

**ORIGINAL RESEARCH**

# Bringing Parent Voices into a Pediatric Research Network Through a Virtual Parent Panel

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**Background:** Additional strategies are needed for longitudinal engagement of parents as key stakeholders in practice-based research networks (PBRNs). Our objective was to create a virtual Parent Panel for our PBRN to engage parents remotely and use their input on child health research.

**Methods:** We used an existing online parent survey study to invite parents to participate longitudinally by completing brief, monthly online questionnaires about child health research topics. The existing survey assessed perceptions and preferences for pain management of routine child vaccinations.

**Results:** Of 412 parents who completed the existing online survey, 233 parents expressed interest in participating in our Parent Panel and 131 parents confirmed interest. Of those parents, 105 provided demographic information: most were female (96%), married (83%), white (84%), between 31 to 40 years (61%), and had a college degree (83%). Parents were motivated to participate in our Parent Panel for a variety of reasons: altruism, a unique perspective, having a voice within child health research, a personal history of working within health care/research, and previous health care experiences with their children. Parents thought their participation could help research, parents, and children. We sent monthly electronic surveys with increasing parent enrollment to up to 131 parents, with monthly response rates ranging from 35% to 80%. Multiple changes have been implemented in our PBRN based on parent feedback.

**Conclusion:** We successfully created and longitudinally maintained a virtual Parent Panel by using valuable parent feedback to make changes in our PBRN. PBRNs could adapt a similar strategy to virtually engage parents as key stakeholders for improving child health research. (J Am Board Fam Med 2020;33:665–674.)

**Keywords:** Altruism, Child Health, Parents, Health Services Research, Practice-Based Research, Stakeholder Participation, Surveys and Questionnaires

## Background

Practice-based research networks (PBRNs) strive to improve health through continuous collaborations among investigators, clinicians, and patients/families

while facilitating the translation of research findings into clinical practice. PBRNs are multidimensional networks that incorporate (1) community-engaged research, (2) participatory implementation research, (3) quality improvement initiatives, (4) continuing education, and (5) the training of future generations of translational investigators.<sup>1</sup> PBRNs help identify problems in daily practice, demonstrate if treatments are effective and sustainable in real-world

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settings, and provide the “laboratory” for testing system improvements.<sup>2</sup> PBRNs directly engage the medical practice community, where communities may be defined as geographic, demographic, disease specific, or a combination of these definitions.<sup>3</sup> PBRN infrastructures allow for adjustments to the footprint of the network, community health issues, and specific needs of the providers, patients, and community members.<sup>4</sup>

For years, PBRNs have focused on engaging community partners and key stakeholders to enhance clinical research efforts in primary care settings. Engaging a community of research participants and their families can improve research participation, knowledge, translation of research-based practices, and trust in science.<sup>5</sup> Although some have argued that practice-based research is community engagement by using a participatory approach,<sup>6</sup> many PBRNs have also engaged community members and clinic staff by forming community advisory boards and patient advisory councils.<sup>3</sup> These PBRN advisory groups often review network research studies and provide feedback,<sup>3</sup> whereas some develop questions with investigators, design studies together, interpret results, and discuss dissemination strategies.<sup>7</sup> However, there are several barriers for PBRNs to engage community members, including (1) loss of autonomy at some local practices given large health care organizations,<sup>8</sup> (2) availability and travel concerns for community members, (3) lack of adequate funds and resources, (4) language barriers, and (5) being outside the scope of a network’s current interest or ability.<sup>3</sup> It can also be challenging to form a nationally represented community board.<sup>3</sup>

In addition to these barriers, PBRNs with a focus on child health can face additional challenges in forming relationships with pediatric patients of various ages and with their parents. As of 2016, there were a total of 173 PBRNs registered in the United States,<sup>9</sup> with only a small subset focused on child health (13%).<sup>10</sup> Therefore, most research on PBRN community engagement has focused on adults.<sup>6,11,12</sup> However, there are some existing models of engaging parents and community-based partners in pediatric PBRNs, including community advisory groups<sup>13</sup> and research advisory boards.<sup>14</sup> These existing models frequently include in-person meetings with a small group of community members for a set period of time with provided compensation. PBRNs spanning a wide geographic region

encounter additional logistic challenges with transportation and scheduling conflicts, which is another barrier for engagement. Therefore, additional strategies are needed to facilitate longitudinal engagement of parents as key stakeholders in PBRNs focusing on child health. Our objective was to create a virtual Parent Panel for our pediatric PBRN to engage parents remotely and seek their input on child health research topics, as well as serve as a foundation for a future Parent Advisory Board that would review study protocols.

