

An Online Survey to Assess Parents' Preferences for Learning About Child Health Research

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Abstract

Background: Child health research is crucial to finding safe and effective treatments for children. However, child health research can be challenging in that it can require significant resources. Additionally, parents may need to make the decision to participate in a study during a stressful situation, such as an emergency department visit. Although innovative study design and methodology are being used to try and address these challenges, a key component of conducting more efficient, relevant and successful child health research is finding better ways to engage and involve parents in the research process from study conception to dissemination of results.

Methods: We employed a cross-sectional, survey design to seek feedback from parents on 1) how they would like to learn about potential child health research studies that their child could participate in; 2) whether they would like to learn more about the research studies they are participating in; and 3) how they would like to receive information about studies they are participating in.

Results: The survey findings demonstrate that parents are interested in hearing about opportunities to participate in child health research, particularly during visits to their general practitioner/pediatrician or walk-in clinics. Most parents would like to receive updates on the progress, results, and researchers involved in studies their child has participated in. Parents would also like to be provided with support to participate in research studies (i.e., travel or child care).

Conclusion: This study is part of a larger initiative that is re-examining recruitment and retention methods to inform research teams in planning child health studies. In order to involve a wider range of parents and children in current and future studies, there must be strong engagement strategies in place, developed *with* parents, to effectively and respectfully share research opportunities, progress and results, and demonstrate that their participation matters.

Plain English Abstract

Research is important to finding safe and helpful treatments for children. But, research with children can be difficult to organize because it usually needs many hospitals to recruit enough children to participate. Also, parents sometimes are asked to make the decision for their child to participate in research during a stressful time, like an emergency department visit. Researchers are looking at new ways to design and organize studies so they are easier to do. An important part of this is finding better ways to let parents know about new studies, how to take part, who the research team is, and what the study results are.

We asked parents to fill out an online survey on how they wanted to hear about research for their child. Most of the parents who completed the survey told us that they are interested in hearing about opportunities for their child to take part in research, particularly during visits to their family doctor/pediatrician or walk-in clinics. Most parents would like to get updates on the progress, results, and the researchers involved in the studies their child has participated in. Parents would also like to be given support to participate in research studies (i.e., travel or child care). These survey results can help research

teams find better ways to share information about child health research with parents and hopefully make it easier for parents and their child to take part in a research study.

Background

Child health research is crucial to determining safe and effective treatments for children (1, 2). However, significant resources are needed to conduct the research; for instance, participation from multiple health centres are usually required in order to recruit enough participants in a timely manner. Participant recruitment challenges can also present when conducting research in acute care settings such as an emergency department. Patients tend to be there for a short time, may not live in the immediate area, there is usually no established relationship between the emergency clinician and potential research participants, and there are less opportunities for follow-up in comparison to a primary care centre or specialist clinic (3). Research in an emergency setting is also further complicated by the understandable, potential reluctance of a parent to hearing about a research study while their child is acutely ill or injured (4). The KidsCAN (5) Pediatric Emergency Research Canada (PERC) (6) Innovative Pediatric Clinical Trials (iPCT) initiative aims to address these challenges by using innovative methodology to design and conduct clinical trials in a children's emergency department (7). A key component to achieving this is finding better ways to engage and involve parents in the research process from study conception to dissemination of results, with the aim of conducting more efficient, relevant and successful child health research.

There is a major gap in the evidence base on effective recruitment strategies for research studies (8). In a recent research prioritization exercise, parents identified emergency department communication as a priority for pediatric emergency research and that community engagement in health services research should be a guiding principle for all pediatric emergency research (9). Parents are gatekeepers to their children's access to study information, and it is crucial to understand their communication preferences (10) in order to improve recruitment and retention strategies. This study sought from parents on: 1) how they would like to learn about potential child health research studies that their child might be eligible for; 2) whether they would like to learn more about the research studies they are participating in; and 3) how they would like to receive information about studies they are participating in. The results will inform the KidsCAN PERC iPCT initiative's re-examination of recruitment and retention strategies for pediatric emergency department research studies.

Methods

Study setting

The study was conducted at the University of Alberta and leveraged our partner organizations' existing parent/public advisory groups within Alberta and Manitoba. The study was approved by the University of Alberta research ethics board (#Pro00081012) with survey completion serving as presumed consent.

Study Instrument

An online survey was developed, guided by the Public and Patient Engagement Evaluation Tool (11). The survey consisted of 29 multiple choice research questions (5-point Likert scale) and 7 demographics questions and took approximately 5-10 minutes to complete. The questionnaire was only available in English.

