

## ORIGINAL RESEARCH

# Parent Perceptions of and Preferences for Participation in Child Health Research: Results from a Pediatric Practice-Based Research Network

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**Background:** Recruitment efforts for child health research are often based on assumptions, therefore improving knowledge about parents' perceptions and preferences could enhance engagement.

**Aim/Objective:** 1) To describe parents' perceptions about and preferences for participation in child health research within a pediatric practice-based research network (PBRN), and 2) to investigate any associations with the presence of on-site PBRN research staff, office location, and child age.

**Methods:** We conducted a 2-phase study with a convenience sample of parents from diverse office settings. Phase 1 was a qualitative assessment using semistructured, in-person interviews. Phase 2 consisted of a quantitative self-administered survey assessing: 1) perceptions of importance, benefits/motivations, and risks/barriers of child health research, and 2) preferences for recruitment method and enrollment location.

**Results:** Parents ( $n = 627$ ) uniformly perceived child health research to be important in prevention (89%), diagnosis (89%), and treatment (92%). They were motivated to participate most commonly by altruism and rarely by compensation. Parents perceived side effects (60%), discomfort (52%), and time (45%) as the main risks of participation. Most parents preferred to learn about research opportunities at their pediatric office (70%), and if interested, to enroll their child in their pediatric office (57%) or in their home (52%). Parents were significantly more altruistic and interested in participation in offices with on-site PBRN research staff and greater proximity to the University.

**Conclusions:** Child health researchers could enhance participation by using recruitment resources and enrollment strategies that match parent preferences, including engagement by on-site PBRN staff. (J Am Board Fam Med 2019;32:685–694.)

**Keywords:** Altruism, Child Health, Motivation, Parents, Practice-based Research, Primary Health Care

Advancing primary care of children depends on their participation in clinical research. However, engaging parents and obtaining required parental

consent for research participation can be challenging in primary care settings. Clinical research staff are tasked with approaching families at the time of their visit with a primary care provider, often with limited time and space. To optimize recruitment and enrollment for child primary care research, we need to understand what factors motivate or hinder parents' interest in participation.

Currently, limited research exists regarding the effectiveness of various methods to engage parents

This article was externally peer reviewed.

Submitted 25 January 2019; revised 7 May 2019; accepted 8 May 2019.

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**Funding:** Funding was obtained from the University of Pittsburgh Clinical and Translational Science Institute (NIH/NCCRR/Clinical and Translational Science Awards Grants UL1TR000005). None of the sponsors/funders participated in any way in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript.

**Conflict of interest:** none declared.

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in primary care research. However, a number of factors have been ascribed to parents' decision to provide consent, including child age,<sup>1,2</sup> race,<sup>3</sup> socioeconomic status,<sup>4</sup> child health status,<sup>2</sup> recruitment strategies,<sup>1,5</sup> type of study, and perceived risks.<sup>4,6</sup> Potential risks and benefits are among the most important factors parents consider when deciding about enrollment in child health research.<sup>7</sup> Some parents cite their main reason for participation is a potential direct benefit on the child's health,<sup>8</sup> while others want to learn more about a particular disease, improve medical knowledge, and receive new medications.<sup>9</sup> While previous research suggests several potential factors affect parental consent, there is a lack of understanding of parental concerns and preferences for recruitment and engagement. This lack of understanding can cause principal investigators to make unfounded assumptions, which could impede enrollment and consume limited resources.

Practice-based research networks (PBRNs) can support clinical research efforts within primary care settings in multiple ways, including enhancing study recruitment and enrollment. At the time of this study, there were a total of 173 PBRNs registered in the United States,<sup>10</sup> with a small subset focused on child health (13%).<sup>11</sup> Accordingly, most research on PBRN recruitment and enrollment has been with adults and has primarily focused on provider and community engagement.<sup>12–19</sup> Few PBRN studies have focused on child or parent perspectives, and these have primarily been from dental or chiropractic PBRNs.<sup>20–22</sup> To address this knowledge gap, we designed and implemented a study within our pediatric PBRN to better understand parents' perceptions about and preferences for participation in child health research. Specifically, we aimed to describe parent perceptions and preferences among various geographic regions within our network and to investigate any associations of parental perceptions and preferences with the presence of on-site PBRN research staff, the office location, and child age.

## Methods

### *PBRN Description*

The pediatric primary care PBRN utilized for this study was founded by our Clinical and Translational Science Institute in 2007. At the time of this study, our PBRN included 30 academic and com-

munity practices with over 50 office sites in urban, suburban, and rural settings across 13 counties in western Pennsylvania. Together, 240 providers served approximately 243,000 privately and publicly insured patients with a wide range of socioeconomic status.