Our pediatric PBRN, Pediatric PittNet, was founded by our Clinical and Translational Science Institute in 2007. As of 2019, our PBRN includes 31 academic and community practices, with 51 office sites in urban, suburban, and rural settings across 13 counties in western Pennsylvania. Together, over 275 providers serve approximately 272,000 privately and publicly insured patients aged 0 to 21 years, with a wide range of socioeconomic statuses. In this article, we describe our process of creating our Parent Panel, parental motivations to contribute to child health research, examples of changes we have implemented to improve our PBRN based on our Parent Panel, and suggested methods to engage parents over time.

We used an existing survey about a common child health topic to inform parents of our Parent Panel. This online survey assessed parent perceptions and preferences for pain management during routine child vaccinations. Despite the availability and efficacy of multiple pain management strategies during vaccinations, not all primary care practices use them routinely.<sup>15,16</sup> We used a cross-sectional online survey of parents aged 18 years and older who had accompanied their child to receive routine vaccines.

## Methods

### *Defining Our Parent Panel*

We defined our virtual Parent Panel as a group of interested parents willing to partner with our PBRN to provide input on child health clinical and research topics, programs, and initiatives to (1) improve families’ experience with research and (2) improve children’s health overall. Our goal was to recruit at least 100 engaged parents from western Pennsylvania. We requested that parents complete online surveys and answer questions on a variety of children’s physical and behavioral health topics via e-mail 1 to 2 times a month with no compensation.

We predicted our monthly requests for feedback would take approximately 10 to 30 minutes for parents to complete, and we requested a response within 1 to 2 weeks. We did not set time parameters for how long we expected parents to participate. We informed parents that their feedback and recommendations would be anonymously shared with research/project teams. We also informed parents that we would provide periodic reports on how their feedback impacted the research and initiatives occurring in our region. As our initial step to enhance our community engagement, we only included parents in this virtual Parent Panel (rather than youth) because we wanted to prioritize parent perspectives.

### **Forming Our Parent Panel**

From October 2018 through October 2019, we used an existing research study involving a brief online parent survey assessing perceptions and preferences for pain management of routine child vaccinations at pediatric primary care practices. We conducted this larger cross-sectional study from a convenience sample by using a 21-item (multiple-choice and free response) anonymous survey assessing parent perceptions of their children's discomfort with prior vaccinations and their preferences for pain management for future vaccines. At the end of this survey, parents were directed to click a link to another survey if interested in entering a random drawing to receive an electronic gift card and to learn more about our Parent Panel. If interested in joining the Parent Panel, parents provided contact information that was separate from any of their previous responses and was not able to be linked to their vaccine survey. Parents were recruited for the vaccine survey in 1 of 3 ways: (1) from an e-mail listing associated with our pediatric PBRN-affiliated practice group, (2) a posting on our Clinical and Translational Science Institute (CTSI) Research Registry, or (3) a targeted e-mail from this CTSI registry based on demographic information and interest in research. Eligible parents for this online survey were 18 years or older and had previously accompanied their child to a pediatric primary care office to receive routine vaccinations.

Once parents confirmed interest in participating in our Parent Panel via e-mail, we then sent new individual online surveys to members of our Parent Panel via e-mail. With ongoing enrollment from our initial survey about vaccines, we sent an online survey link requesting demographic information

from December 2018 through October 2019. Parents were sent monthly online questionnaires regarding feedback on our PBRN website and electronic message boards in waiting rooms, preferences for participation in research and the Parent Panel, ideas for improvement in pediatric offices, and specific items from research/quality improvement initiatives. Please refer to Figure 1 for our specific timeline of electronic surveys and topics sent to parents via e-mail each month. Each monthly survey included a combination of multiple choice and free response items and generally took between 10 to 20 minutes to complete. We used descriptive statistics to analyze results each month. We did not use qualitative analysis techniques to identify themes in parent responses, but rather we included a range of common topics that multiple parents described in our results below. To regularly disseminate results and keep parents up to date, we sent generalized results from the previous month's survey in an e-mail with the information and link to our next monthly survey. We included all interested parents in western Pennsylvania, even if their pediatric primary care office was outside of our PBRN, because we wanted to encourage parents to engage in child health research across our region.

