offering PACT members other forms of engagement (i.e., remote review of protocols, forms, questionnaires, etc.) allowed for flexibility and continuous feedback throughout the project.

Parent partners were consistently willing to participate, possibly because they were curious about how COVID-19

would affect their families, hopeful to express their concerns about the pandemic and interested in developing solutions to the challenges many children and families were facing. As one parent partner said, “It was an amazing outlet to have in such a stressful time.”

Parent partners may have also felt a sense of security and connectedness, where their relationships with peer parents and researchers allowed them to keep abreast of emerging COVID-19 evidence and recommendations for children and families. Another parent said:

I felt a sense of purpose and control I may not otherwise have, being part of the PACT. Knowing that we were in this together and that there was a group of researchers working to ensure we leveraged what we could to help our future selves really gave me a sense of control in a really uncertain time.

The evolution of the pandemic may have fostered ongoing creative thinking and input from PACT members as concerns and questions shifted over time from transitioning from school and childcare to absence of friends, family and regular activities to the introduction of vaccinations and variants of concern. Finally, PACT engagement during the pandemic strengthened parents’ engagement in the TARGet Kids! study overall. By attending regular PACT meetings, parent partners were able to learn about opportunities to be involved in other studies in the cohort, which served to broaden parent engagement activities across a variety of ongoing projects.

Researchers’ experiences of engagement were positive. Gaining an understanding of PACT members’ experiences, concerns and priorities at different stages throughout the pandemic allowed the research team to direct resources, prioritize research questions and adjust the frequency and length of questionnaires families were asked to complete accordingly. Though it was evident that parents were facing multiple demands at home, their enthusiasm and willingness to contribute to research was unhindered. Though encouraged by this, the research team felt unprepared at times to provide sufficient opportunities for parents to contribute meaningfully in the midst of fast-paced funding calls, protocol development deadlines and changing public health guidelines.

Areas for Improvement

It was challenging to recruit new parent partners who represented the ethnic and sociodemographic diversity of the study’s participants. TARGet Kids! participants’ primary care visits during the pandemic were reduced and research assistants were removed from the clinics, limiting face-to-face interaction between the research team and parents. Increased social stress on families or a lack of resources among unengaged families,

such as Internet access or knowledge about patient engagement in research, were other limitations. As a result, accessing hard-to-reach individuals was increasingly difficult. Other limitations of our study were the inability to recruit fathers and gender imbalance within the team. We have explored options such as “fathers only” meetings (as the group initially comprised only mothers), different types of engagement (document review or online surveys instead of meetings) and alternating parent attendance to PACT meetings. Due to the fast-paced nature of the pandemic and COVID-19 research, it was challenging to engage parent partners and solicit feedback before each step in the research process. While PACT members were consulted, they were not always actively involved in the research design stage owing to rushed timelines for COVID-19 grant applications. Active participation and collaboration would have been preferred had timelines been less rushed and if more preparation was possible. Parent partners were keen to be involved, but having the foresight to arrange this was not always possible. We also did not implement a formal evaluation process, which would have been helpful to understand the qualitative and quantitative impacts of parent engagement in this study.

Next Steps

PACT involvement in TARGet Kids! COVID-19 research has encouraged us to consider new research questions about COVID-19 vaccination and long-term implications of the pandemic for children and families, and parents are now involved in developing proposed methods for examining these key questions. As results become available from initial analyses of the TARGet Kids! COVID-19 Study of Children and Families, PACT members will be invited to co-present findings at webinars and virtual conferences and co-author publications. PACT members are currently helping to develop knowledge translation tools and knowledge mobilization strategies such as a new website and regular e-mail newsletters, which will be distributed to the PACT between meetings. TARGet Kids! research assistants are increasingly interacting with families virtually over Zoom, which is aimed at supporting relationships and opportunities for future engagement. Support from the OSSU EMPOWER award has allowed for training on patient engagement for research assistants, which is intended to facilitate recruitment of new PACT members who are representative of the entire cohort (i.e., from a variety of neighbourhoods and ethnic and racial backgrounds) as they return to in-person research roles. Recruitment of fathers is growing through a variety of approaches including alternating parents who attend meetings, peer referrals and targeted recruitment at TARGet Kids! participants’ primary care visits. To promote more active participation of PACT members, we are leveraging support from the OSSU EMPOWER award to designate small teams of parent partners based on their interests and skills – for

example, re-designing the website, creating new recruitment and retention strategies for TARGet Kids! and engaging in grant writing. Two PACT members who serve as champions for engaging fathers are leading innovative ideas for recruitment and creative involvement of fathers. Youth engagement in the PACT is also a priority for future development, where young people will help advise on research priorities and developing child-centred interventions. Going forward, we are considering different meeting formats that will best serve PACT members. Though in-person meetings can facilitate relationship building, virtual meetings have introduced a number of benefits to the structure and conduct of PACT collaboration. A mixed approach may be beneficial to continue to engage parents with varied preferences, resources and availability. Finally, we will ask PACT members to complete the Patient Engagement in Research Scale (Hamilton et al. 2021) to assess our approach to parent engagement in TARGet Kids! and develop strategies to address limitations we identify through this evaluation.