### *Study and Survey Design*

We conducted a 2-phase study with 2 convenience samples of parents age 18 years and older. A member of the medical team (eg, medical assistant, nurse, provider) asked families if they would like to discuss a potential research study with a PBRN research staff member for both phases. Phase 1 was a qualitative assessment, consisting of semistructured, in-person parent interviews. Parents were interviewed by PBRN research staff in June 2015. Several reviewers from the research team analyzed responses to identify themes. Multiple choice response options were developed for the second phase based on the themes from Phase 1. Before distribution, we piloted the surveys with a small multidisciplinary group of primary care providers and researchers. Phase 2 was a quantitative assessment in which parents completed a brief, self-administered survey on paper or computer. PBRN research staff invited parents to complete the survey at their child's acute or preventative health maintenance visit. The survey asked a total of twenty questions, addressing: 1) perceptions of importance, benefits/motivators, and risks/barriers of child health research; 2) recruitment method preferences; and 3) enrollment location preferences. We collected surveys from August through October 2015 and July through November 2016.

### *Sample*

Eligible participants were at least 18 years of age, English speaking, and accompanying their child for an acute or preventative health care visit at their primary care office. All potentially eligible parents were approached from a total of 8 diverse pediatric primary care offices across 3 counties within the same PBRN. Four of these offices were included in Phase 1, while 6 offices were included in Phase 2: 1 was urban, 2 were suburban located north of the city, 2 were suburban located south of the city, and 1 was rural. These offices were strategically chosen to enhance future generalizability of results by representing a broad range of sample characteristics

including, but not limited to, patient race, ethnicity, and socioeconomic status.

### **Measures**

For Phase 1, we asked a general open-ended question, “What comes to mind with ‘child health research’?” We asked additional open-ended questions about previous participation in research, willingness to participate in the future, and perceived benefits and risks of children participating in health research.

For Phase 2, we asked closed-ended questions regarding parent perceptions and preferences about child health research. The main outcomes included: 1) parent perceptions about importance, benefits/motivations, and risks/barriers to participating in child health research; and 2) preferences regarding future research recruitment strategies; and 3) preferences for enrollment location. We also included 7 demographic questions: parent and child age and gender, parent race and ethnicity, and child health insurance. We used 5-point Likert scales (1 = “not at all important” to 5 = “very important”) to assess parent perceptions regarding the importance of child health research to 1) prevent childhood illnesses, 2) diagnose or identify problems, 3) treat or cure conditions, and 4) be available in this office. We used multiple choice questions to assess parent preferences for recruitment strategies. We also used 5-point Likert scales (1 = “not at all likely” to 5 = “very likely”) to assess likelihood of future enrollment in research based on location. Access to our full list of survey questions is provided in the Appendix.

### **Analytic Procedures**

Descriptive statistics were utilized to assess qualitative responses in Phase 1 to determine which response options would be included in Phase 2. For Phase 2, the 6 practices were combined into 4 groups based on geographic regions: urban, suburban 1 (north), suburban 2 (south), and rural. For questions with Likert scales, we combined response options 4 and 5 regarding the importance of research, research availability in the pediatric office, and the likelihood of future enrollment based on location. We used  $\chi^2$  analyses to evaluate differences in perceptions, preferences, and demographic characteristics among our 4 different groups. We used multivariable logistic regression to determine associations between the most common parent per-

ceptions and preferences with 1) pediatric offices with on-site PBRN research staff, 2) pediatric offices that were less than 15 miles away from the University, and 3) child age 5 years and older. Of the 6 included offices, 3 had an on-site research staff associated with our PBRN: the urban and 2 northern suburban practices. The University was chosen based on being a centralized location in the city and the well-known research hub throughout the region. The urban and 2 southern suburban offices were less than 15 miles away from the University. We performed sensitivity analyses for various distances away from the University (ie, 10 miles, 15, and 25 miles), and chose 15 miles as our cut point since that split our 6 offices equally. We chose child age of 5 years since we wanted to investigate any potential differences in parents’ perceptions and preferences based on school enrollment. We have noted missing data when participants did not answer certain questions and we perceive the data as missing completely at random. All statistical procedures were performed in SPSS Statistics, version 25 (IBM, Chicago, IL).

## **Results**

### **Study Population**

For Phase 1, 63 parents were approached and 52 completed the interview. For Phase 2, 785 parents were approached and 627 parents completed the survey. Characteristics of the parents from all 6 offices across the 4 geographic regions are shown in Table 1. Parents were mostly mothers, aged 20 to 49 years old and white. Most of their children were male, between ages 1 to 9 years, and had private health insurance. About a fifth of parents had previously participated in research, while 13% of their children had participated in clinical research.