## **Results**

### **Description of Our Parent Panel Members**

We had 412 parents complete the initial survey regarding vaccines, and, of those 233 parents expressed interest in participating in our Parent Panel. After a follow-up e-mail, 131 parents confirmed interest in Parent Panel participation and 105 parents (80% of 131) completed our baseline demographic survey. As shown in Table 1, of these 105 individuals, most were female (96%), married (84%), white (85%), between 31 to 40 years (61%), and had obtained a college or graduate degree (83%). Most children of our Parent Panel members had private insurance (87%), while 22% also had Medicaid. Nearly half of our members (49%) had previously participated in a research study, and about 42% of their children had participated in a research study. Our Parent Panel members came from 57 different zip codes, spanning 37 different pediatric primary care offices. All but 3 primary care practices were within our PBRN, meaning 96% of parents and their children received care in pediatric offices within our PBRN. We have

**Figure 1. Timeline, survey topic, and PBRN response to electronic parent monthly surveys.**

Date Sent	Total Recipients	Total Responses	Response Rate (%)	Survey Topic	PBRN Response
12/2018-10/2019	131	105	80	Demographic information	Analyzed data; working to diversify our Parent Panel
<b>Monthly Online Surveys</b>					
3/2019	70	37	53	PittNet Website	Updated PBRN website based on parent feedback
4/2019	80	42	53	History with health research, motivations to participate in PittNet Parent Panel, how participation can improve children's health, ideas to stay engaged with the Parent Panel, interest in joining Parent Advisory Board	Started sending parents monthly results from previous surveys; Presented information at the North American Primary Care Research Group Practice-Based Research Network Conference in Bethesda, MD in June 2019
5/2019	101	58	57	Preferences and experience with health research in pediatric primary care practice	Continually inform investigators how parents prefer to be approached about research studies they/their child may be eligible for; designed and distributed window clings to PBRN practices stating "Pediatric PittNet Research Happens Here"
6/2019	105	51	49	PittNet e-message boards in clinic waiting rooms	Updated content on e-message boards for studies based on feedback, and started to include additional slides with medical information related to preferred child health topics and our PBRN
7/2019	32	19	59	Resent 4/2019 survey to new members who had joined since the survey was first sent	PBRN team started counting each parent's monthly response and coding quality of responses to select parents from those interested in joining our Parent Advisory Board
8/2019	112	59	53	Parent Research Interest, Parent Wellness, one question parents could "Ask the Expert"	Had a national expert answer parent questions about pediatric acute otitis media infections and relayed that information back to parents
9/2019	120	56	47	Quality Improvement (QI) Project to improve adolescent chlamydia screening in network practices	Distributed parent feedback, especially regarding parent and teen clinic letters for the project, to the QI leadership team
10/2019	129	71	55	Pediatric Telemedicine	Relayed parent feedback regarding telemedicine to our local national expert and member of our clinical leadership team for the majority of network practices
11 – 12/2019	No surveys sent for winter holidays				
1/2020	128	45	35	Primary Care Provider (PCP) "After Hours" Experiences and Urgent Care Experiences	Will distribute parent feedback to network practices (delayed due to COVID-19)
2/2020	127	49	39	Parent Preferences to learn of PBRN research study results, Experiences and preferences to transition Adolescents/Young Adults to adult medical care	Will periodically include research study results in our monthly emails; Relayed information to academic practice working to improve transition process for patients (resources will then be shared to many other network practices)
3/2020	No survey sent. A message was sent to the Parent Panel with resources for COVID-19				
4/2020	127	57	45	After Visit Summary (and other practice handouts), Using the internet for health information and communication	Relayed results to clinical leadership teams; sent results to investigator requesting parent feedback on using the internet for health information and communications with PCPs

