



TARGetKids!
The Applied Research Group



Parent Engagement in COVID-19 Research



**COVID-19 IMMUNITY
TASK FORCE**



**ST. MICHAEL'S
UNITY HEALTH TORONTO**

SickKids®



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The largest primary care research network in Canada

Ongoing longitudinal data collection at well-child visits

Over 11,500 children and their parents enrolled since 2008

14 large practices across GTA, Montreal and Kingston

Visit us at www.targetkids.ca



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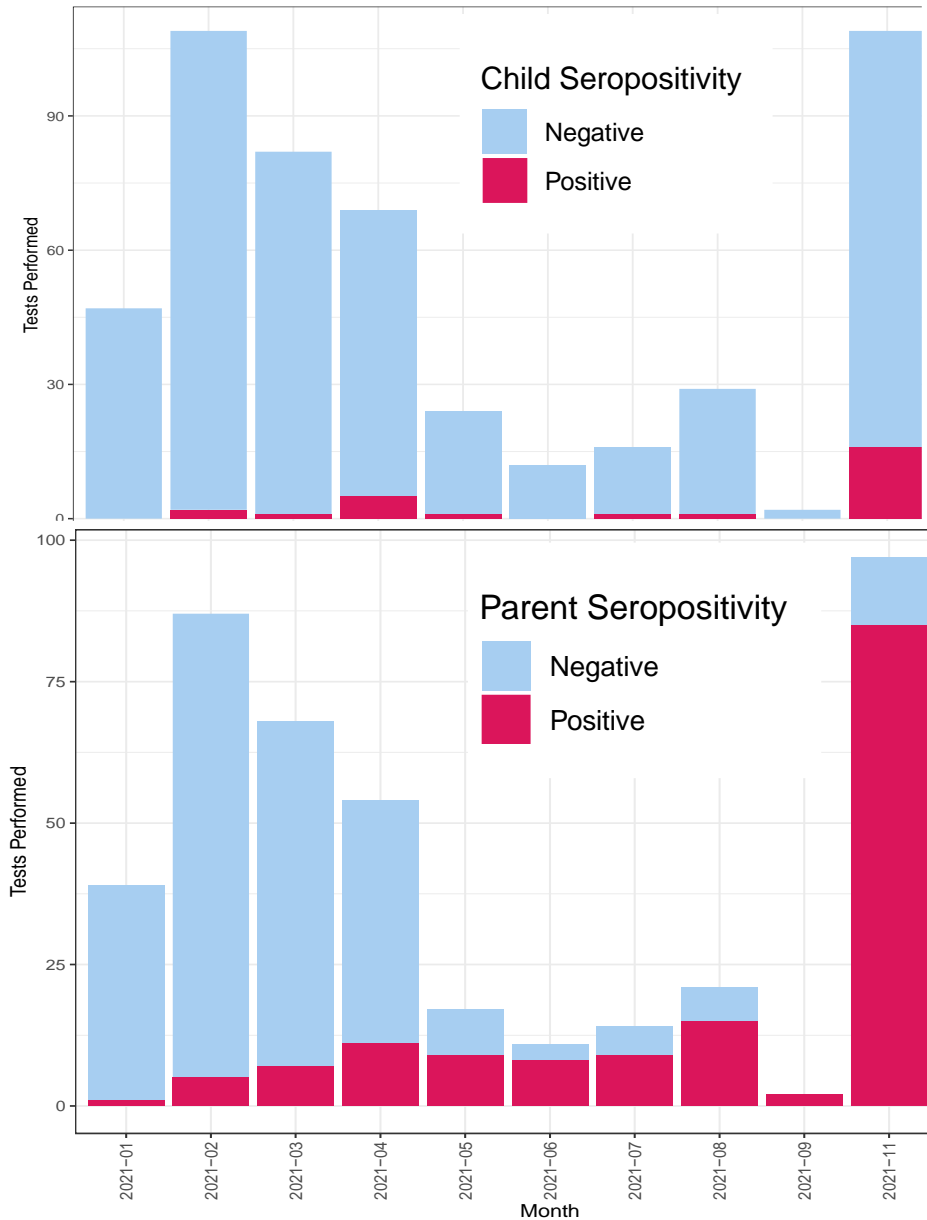
COVID-19 Study of Children and Families

How does COVID-19 infection and vaccination impact health, well-being, and learning in children and their families?