### **Parent Perceptions of Child Health Research**

#### **Importance**

The majority of parents believed that child health research was important/very important to 1) prevent childhood illnesses, such as creating new vaccines (89%), 2) diagnose or identify problems, such as depression in teens (89%), and 3) treat or cure conditions, such as childhood cancer (92%). Twelve (2%) participants chose not to answer this question.

#### **Benefits and Risks**

As shown in Table 2, parents reported multiple benefits and/or motivations to enroll their children in

**Table 1. Sample Characteristics**

	Total, n (%)	Urban, n (%)	Suburban 1, n (%)	Suburban 2, n (%)	Rural, %	P-Value*
N	627	106	221	200	100	
Parent						
Gender: female	516 (82.3)	83 (78.3)	186 (84.2)	167 (83.5)	80	.322
Age, years						<.001
18 to 29	152 (24.2)	53 (50.0)	22 (10.0)	35 (17.5)	42	
30 to 39	295 (47.0)	35 (33.0)	114 (51.6)	103 (51.5)	43	
40 to 49+	164 (26.2)	17 (16.0)	82 (37.1)	55 (27.5)	10	
Race (n = 601)						<.001
White	478 (79.5)	7 (6.6)	210 (95.0)	175 (87.5)	86	
Black	87 (14.5)	83 (78.3)	0	0	4	
Other	23 (3.7)	6 (5.7)	6 (2.7)	10 (5.0)	1	
>1 race	13 (2.2)	4 (3.8)	1 (0.5)	4 (2.0)	4	
Hispanic/Latino	8 (1.3)	0	3 (1.4)	3 (1.5)	2	<.001
Prior participation in research	135 (21.5)	32 (30.2)	50 (22.6)	45 (22.5)	8	.001
Child						
Age, years						.011
<1	125 (19.9)	29 (27.4)	28 (12.7)	37 (18.5)	31	
1 to 4	221 (35.2)	32 (30.2)	78 (35.3)	77 (38.5)	34	
5 to 9	142 (22.6)	23 (21.7)	58 (26.2)	41 (20.5)	20	
10+	121 (19.3)	21 (19.8)	53 (24.0)	37 (18.5)	10	
Gender: male	333 (53.1)	64 (60.4)	114 (51.6)	105 (52.5)	50	.558
Insurance (n = 600)						<.001
Private	416 (69.3)	23 (21.7)	201 (91)	149 (74.5)	43	
CHIP	23 (3.8)	5 (4.7)	3 (1.4)	7 (3.5)	8	
Medical assistance	142 (23.7)	69 (65.1)	9 (4.1)	28 (14)	36	
>1	19 (3.2)	4 (3.8)	2 (0.9)	9 (4.5)	4	
Prior participation in research	82 (13.1)	14 (13.2)	37 (16.7)	22 (11.0)	9	.077

\*P-value derived from  $\chi^2$  analysis with varying degrees of freedom. CHIP, children's health insurance program.

child health research. The majority of parents believed that their child's participation in research could 1) improve care of children, such as having earlier diagnoses and treatment (74%); 2) find answers that may help other children and families (67%); 3) allow their child to receive better care than currently available, including tests and treatments (55%); and 4) learn more about their child's health condition (55%). Approximately 17% of parents selected compensation for participation as a benefit or reason to participate. In addition, 17% perceived that their child might want to participate in research as a benefit or reason to participate. Parents on average selected 3.5 ( $\pm 2.24$  SD) response options (out of 8 total) for benefits and/or motivations, while 54 (9%) participants choose not to answer.

When asked about the risks and/or barriers of children participating in health research (Table 3),

the majority of parents were concerned about side effects from treatments (60%) and discomfort from tests/treatments (52%). A significant proportion of parents also commented that their family was too busy (45%) and participation would take too much time (39%). There were statistically significant differences between the 4 groups for all potential responses, except privacy/confidentiality concerns. Parents on average selected 3.2 ( $\pm 2.1$  SD) response options (out of 8 total) for risks of participation or reasons not to participate, while 46 (7.3%) participants chose not to answer.