**Table 1. Parent Panel Sample Characteristics**

Characteristic	Total n (%) (n = 105)
Gender: female	101 (96.2)
Age (years)	
18–25	0
26–30	6 (5.7)
31–40	64 (61.0)
41–50	28 (26.7)
51 to older than 55	7 (6.6)
Race	
White	89 (84.8)
Black	5 (4.8)
Native Hawaiian or other Pacific Islander	1 (1.0)
Asian	5 (4.8)
More than 1 race	
Hispanic/Latino	0 (0)
Marital status	
Single	9 (8.6)
Married	88 (83.8)
Living with romantic partner, not married	4 (3.8)
Other (divorced, separated)	4 (3.8)
Education (n = 103)	
High school graduate/GED equivalent	4 (3.9)
Technical/secretarial/specialized training	1 (1.0)
Partial college	6 (5.8)
Associate or 2-year degree	7 (6.8)
College/university graduate	26 (25.2)
Graduate training/degree (Master’s, MD, PhD)	59 (57.3)
Yearly income (n = 96)	
Less than \$20,000–\$40,000	24 (25.0)
\$40,001–\$60,000	18 (18.8)
\$60,001–\$80,000	16 (16.7)
\$80,001–\$100,000	12 (12.5)
More than \$100,000	26 (27.1)
Number of children	
1	28 (36.2)
2	42 (40.0)
3	15 (14.3)
4 or more	10 (9.5)
Child insurance	
Private	91 (86.7)
CHIP	3 (2.9)
Medical assistance	23 (21.9)

GED, General Educational Development; CHIP, Children’s Health Insurance Program.

included some parent responses below if they gave us permission in writing to publish their anonymous answers.

**Parent Interest in Joining Our Pediatric PittNet**

**Parent Panel**

As shown in Table 2, we categorized parent responses into 6 main themes for parent interest in our Parent Panel. First, some parents were motivated to participate because of the importance of research. Second, many were motivated by altruistic reasons, such as “improv[ing] health care delivery,” and “further[ing] research to benefit all children.” Third, many felt they could provide a unique perspective as a parent. For example, parents “have children of various ages” and seemed excited to provide insight from a different view point. Fourth, parents were interested in participating to “have a voice” within research and to provide “feedback [that] could be a valuable component of research.” Several parents seemed excited by our Parent Panel, as 1 reported a motivation for participation was the “opportunity to provide input that could improve my children’s quality of care.” Fifth, many parents were interested in participating based on a history of health care or research employment. Last, some parents were interested in participating based on previous health care experiences with their children, including a previous “NICU experience” or experiences with “a rare genetic disorder.”

**Parent Perceptions on Improving Child Health through the Parent Panel**

As shown in Table 3, we grouped responses based on how parents anticipated their participation can help research, parents and children, and both research and parents/children simultaneously. Many parents thought their participation in our Parent Panel could improve children’s health through research, such as “giving researchers the insight I have with my child to compare with other kids,” or “contribut[ing] to research that can determine causes, cures, and prevention.” Other parents thought their participation could improve children’s health by learning from the Parent Panel and potentially helping them as parents. As an example, 1 parent thought participation in our Parent Panel could “show what might be the best for everyone, and what I can change.” Last, some parents perceived their participation could improve research/health care, as well as provide parents with up-to-date information. Several of these parents have experience in the health care field, allowing them to have various perspectives as it relates to participating in the Parent Panel.

**Table 2. Parent Motivations for Joining Our Practice-based Research Network Parent Panel\***

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Importance of research  
 “I think research into pediatric issues is very important, and I felt that if I could be a part of helping with that, that I should do so.”  
 “I think research is important so I am happy to help when I can!”

Altruistic reasons  
 “I like to assist in making things better in this world, and having more research assists in that.”  
 “Our family has been part of a research study for many years and anything I can do to help towards helping to improve the research community and families looking for help I’m glad to be a part of. I would want others to be willing to share so if my family were in need someone may have helped toward finding the answers we need.”  
 “I felt it was an opportunity to support work that could improve health care delivery, that I could fit within my existing life and schedule.”  
 “I have always been interested in helping to make care for my children, and all children, better in any way possible.”  
 “I am all for improving the health and well-being of those around me and for future generations. I have always loved science and I believe in it.”  
 “I enjoy providing my opinion:)! Plus, I’ve been lucky enough to receive great pediatric care for my child and I’d like to help make sure others also have that experience.”  
 “I’d like to help other parents!”  
 “Improving pediatric healthcare.”  
 “I believe it is important to participate in surveys to further research (in a non-invasive way) to benefit ALL children, including my own. I hope we can really help families with the research with cures and prevention. Being healthy is important. It is so easy to be in contact with people to do this with today’s technology.”

Unique perspectives  
 “I have children of various ages and interested in what would be helpful to researchers as an ‘old mom.’”  
 “I have 3 kids and I thought I could lend some good insight.”  
 “Interest in health disparities and things that make some children’s immune systems so much stronger than others.”