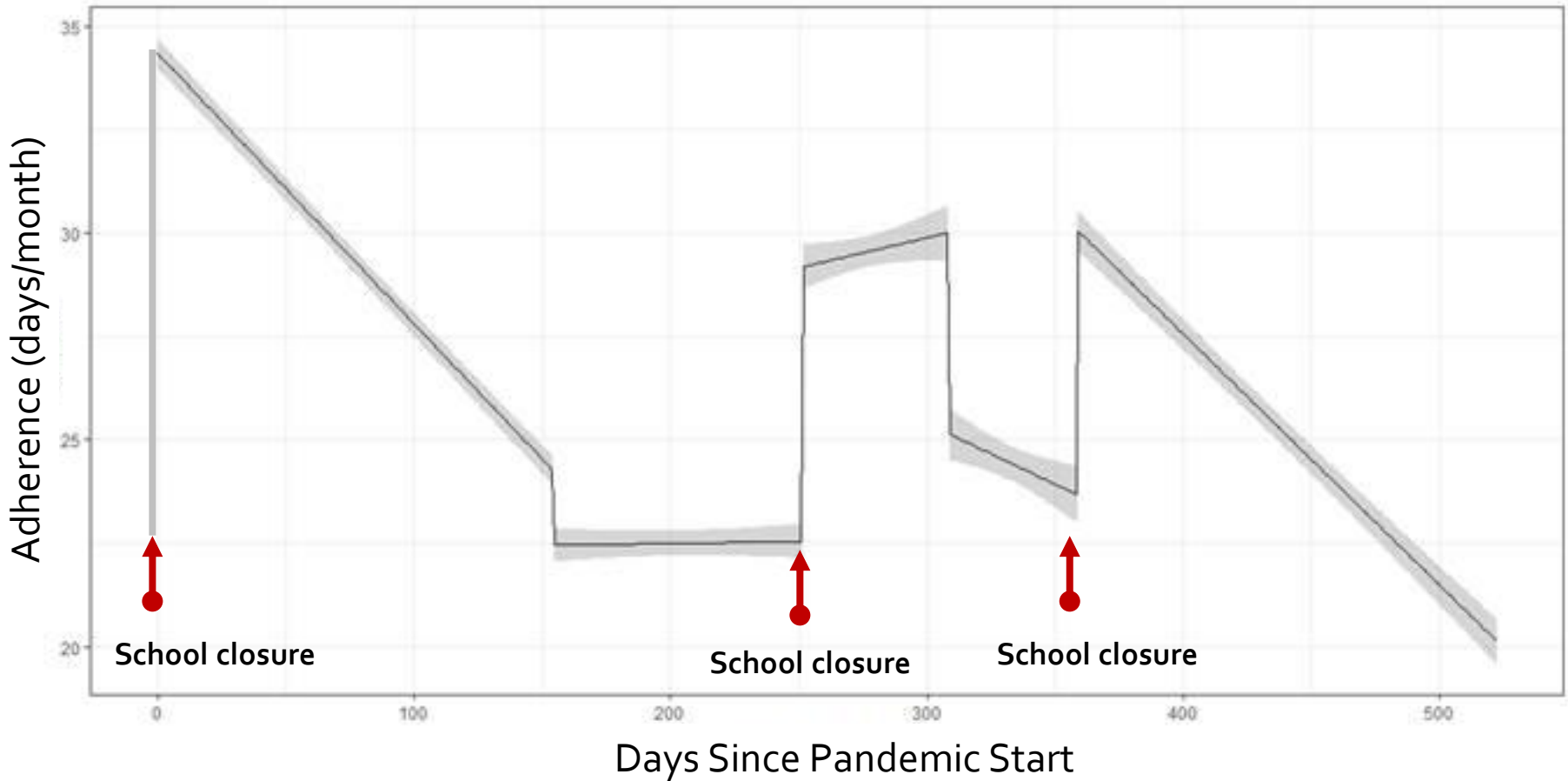
- **Seropositivity**
- **Adherence to public health measures**
- **Vaccination hesitancy and uptake**
- **Mental health**
- **School and learning outcomes**