### **Parent Preferences Regarding Future Research Opportunities and Enrollment Location**

#### *Future Research Opportunities*

The majority of parents (64%, n = 400) wanted to be asked to consider enrolling their child in a research



**Table 2. Parents' Perceptions of Benefits of Child Health Research or Reasons to Participate\***

	Total, n (%)	Urban, n (%)	Suburban 1, n (%)	Suburban 2, n (%)	Rural, %	P-Value <sup>†</sup>
N	627	106	221	200	100	
<b>We could improve care of children (earlier diagnoses, treatment)</b>	465 (74.2)	75 (70.8)	183 (82.8)	136 (68.0)	71	.003
<b>We could find answers that may help other children and families</b>	422 (67.3)	68 (64.2)	170 (76.9)	124 (62.0)	60	.002
<b>My child may get better care (tests/treatment)</b>	347 (55.3)	74 (69.8)	123 (55.7)	103 (51.5)	47	.005
<b>We could learn more about my child's health condition</b>	346 (55.2)	70 (66.0)	134 (60.6)	101 (50.5)	40	.001
<b>Convenient (not much time, travel)</b>	169 (26.9)	29 (27.4)	74 (33.5)	54 (27.0)	12	.001
My child's doctor recommends that we participate	128 (20.4)	24 (22.6)	47 (21.3)	39 (19.5)	18	.829
<b>Compensation</b>	109 (17.3)	27 (25.5)	34 (15.4)	42 (21.0)	6	.001
<b>My child may want to participate</b>	106 (16.9)	33 (31.3)	36 (16.3)	26 (13.0)	11	<.001

\*Survey question: "What do you feel are the benefits of participation, or reasons to participate, in child health research? (Choose ALL of the following that are true for you.)"

<sup>†</sup>P-value derived from  $\chi^2$  analysis with varying degrees of freedom. Parent perceptions are bolded to indicate statistical significance.

study at a future visit to their pediatric office (Table 4). This same number of parents (64%) wanted to learn about future child health research opportunities. Of these 400 parents, 70% wanted to be asked about participation in person in their pediatric primary care office (by a physician, nurse, or research staff), while 56% wanted to learn of opportunities through email and/or text. A smaller percentage of parents wanted to learn of research opportunities through brochures (25%), messages in the waiting room (23%), practice or research web sites (23%), local Clinical and Translational Science Awards research registry (22%), and US mail (20%). Only 11.5% of parents wanted to learn of child research opportunities via social media.

There was the greatest interest in learning about future research opportunities from parents with an on-site PBRN research staff at their pediatric primary care office. Over 70% (n = 282) of participants selected more than 1 answer choice.

#### **Enrollment Location**

For all parents interested in being asked to enroll in a child research study, 57% were likely to enroll their child if the study took place at their pediatric primary care office. Parents more frequently selected a high likelihood of enrolling in their pediatric office if there was on-site PBRN research staff (61% vs 43% to 57%,  $P < .001$ ). About half of

**Table 3. Parents' Perceptions of Risks of Child Health Research or Reasons Not to Participate\***

	Total, n (%)	Urban, n (%)	Suburban 1, n (%)	Suburban 2, n (%)	Rural, %	P-Value <sup>†</sup>
N	627	106	221	200	100	
<b>Side effect concerns from treatments</b>	377 (60.1)	54 (50.9)	126 (57.0)	129 (64.5)	68	.032
<b>Concerns about discomfort from tests/treatments</b>	326 (52.0)	41 (38.7)	119 (53.8)	111 (55.5)	55	.027
<b>My family is too busy</b>	282 (45.0)	33 (31.3)	124 (56.1)	96 (48.0)	29	<.001
<b>Would take too much time</b>	244 (38.9)	27 (25.5)	114 (51.6)	82 (41.0)	21	<.001
<b>Research is too risky/not safe</b>	231 (36.8)	32 (30.2)	66 (29.9)	90 (45.0)	43	.003
<b>My child wouldn't want to participate</b>	178 (28.4)	19 (17.9)	73 (33.0)	61 (30.5)	25	.029
<b>My child is too young</b>	131 (20.9)	24 (22.6)	32 (14.5)	46 (23.0)	29	.017
Privacy/confidentiality concerns	61 (9.7)	15 (14.1)	21 (9.5)	18 (9.0)	7	.342

\*Survey question: "What do you feel are the risks of participation, or reasons not to participate, in child health research? (Choose ALL of the following that are true for you.)"

<sup>†</sup>P-value derived from  $\chi^2$  analysis with varying degrees of freedom. Parent perceptions are bolded to indicate statistical significance.