Conclusion

Engaging parents as partners in a study about COVID-19 in healthy children and families allowed family perspectives, priorities and insights to be incorporated into the design, conduct and dissemination of the research. Building on trusting relationships and maintaining consistent contact with parent partners allowed for dynamic and productive teamwork to suit the fast-paced nature of the COVID-19 pandemic. Parents' active engagement served to co-build the PACT in the TARGet Kids! cohort, which we foresee will support future child health research. Going forward, we are committed to increasing the diversity of parent partners and conducting evaluations that will improve our approach to patient engagement. **HQ**

Acknowledgements

The authors thank the TARGet Kids! PACT for their generous contribution of time and participation in child health research. The authors would also like to thank all participating families for their time and involvement in TARGet Kids! and are grateful to all practitioners who are currently involved in the TARGet Kids! research network.

References

- Canadian Institutes of Health Research (CIHR). 2019, September 15. Considerations When Paying Patient Partners in Research. Government of Canada. <<https://cihr-irsc.gc.ca/e/51466.html>>.
- Carsley, S., C.M. Borkhoff, J.L. Maguire, C.S. Birken, M. Khovratovich, B. McCrindle et al. 2015. Cohort Profile: The Applied Research Group for Kids (TARGet Kids!). *International Journal of Epidemiology* 44(3): 776–88. doi:10.1093/ije/dyu123.
- Domecq, J.P., G. Prutsky, T. Elraiyah, Z. Wang, M. Nabhan, N. Shippee et al. 2014. Patient Engagement in Research: A Systematic Review. *BMC Health Services Research* 14(1): 89. doi:10.1186/1472-6963-14-89.
- Frank, L., L. Forsythe, L. Ellis, S. Schrandt, S. Sheridan, J. Gerson et al. 2015. Conceptual and Practical Foundations of Patient Engagement in Research at the Patient-Centered Outcomes Research Institute. *Quality of Life Research* 24(5): 1033–41. doi:10.1007/s11136-014-0893-3.
- Hamilton, C.B., A.M. Hoens, A.M. McKinnon, S. McQuitty, K. English, L.D. Hawke and L.C. Li. 2021. Shortening and Validation of the Patient Engagement in Research Scale (PEIRS) for Measuring Meaningful Patient and Family Caregiver Engagement. *Health Expectations* 24(3): 863–79. doi:10.1111/hex.13227.
- Kirwan, J.R., M. de Wit, L. Frank, K.L. Haywood, S. Salek, S. Brace-McDonnell et al. 2017. Emerging Guidelines for Patient Engagement in Research. *Value in Health* 20(3): 481–86. doi:10.1016/j.jval.2016.10.003.
- PORCCH. n.d. Patient-Oriented Research Curriculum in Child Health. Retrieved August 10, 2021. <<https://porcch.ca/>>.
- Vanderhout, S.M., C.S. Birken, P. Wong, S. Kelleher, S. Weir and J.L. Maguire. 2020. Family Perspectives of COVID-19 Research. *Research Involvement and Engagement* 6(1): 69. doi:10.1186/s40900-020-00242-1.
- Vanderhout, S.M., C.S. Birken, M. Zaccaria Cho and J.L. Maguire. 2021. Forming a Parent and Clinician Team (PACT) in a Cohort of Healthy Children. *Research Involvement and Engagement* 7(1): 47. doi:10.1186/s40900-021-00293-y.

About the authors

Shelley M. Vanderhout, PhD, RD, is a registered dietitian and postdoctoral researcher at the University of Ottawa and Children's Hospital of Eastern Ontario in Ottawa, ON and St. Michael's Hospital in Toronto, ON.

Catherine S. Birken, MD, MSc, FRCPC, is a pediatrician at The Hospital for Sick Children and a professor in the Department of Pediatrics at the University of Toronto in Toronto, ON. She co-leads TARGet Kids! and is the Edwin S.H. Leong chair in Child Health Intervention.

Peter D. Wong, MD, PhD, FRCPC, is a community pediatrician and an associate professor at the Department of Paediatrics

and Dalla Lana School of Public Health, University of Toronto in Toronto, ON.

Shannon Weir, MSc, PMP, is a parent volunteer from Toronto, ON, and co-leads the TARGet Kids! Parent and Clinician Team.

Jennifer Batten is a parent volunteer and a mother of two daughters from Toronto, ON.

Jonathon L. Maguire, MD, MSc, FRCPC, is a pediatrician at the St. Michael's Hospital, Unity Health Toronto, and co-leads TARGet Kids! He is a professor of Pediatrics and Lawson Family Chair in Patient Engagement in Child Nutrition at the University of Toronto in Toronto, ON. He can be contacted at jonathon.maguire@utoronto.ca.