Having a voice  
 “I value the ability to contribute to children’s health research by having my voice heard as a parent. It is also a way of staying current with what is happening in kids’ health community and learning new things that are gaining interest in the research community.”  
 “I enjoy having a voice when it comes to my child and their health. I have always said that you can’t complain about something if you are not doing anything to make it better.”  
 “I recognize the importance of good communication between parents and medical staff and wanted to further my participation in this vital conversation in our community.”  
 “I like sharing my opinion and potentially helping with improving things, especially now that I have a child.”  
 “I feel that my feedback could be a valuable component of research.”  
 “Opportunity to provide input that could improve my children’s quality of care.”

History of health care or research work  
 “I want to help the pediatric population in any way that I can. As a nurse, I value research in the positive outcomes it brings.”  
 “I work in the field of healthcare (behavioral health) and a strong connection between primary care and behavioral health services has always been a passion of mine. I thought this would be a good place to share my thoughts on that and other things.”  
 “I used to work in research for 10 years.”  
 “I work in a health field. I enjoy sharing experiences because as a parent and health provider I can see two perspectives for situations at times.”  
 “I work in behavioral health research and wanted to contribute to research as a participant.”  
 “I am an epidemiologist - medical research is an interest of mine.”

Previous healthcare experiences with children  
 “My son’s condition and NICU experience.”  
 “I have a medically fragile child with a rare genetic disease that I also have.”  
 “My family consumes a lot of health care services, and we see a need for the system to improve.”

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\*Survey question: What made you interested in joining our Parent Panel?

NICU, Neonatal Intensive Care Unit.

***Experience of 1 of Our Parents: Kate Pompa***

“When I first joined the Panel, I was not sure what it would be like or if I would participate regularly, however, as they connected with us month after month with pertinent issues and questions that really mattered, I became fully engaged with the process. Being a part of Pediatric PittNet’s Parent Panel has allowed me the opportunity to share my opinions and views with regard to many initiatives

that affect the physical and behavioral health care that my children receive. It has also allowed me to have input on research opportunities, how I like to receive information from my primary care provider (PCP), as well as, what the best approaches are for reaching parents to keep them informed at their pediatrician’s office. It has been very rewarding to see some of our suggestions and ideas happen in my very own pediatric office, which is why I continue

**Table 3. Parent Responses on How Participating in a Practice-based Research Network Parent Panel Can Improve Children’s Health\***

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Parent responses demonstrating how participation can help research

“Better awareness of what is important to parents at the moment means health professionals can address these concerns and better children’s health.”

“I think it can give researchers and practitioners a better understanding of what we, as parents, have concerns about when it comes to our child’s health. I also feel like it might possibly draw attention to issues that aren’t generally thought about.”

“I think the more you learn about children’s health, the more you can positively influence it.”

“I hope the collective opinions of the group can influence procedures and policies. If enough of us parents share a similar experience or feeling, I hope it’s taken into consideration for future adjustments.”

“I hope the collective opinions of the group can influence procedures and policies. If enough of us parents share a similar experience or feeling, I hope it’s taken into consideration for future adjustments.”

“Our answers will contribute to research that can determine causes, cures, and prevention.”

“By giving researchers the insight I have with my child to compare with other kids.”

“Provide input as a mom and healthcare provider into programs to help other parents.”

“I look forward to contributing a parent’s point of view by sharing my opinions, thoughts, ideas and experiences to improve the services that children receive.”

“Help guide the choices and priorities of healthcare groups.”

“Hopefully with many people participating it will help in some way to improve some child’s health and in turn the family and the entire health community.”

“The more information that can be captured and utilized to inform the understanding of health, the better.”

Parent responses demonstrating how participation can help parents

“They can show what might be the best for everyone, and what I can change.”

“Having an easy way to reach out to parents to inform them of research opportunities.”

“By me having more knowledge.”

“Learning what works for others may also help my children.”

“If parents have the tools and information they need from their primary care physician, many gaps can be addressed. Parents trust their Pediatrician.”

“If we can learn how to reach parents better we can then help kids better.”

Parent responses demonstrating how participation can help both parents and research

“I believe that it can help those that play a role in my child’s healthcare to understand where parents are coming from. It also makes me aware of up and coming ideas or things going on in the healthcare field.”

“Again, having insight as a healthcare provider and a mother, I feel sometimes it helps to be able to see both sides of care.”