**Table 4. Preferences for Recruitment Method and Enrollment Location**

	Total, n (%)	Urban, n (%)	Suburban 1, n (%)	Suburban 2, n (%)	Rural, n (%)	P-Value*
N	627	106	221	200	100	
Would you like to learn about child health research opportunities in the future?	400 (63.8)	79 (74.5)	139 (62.9)	125 (62.5)	57 (57)	.235
How would you like to learn about potential research opportunities?†						
<b>Asked in person in this office</b>	280 (70.0)	58 (73.4)	103 (74.1)	81 (64.8)	38 (66.7)	.049
Email or texts	223 (55.8)	37 (46.8)	80 (57.6)	75 (60.0)	31 (54.4)	.730
<b>Brochure</b>	99 (24.8)	28 (35.4)	28 (20.1)	30 (24.0)	13 (22.8)	.010
Message in waiting room	91 (22.8)	15 (19.0)	32 (23.0)	31 (24.8)	13 (22.8)	.95
<b>Practice or research website</b>	90 (22.5)	9 (8.5)	25 (18.0)	40 (32.0)	16 (28.1)	.018
<b>CTSI research registry</b>	87 (21.8)	18 (22.8)	46 (33.1)	16 (12.8)	7 (12.3)	<.001
Computer screen savers in exam rooms	85 (21.3)	20 (25.3)	27 (19.4)	26 (20.8)	12 (21.1)	.369
<b>US mail</b>	79 (19.8)	0 (0)	21 (15.1)	35 (28.0)	23 (40.4)	<.001
Social media	46 (11.5)	10 (12.6)	12 (8.6)	18 (14.4)	6 (10.5)	.400
If you were interested in a research study, how likely would you be to enroll your child if the study took place in. . .						
<b>This office</b>	357 (56.9)	65 (61.3)	136 (61.5)	113 (56.5)	43 (43)	<.001
<b>Your home</b>	324 (51.7)	52 (49.1)	124 (56.1)	101 (50.5)	47 (47)	<.001
<b>Pediatric practice nearby</b>	179 (28.5)	33 (31.1)	66 (29.8)	61 (30.5)	19 (19)	<.001
<b>Children's Hospital</b>	147 (23.4)	30 (28.3)	39 (17.6)	56 (28.0)	22 (22)	<.001
<b>Children's Hospital Satellite</b>	146 (23.2)	26 (24.5)	64 (28.9)	37 (18.5)	19 (19)	<.001
<b>University of Pittsburgh</b>	91 (14.5)	40 (37.7)	15 (6.8)	20 (10.0)	16 (16)	<.001

\*P-value derived from  $\chi^2$  analysis with varying degrees of freedom. Parent preferences are bolded to indicate statistical significance.

†N = 400 for the total, rather than 627, as this question was only presented to those who answered yes to the previous question ("Would you like to learn more about child health research opportunities in the future?"). N = 79 parents in the Urban practice, N = 139 parents in Suburban 1, N = 125 parents in Suburban 2, and N = 57 parents in the Rural practice. CTSI, Clinical and Translational Science Institute.

parents (52%) would be likely to enroll their child in a research study that took place in their home. Less than a third of parents (29%) would enroll their child if a study took place at a pediatric practice nearby. A smaller percentage of parents would enroll their children if a research study took place at the children's hospital (23%), a satellite of the children's hospital (23%), and at the University associated with the children's hospital (15%). There were statistically significant differences for all locations among the 4 groups, but those in the urban setting selected a higher likelihood to enroll in a study at the University, compared with all other regions farther away (38% vs 6% to 16%,  $P < .001$ ). Fifty-four participants (9%) chose not to answer this question.

#### **Associations of Parent Perceptions and Preferences in Child Health Research Participation**

We were interested in evaluating any associations of parent perceptions of benefits/motivators and

risks/barriers of participation, as well as parental preferences for future enrollment based on 1) the presence of on-site PBRN research staff, 2) the location of their pediatric office being less than 15 miles away from the University, and 3) child age 5 years and older. As demonstrated in Table 5, we controlled for parent age, gender, race, and previous participation in research; child age, gender, previous participation in research; and distance from the University throughout all logistic regression analyses. The odds that parents perceived better care for their child by participating in research was 1.8 times higher in parents with on-site office PBRN research staff (compared with parents without on-site staff), and 1.6 times higher if they lived <15 miles away from the University (compared with those living >15 miles away from the University). The odds that parents perceived that research participation could enhance learning about their child's health condition was 1.9 times higher in