Seropositivity

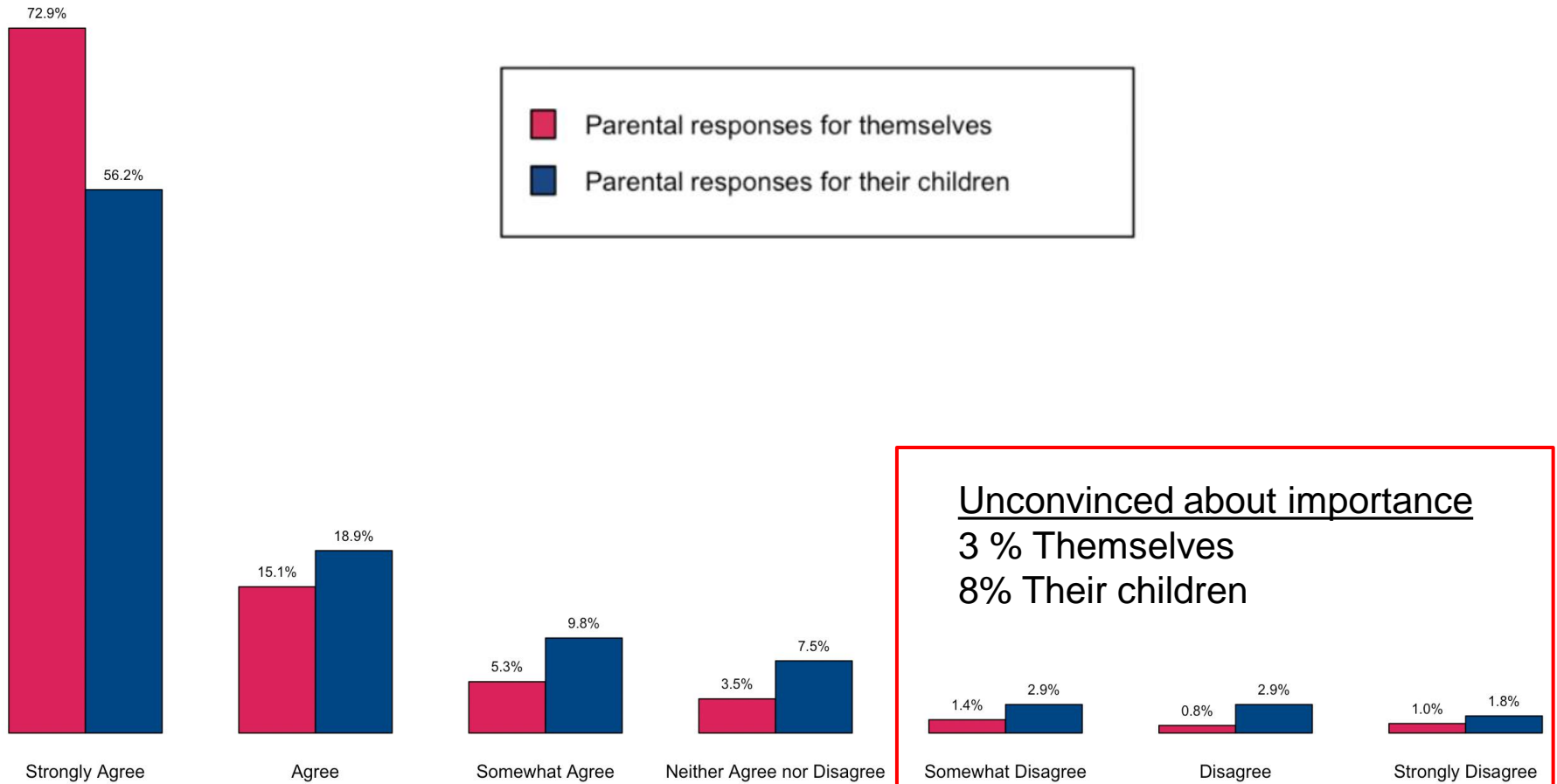


Adherence to Public Health Measures



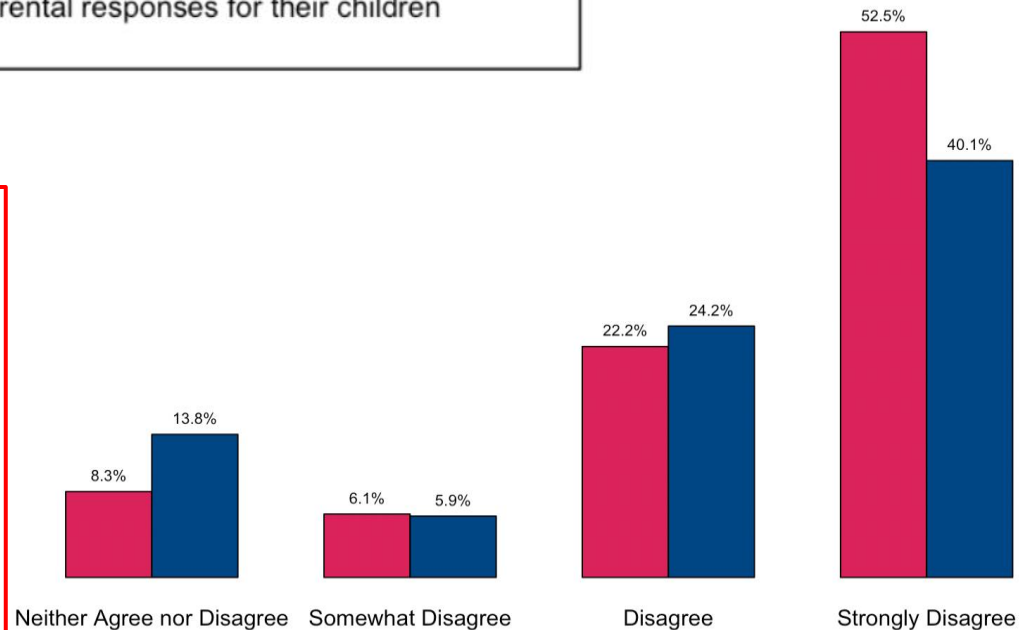
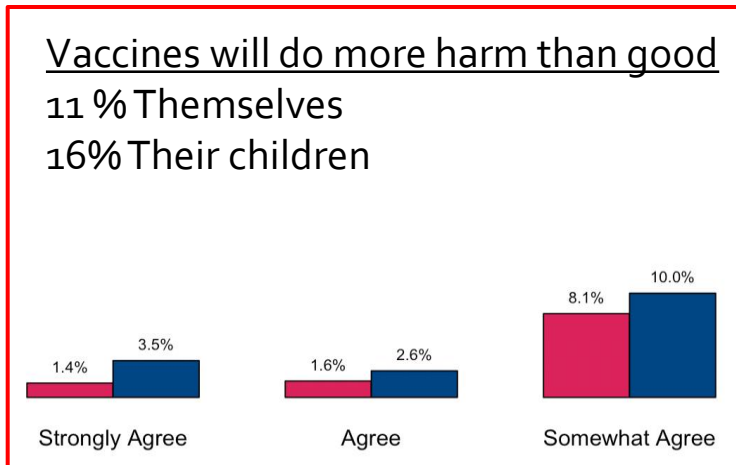
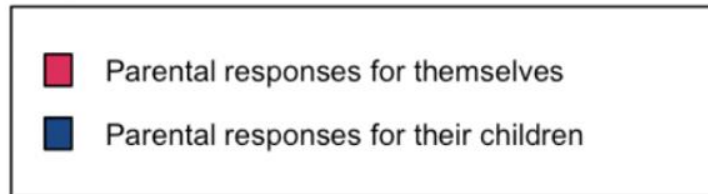
Vaccine Hesitancy

“I am convinced of the importance of COVID-19 vaccines”



Vaccine Hesitancy

“I worry that COVID-19 vaccines will do more harm than good”



Parent engagement in TARGet Kids!

- Parent And Clinician Team (PACT)
 - Est. 2018
 - A collaboration of TARGet Kids! parents and researchers to orient research around parent identified priorities
- Semi-annual meetings include
 - ~10-12 parents
 - ~2-3 researchers
 - 1 research coordinator
 - 1 student



Parent engagement in TARGet Kids!

Purpose of the Parent And Clinician Team (PACT):

- To engage parents, families, researchers and clinicians in the holistic research process, through:
 - idea generation
 - grant writing
 - protocol design
 - advocacy
 - communicating findings
 - changing clinical practice

... ultimately, improving children's health



Role of Parent Partners in COVID-19 Research

- Co-develop the study protocol
- Inform study aims by voicing their concerns and priorities as parents
- Support study feasibility by recommending changes to enhance recruitment and retention
- Co-develop questionnaires and review outcome measurement instruments, indicating what was relevant and appropriate
- Provide key logistical and technical feedback about online vs. paper questionnaires
- Serve as patient partner co-investigators on funding applications



Parent Engagement in COVID-19 Research

- Engagement among PACT members seemed to increase
 - Meetings held virtually, more often
 - Parents felt connected to the study topic
 - Parents expressed finding a sense of purpose and community

"I felt a sense of purpose and control I may not otherwise have being part of the PACT. Knowing we were in this together and 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."



Benefits



- Opportunity for parents to share their lived experience to co-produce COVID-19 research and communicate findings with their communities
- Study methods and instruments were more patient-centred
- Holding meetings over Zoom and using online document sharing was more accessible to parents and improved attendance, productivity
- PACT members learned about and volunteered for other engagement opportunities in TARGet Kids!

Next steps

- Evaluate our patient engagement strategy and PACT member experiences
- Co-present and publish study findings alongside PACT members
- Continue to improve the diversity of PACT members
 - Fathers
 - Ethnic and socio-demographic representation



Conclusion

"I have felt so fortunate to have the opportunity to participate as a parent partner. It is empowering to be able to translate the experiences we have struggled with during the pandemic into something actionable and hopefully helpful for other families. The process of providing feedback on questionnaires and how parents are engaged in research, has been very welcoming and collaborative. As well, in a time when clear and consistent messaging has not always been the case, it is reassuring to know that we are trying to provide parents and families with transparent and accurate information so they can make an informed decision that is best for them."

- PACT member



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Questions?

Acknowledgements

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