“I am the mom of a son with autism and epilepsy and also a pediatric nurse. I can view information from [different] points.”

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\*Survey question “How do you think your participation in the Pediatric PittNet Parent Panel can improve children’s health?”

to participate regularly. I enjoy taking the surveys and sharing my views and opinions, because it does feel like the information we share matters and I have seen firsthand some of the suggestions and initiatives being implemented at my pediatrician’s office, which makes it all the more rewarding! I hope that the Pediatric PittNet Parent Panel continues and that we can have an ongoing partnership in the future!”

**Examples of Changes within Our PBRN Prompted by Our Parent Panel**

In addition to providing generalized survey results to parents each month and frequently to study/project team leadership, our PBRN has been working to implement internal changes based on parent feedback.

*Kate Pompa*

“I have witnessed changes based on Pediatric PittNet parent feedback. I have seen television screens with [updated clinical] information [in addition to research information] in our Pediatrician’s waiting room, which was a suggestion given by this panel.”

More specifically, we have updated the research study content on our e-message boards, included some slides with information on our PBRN, and included slides containing requested medical information on common child health topics. Other examples of change include updating our PBRN website based on parent feedback to improve readability and ease of navigation. We designed and distributed PBRN signs for network practice waiting rooms to increase parental awareness of our PBRN

and pediatric research. Please see a full list of responses from our PBRN to parent feedback from each monthly survey in Figure 1. We have also directed parents to other child health resources including our CTSI Research Registry, our children's hospital website, and our health care network mobile clinical application.

### ***Engagement of Our Parent Panel Members over Time***

We sent monthly surveys starting in December 2018 and received a varying response rate from parents each month (shown in Figure 1). We received a range of 35% to 80% of parents completing each monthly survey after sending to 70 to 131 parents (increasing numbers with ongoing enrollment). Most parents provided detailed responses in several optional free-response survey questions month after month. We designed and sent parents a magnet with our logo as a small token of appreciation and to serve as a reminder of the group to which they belong. Parents also provided ideas to keep them engaged over time, including having our PBRN send a monthly newsletter of the latest updates and survey results, creating a private social media group, creating a smartphone app with notifications/alerts, and providing incentives over time.

### ***Parent Interest in Becoming More Involved in Our Parent Panel***

About 84% of parents were willing to provide feedback on specific research studies and materials more frequently than once a month. Most parents (80%) were willing to meet with our Pediatric PittNet team via teleconference or videoconference to offer in-depth input on child health research. We also had a significant interest (63%) from parents in joining a Parent Advisory Board, which we defined as a small group of engaged parents (10 to 20) who would occasionally meet in person or online. Following completion of a screening interview and training in clinical research principles and methodology, members of our Parent Advisory Board would review sections of research protocols. The training for members of our Parent Advisory Board is entitled Community Partner Research Ethics Training and Certification. This training was developed and is maintained by our University's CTSI.

### ***Future Directions***

Given the setup of our convenience sample, we need to diversify our Parent Panel by actively seeking parents of various backgrounds. Some strategies we will use to diversify our Parent Panel will be to send direct e-mails regarding research opportunities based on self-identified demographic information through our CTSI Research Registry. We can also increase advertisements and the presence of our PBRN research staff at practices with a wide range of parent backgrounds and a higher number of minority groups. We will also identify active parents to form our smaller Parent Advisory Board. Other future directions include sending interested parents separate e-mails to potentially participate in specific research studies, such as in-person or online focus groups. This group is not meant to be a research registry but rather another recruitment method for PBRN investigators that would allow engaged parents to continue to contribute to child health research. We will also work to determine the best strategies for informing investigators about using our Parent Panel in an ongoing way. Ultimately, we hope to use our Parent Panel as an additional strategy to train young investigators and research staff on best practices for recruitment and enrollment in child health research. We also plan to expand our community engagement strategies to include children, adolescents, and young adults from our PBRN.

### ***Discussion***

We set out to form a virtual Parent Panel associated with our pediatric PBRN as a model to engage key community stakeholders in child health research. We used an online survey regarding a common topic of parent experiences with child vaccines and preferences for pain management. Parents were motivated to participate in our virtual Parent Panel for a variety of reasons, including altruism, providing a unique perspective, having a voice, having a personal history of working within health care or research, and/or having previous health care experiences with their children. Our PBRN was pleased to see these common motivations for participation in our Parent Panel, as parents have various backgrounds and experiences to contribute in efforts to improve child health research. Parents also thought their participation in our Parent Panel could help research, parents, and children. Our PBRN has and will continue to use parent feedback by relaying it



to local investigators and to help form policies and strategies for child health research within our PBRN. Our PBRN has implemented changes based on parent feedback, which we hope can also improve the experiences for children and families receiving medical care within the clinical network associated with our PBRN.