**Table 5. Associations of Parent Perceptions of and Preferences for Child Health Research Participation\***

	On-site PBRN Research Staff, OR (95% CI) <sup>†</sup>	<15 Miles Away from University, OR (95% CI) <sup>‡</sup>	Child Age ≥5 Years, OR (95% CI) <sup>§</sup>
Parent perceptions of benefits			
We could improve care of children (earlier diagnoses, treatment)	1.10 (0.72, 1.67)	<b>0.58 (0.38, 0.89)</b>	0.92 (0.58, 1.46)
We could find answers that may help other children and families	1.32 (0.89, 1.95)	0.70 (0.75, 1.32)	1.17 (0.75, 1.30)
My child may get better care (tests/treatment)	<b>1.80 (1.24, 2.63)</b>	<b>1.62 (1.11, 2.38)</b>	1.00 (0.67, 1.49)
We could learn more about my child's health condition	<b>1.91 (1.32, 2.77)</b>	1.37 (0.94, 1.99)	1.24 (0.83, 1.85)
Parent perceptions of risks			
Side effect concerns from treatments	<b>0.52 (0.36, 0.76)</b>	0.74 (0.51, 1.09)	0.78 (0.52, 1.16)
Concerns about discomfort from tests/treatments	<b>0.59 (0.41, 0.85)</b>	0.69 (0.48, 1.01)	<b>0.62 (0.42, 0.92)</b>
My family is too busy	1.29 (0.89, 1.87)	1.20 (0.82, 1.76)	1.09 (0.74, 1.62)
Would take too much time	1.38 (0.93, 2.05)	1.11 (0.74, 1.66)	0.99 (0.66, 1.50)
Parent preferences for enrollment			
Asked in this office	1.30 (0.89, 1.89)	0.99 (0.67, 1.44)	0.74 (0.49, 1.11)
Asked via email/text	0.93 (0.64, 1.37)	1.03 (0.69, 1.53)	<b>1.50 (1.00, 2.25)</b>
Parent preferences for participation			
In this office	<b>2.14 (1.40, 3.27)</b>	1.45 (0.95, 2.20)	0.89 (0.57, 1.39)
Your Home	<b>1.81 (1.19, 2.74)</b>	1.15 (0.76, 1.74)	0.83 (0.53, 1.28)
Pediatric Practice nearby	<b>1.56 (1.02, 2.39)</b>	1.48 (0.96, 2.28)	1.13 (0.72, 1.78)

OR, odds ratio; PBRN, practice-based research network; CI, confidence interval.

\*Bolded OR's are statistically significant with  $P < .05$ .

<sup>†</sup>Logistic regression models are controlled for parent age, gender, race, and previous participation in research; child age, gender, health insurance, and previous participation in research; and office <15 miles from the University.

<sup>‡</sup>Logistic regression models are controlled for parent age, gender, race, and previous participation in research; child age, gender, health insurance, and previous participation in research; and on-site PBRN research staff.

<sup>§</sup>Logistic regression models are controlled for parent age, gender, race, and previous participation in research; child gender, health insurance, and previous participation in research; presence of on-site PBRN research staff; and office <15 miles from the University.

parents with on-site office PBRN research staff, compared with those without. Lastly, the odds that parents preferred to participate in research in their pediatric office was 2.1 times higher in parents with on-site PBRN research staff (compared with those without).

## Discussion

This study captures parental perceptions of and preferences for participation in child health research. Despite various backgrounds and diverse settings, many parents shared similar perceptions regarding the importance, benefits, and risks of child health research participation. Nearly all parents, regardless of setting, perceived the important role of child health research in preventative care, diagnosis, and identification of problems, and treatment of childhood conditions. Parents reported multiple motivations to participate in child health

research, with altruistic reasons being most common. Interestingly, few parents, including those in low-income families, identified compensation as a motivation for participating in child health research. Parents uniformly perceived several risks to participation in child health research, including potential side effects, discomfort, and time requirements. Most parents preferred to be contacted about future research opportunities in person (by a physician, nurse, or research staff) at their pediatric office, followed by email and/or text. More than half of parents preferred enrolling their child in a research study that took place in their child's pediatric office, followed by their own home. After controlling for several demographic variables, there were significant differences in parent motivations and preferences for recruitment and enrollment based on the presence of on-site PBRN research staff, proximity to the University, and older child age.

Our findings regarding parental perceptions about benefits/motivations and risks/barriers to participation are similar to previous studies. Several studies report that parents frequently describe altruistic motivations and benefits of participation, including health benefits to children due to improvements in treatments, quality of life, and their understanding of health conditions.<sup>4,8,23,24</sup> Similar to our findings about risks of participation, parents have significant concerns about safety and see their role in research as guaranteeing their child's best interests, while protecting them from harm.<sup>25,26</sup> Many investigators assume that compensation can be a motivating factor to participate in research, yet our study found only a small proportion of parents were motivated by compensation. This finding is similar to other reports of parental concerns regarding compensation for their adolescents, including 21% of parents concerned about bribery and 17% of parents concerned that compensation would encourage teenagers to do something they did not want to do.<sup>27</sup>

Understanding parent recruitment preferences is important to enhance engagement and collaboration in primary care research. The majority of parents in our study wanted to be asked in person in their pediatric office. It is likely that parents want to discuss all potential benefits and risks of participation, and important factors like trust and a personal connection are lost with other methods of recruitment, such as advertisements using web sites or social media. Primary care providers have long-term trusting relationships with families and can provide reassurance to parents when they learn of a new research opportunity. Perhaps parents frequently prefer email and/or text based on the high prevalence of smart phones and their ability to provide information conveniently. Interestingly, there was a significant difference with parents in our urban practice preferring brochures to learn of future research opportunities, compared with other offices. This office had the highest percentage of children on medical assistance in our study, so it is possible financial or other psychosocial stressors could limit parents' ability to engage in research recruitment using smart phones including texts, email, Web sites, and social media.