Our virtual Parent Panel design is a unique strategy for PBRNs to include a large group of people in community engagement. Previous literature from pediatric PBRNs frequently involve parents participating on a Parent Advisory Board, such as the Children's Hospital of Philadelphia Pediatric Research Consortium that requires parent approval to move forward with prospective research protocols;<sup>14</sup> or Colorado Children's Outcomes Network Advisory Board asking parents to participate in working groups, design research projects, and develop aims for grant proposals.<sup>13</sup> However, these 2 models require parents to attend meetings at least quarterly or twice annually, and these PBRNs provided compensation to parents. Engaging parents longitudinally via monthly online surveys on a voluntary basis presents another strategy for community members to have a voice in child health research. Through e-mails and online surveys, we were able to longitudinally "hear" from parents month after month, without the requirement to meet in-person or online via video chat. Our PBRN has been impressed with the quantity and quality of parent responses to our monthly surveys on various topics related to children's health over time. We were also impressed that despite busy lives, most parents were interested in becoming more involved with our PBRN. Although our PBRN team enjoyed e-mail communications with parents and learning from their feedback each month, with virtual engagement, we did not have the ability to form strong interpersonal relationships, including PBRN team-to-parents and parent-to-parent relationships. Despite this trade-off, virtual engagement for our Parent Panel was a great strategy to include busy parents from many different pediatric practices and zip codes. Some parents were willing to meet other parents from the Parent Panel online or in-person, but we have not yet scheduled this opportunity. Our PBRN will continue to work on ways to keep our parents engaged over time, including allowing for the formation of interpersonal relationships.

We faced some challenges while creating our Parent Panel. Although our current Parent Panel is

generally representative of our network as a whole (predominantly non-Hispanic white, educated families), it is not representative of Pittsburgh or the nation as a whole. The racial diversity in several counties in western Pennsylvania included in this study is relatively limited compared with other regions of the country (64.8% to 94.7% of individuals self-identifying as non-Hispanic White.) Our percentage of Black Parent Panel members (4.8%) lies within the range of 1.1% to 13.4% of individuals self-identifying as Black in several suburban counties, compared with 23.2% self-identifying as Black in the city of Pittsburgh (as of 2019).<sup>17</sup> The practices encompassing our PBRN serve predominantly non-Hispanic White patients and families, with each practice having a variable number of patients with private/CHIP/Medicaid insurance. Given the nature of forming a virtual Parent Panel for our large network via a convenience sample through an online research survey, it is not surprising that more affluent, educated parents volunteered to participate. Parents who are more affluent and educated likely have more time and resources to participate in monthly online surveys. We are also not surprised that our group is primarily female given the topic of our original survey. We know that mothers typically attend their children's doctor appointments,<sup>18-20</sup> so it is likely mothers were more willing than fathers to volunteer to complete an online survey about their experiences accompanying their child to receive routine childhood vaccinations. However, as we know from previous research, many parents across the socioeconomic status spectrum are motivated to participate in research for similar reasons, most commonly altruistic reasons.<sup>21</sup> As stated above, we will actively try to engage parents of various backgrounds moving forward to ensure parent voices from minority groups are also represented. Another barrier to forming our virtual Parent Panel was that due to our anonymous survey, it was not feasible to collect information from parents who completed our vaccine survey but were not interested in learning more about or participating in our Parent Panel. In an ideal setting, our PBRN could reach families who chose not to participate in our Parent Panel to determine and potentially improve any limitations or barriers they faced.

Overall, Pediatric PittNet's Parent Panel provides a model for parent engagement in research that can be adapted by other PBRNs. We successfully created and maintained a virtual Parent Panel

using monthly online surveys and we used relevant parent feedback to make changes within our PBRN. By involving parents virtually in our Parent Panel and in a volunteer fashion, we were able to include parents from a wide geographic region and to accommodate busy schedules with limited PBRN funding. Our Parent Panel model allows for longitudinal relationships between parents and our PBRN to support pediatric research with the overall goal of improving children's health.

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