We found significant associations of parent perceptions and preferences based on the presence of on-site PBRN research staff, office location <15 miles from the University, and child age 5 years and

older. Parents with an on-site PBRN research staff may feel more engaged with research and therefore are more likely to report altruistic motives, be less concerned with risks, and be more likely to participate in their pediatric office, home, or nearby practice. We expected to see a significant difference in parent preferences for research participation for those located >15 miles from the University, since distance is likely to serve as a significant barrier, especially when combined with the bridges and tunnels associated with our region's topography. However, despite controlling for several covariates, our survey likely did not capture all barriers parents perceive. Parents of older children (age 5 years and older) were more likely than parents of younger children to prefer email/text when considering enrolling their child in research. Perhaps electronic communication is more convenient or less time-consuming for parents with children who might be involved with extracurricular activities. Parents of older children may have been less worried about the risks of participation (side effects/discomfort) in child research, when compared with risks perceived for younger children. Most parents selected more than 1 preferred method to learn of future research opportunities, which suggests that PBRNs should use multiple enrollment strategies to engage as many parents as possible.

Despite multiple strengths, there were several limitations to our study. First, this was a cross-sectional study involving an office-based convenience sample of parents. While we were successful in selecting offices representing the range of economic and racial backgrounds of our large pediatric PBRN, our sample is not representative of the nation as a whole. Because the racial diversity of the 3 counties included in this study is relatively limited compared with other regions of the country (with 78.6% to 94.7% of individuals self identifying as non-Hispanic white), we purposely oversampled Black parents to achieve 14.5% of our total sample (compared with 1.1% to 13.4% of individuals self identifying as Black). Our sample demographics could limit the generalizability of our results to parents of different regions and/or racial/ethnic backgrounds. In addition, clustering effects are likely present within practices, yet we could not adjust for these confounding effects given our limited number of practices in our single PBRN. Both phases of this study were conducted during the same time of year (summer–fall), which could have



affected our sample characteristics. Recruitment in our rural and southern suburban practices was completed in the fall, so fewer school-aged children were seen at these offices during the academic school year. Parent perceptions and preferences regarding child health research are likely multifactorial, potentially with significant interactions among many factors, so it is possible our brief survey did not capture all potential factors and interactions. Furthermore, 1 office had research staff not associated with the PBRN, which could have biased parents' perceptions. In addition, this study collected parent perceptions and preferences from 1 time point and previous research demonstrates that parent attitudes regarding child health research can change over time,<sup>28</sup> further supporting the need for additional research in this area.

This study evaluates parent perceptions of and preferences for participation in child health research in primary care, which hopefully will prompt additional research in this area. Future research should include a longitudinal study of a large demographically diverse sample of parents. Additional research is also warranted to determine variations and demographic associations among parent perceptions and preferences and should consider surveying children to compare responses.

This cross-sectional study of a large sample of parents throughout a pediatric PBRN provides insight into the variations of parent perceptions and preferences for child health research in primary care settings. Overall, understanding parent perceptions and preferences could enhance engagement with these key stakeholders. Child health researchers should aim to use their recruitment resources more effectively by focusing on strategies and locations that match parent preferences, including using office-based PBRN staff to approach families in pediatric primary care.

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Participating parents and Pediatric PittNet practices: Children's Community Pediatrics (CCP) Armstrong: Kittanning office, Bass-Wolfson: Cranberry office, CCP GIL Pediatrics: Pittsburgh office, CCP Moon and Wexford: Wexford and South Fayette offices, CCP South Hills Pediatric Associates: Brentwood and Mon Valley offices, Children's Hospital of Pittsburgh Primary Care Center.

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# Parent Perceptions of and Preferences for Participation in Child Health Research: Results from a Pediatric Practice-Based Research Network

## Full Survey Questionnaire

Has your child ever participated in a child health research study (a research study about children's physical or emotional health, such as a clinical trial, experiment or questionnaire/survey study?)

- ☐ Yes
- ☐ No
- ☐ Don't know/Don't remember

Have you ever been asked to consider enrolling your child in a research study in this office?

- ☐ Yes
- ☐ No
- ☐ Don't know/Don't remember

If Yes, did you enroll your child?

- ☐ Yes
- ☐ No
- ☐ Don't know/Don't remember

Have you ever participated in a research study?

- ☐ Yes
- ☐ No
- ☐ Don't know/Don't remember

Are you registered in the Research Participant Registry?

- ☐ Yes
- ☐ No
- ☐ Don't know/Don't remember

How important do you feel child health research is to helping doctors and parents: (To use the sliding scale, tap on the bar under the number you want to select OR you may drag the tab to the number on the bar.) (1= "not at all important" to 5= "very important")

1\_\_\_\_\_5 Prevent childhood illnesses, such as creating new vaccines

1\_\_\_\_\_5 Diagnose or identify problems, such as depression in teens

1\_\_\_\_\_5 Treat or cure conditions, such as childhood cancer

How important do you feel it is to have research opportunities available in this office?

(To use the sliding scale, tap on the bar under the number you want to select OR you may drag the tab to the number on the bar.) (1= "not at all important" to 5= "very important")

1\_\_\_\_\_5

At a future visit to this office, would you like to be asked to consider enrolling your child in a research study?

- ☐ Yes
- ☐ No

If you were interested in a research study, how likely would you be to enroll your child if the study took place at: (To use the sliding scale, tap on the bar under the number you want to select OR you may drag the tab to the number on the bar.) (1= "not at all likely" to 5= "very likely")

- 1 \_\_\_\_\_ 5 This office  
 1 \_\_\_\_\_ 5 A pediatric practice nearby  
 1 \_\_\_\_\_ 5 A Children's Hospital satellite (North, East, South)  
 1 \_\_\_\_\_ 5 Your home  
 1 \_\_\_\_\_ 5 At Children's Hospital of Lawrenceville  
 1 \_\_\_\_\_ 5 At the University of Pittsburgh in Oakland

Would you like to learn about child health research opportunities in the future?

- ☐ Yes  
☐ No

If Yes, how would you like to learn about these opportunities? (Choose ALL that are true for you.)

- ☐ Be asked in person in this office (by your doctor, nurse, or research staff)  
☐ Message (TV) screen in our waiting room  
☐ On the computer screens in our exam rooms  
☐ Our Practice website  
☐ Research Website  
☐ Brochures  
☐ Email  
☐ U.S. mail  
☐ Texts  
☐ Social media (such as Facebook or blogs)  
☐ CTSI Pediatric Research Registry (Parents of enrolled children receive a notice by email or US mail four times each year about studies that they may be interested in, based on their children's age and health conditions and their health interests. There is no obligation to sign up for any studies.)  
☐ Other: please specify \_\_\_\_\_

What do you feel are the benefits of participation, or reasons to participate, in child health research? (Choose ALL of the following that are true for you.)

- ☐ My child may get better care (tests or treatment) than is currently available from our doctor  
☐ We could learn more about my child's health condition  
☐ We could improve care of children, such as finding earlier diagnosis or treatment for conditions  
☐ We could help to find answers that may help other children and families  
☐ My child may want to participate  
☐ My child's doctor recommends that we participate  
☐ I trust the researchers  
☐ The study is convenient (not too much time or travel needed)  
☐ Compensation  
☐ Other: please specify \_\_\_\_\_

What do you feel are the risks of participation, or reasons not to participate, in child health research? (Choose ALL of the following that are true for you.)

- ☐ Research would take too much time  
☐ My family is too busy  
☐ My child is too young  
☐ My child would not want to participate  
☐ Concern about side effects of study treatments  
☐ Concerns about discomfort from study tests and treatments, such as blood draws  
☐ Concern about my child testing something new, such as a new drug



- ☐ Fear that research is too risky or not safe
- ☐ Privacy or confidentiality concerns
- ☐ I don't trust researchers
- ☐ I don't want my child to be a "guinea pig"
- ☐ Other: please specify \_\_\_\_\_

What is your relationship to the child who has an appointment today?

- ☐ Mother
- ☐ Father

Please specify your age range:

- ☐ Less than 20 years old
- ☐ 20-29 years
- ☐ 30-39 years
- ☐ 40-49 years
- ☐ 50 years or older

Are you Hispanic or Latina/Latino?

- ☐ Yes
- ☐ No

What is your race?(Choose ALL that are true for you.)

- ☐ Black or African American
- ☐ White
- ☐ American Indian
- ☐ Alaska Native
- ☐ Native Hawaiian or other Pacific Islander
- ☐ Asian

Please specify your child's age:

- ☐ Less than 1 year old
- ☐ 1-4 years
- ☐ 5-9 years
- ☐ 10-12 years
- ☐ 13 years or older

What is your child's gender?

- ☐ Female
- ☐ Male

Please specify your child's type of health insurance:(Choose ALL that apply.)

- ☐ Private (such as UPMC or Highmark)
- ☐ CHIP
- ☐ Medical Assistance (such as UPMC For You or Gateway)