The first page of the survey contained information about the study purpose. Participants were able to read through this page before deciding on whether to participate in the study. By clicking the "yes" button to the question "Do you agree to participate in this study?" and completing the survey, consent was implied. Participants could refuse to answer any questions, stop the survey at any time, or withdraw from the study prior to submitting the survey. Participants who did not submit their survey data by pressing the submit button were not included in the data analysis. Once submitted, the completed surveys were uploaded to a secure, Canadian server. At this point, data were anonymous, contained no identifying information and data withdrawal was no longer possible. All submitted surveys had a 100% completion rate. The completed surveys were anonymous.

Study Participant Recruitment

Participants needed to be a parent or guardian of a child and able to read English. The survey was distributed through our partner organizations' research or patient/public advisory group electronic mailing lists, which included the: (1) Alberta Strategy for Patient Orientated Research (SPOR) SUPPORT Unit Patient Engagement Panel, (2) University of Alberta - Edmonton Pediatric Parent Advisory Group, (3) George & Fay Yee Centre for Healthcare Innovation Patient and Public Advisory Group, (4) Translating Emergency Knowledge for Kids - Winnipeg Parent Advisory Group, and (5) University of Alberta and University of Calgary Healthy Infants and Children Clinical Research Program (HICCUP) database. The circulated email included the full study information letter along with a link to the survey website.

Study Design

We employed a cross-sectional, survey design. An initial email, followed by a reminder email approximately two weeks later, was sent to 261 potential participants from the electronic mailing lists between April 12, 2018 and July 15, 2018. As surveys were completed, data were submitted to the SimpleSurveys (simplesurvey.com) secure servers. SimpleSurveys software is a secure, online platform that stores data on servers in Canada, employing firewalls and three physical layers of security. Once data collection was completed, data were transferred to the researchers for analysis and long term, secure storage, and subsequently deleted from the SimpleSurveys servers. Data were cleaned and analyzed using SPSS v.25. Descriptive frequencies were calculated for demographic data and survey questions.

Results

We received 77 responses out of a potential 261 participants (30% response rate). Demographic data (Table 1) were obtained in order to understand the population sample that responded to our questionnaire. This information was self-reported, submitted anonymously and could not be traced back

to any individual. The majority of participants were female (94.8%), aged 31-40 years (51.9%) and married (88.3%). The majority of participants had either a post-secondary (28.6%) or graduate degree (49.4%), a gross annual household income of over \$100,000 (29.9%) or over \$150,000 (37.7%), and either one child (27.3%) or two children (48.1%). Most parents (77.9%) had a child that had participated in a research study, but only 28.6% had received results from that study. Parents also expressed the importance of providing the supports needed (e.g., travel, child care, etc.) to participate in a research study (83.2% agreed or strongly agreed).

Parents were asked their preference for hearing about opportunities to participate in child health research studies. Respondents were interested in hearing about opportunities to participate in child health research (Table 2) with participants stating they strongly agreed (70.1%) or agreed (28.6%). Parents were most interested (i.e., stated they either strongly agreed or agreed) in hearing about these opportunities from their child's general practitioner/pediatric appointments (88.4%), via their child's school newsletter (87.1%), in an email from their child's healthcare provider (85.8%), via a poster on a clinic waiting room bulletin board (85.8%), or via a community centre newsletter (84.5%). The use of social media to communicate about child health research had mixed responses with 20.8% of parents strongly agreeing to this form of communication and 20.8% disagreeing with its use. Radio and TV advertisements were not the preferred choices. Although most respondents either strongly agreed (19.5%) or agreed (37.7%) that they were interested in hearing about child health studies during an emergency department visit, 19.5% of respondents strongly disagreed with this approach. Interestingly, this was the highest percentage of strongly disagree responses for this category.

Parents were interested in receiving information about studies their child had participated in (72.7%). Respondents agreed or strongly agreed that they would like to receive information about study results (100%), progress (79.3%) and the researchers involved (68.9%). They preferred (i.e., agreed or strongly agreed) to receive this information via an email newsletter (92.2%) or via an email with an online link to more information (90.9%). Most parents did not prefer to get a mailed newsletter (36.4%) and 28.6% of parents neither agreed nor disagreed with this approach. Most parents also did not prefer to receive study updates via Facebook (45.5%), Instagram (61.1%) or Twitter (63.7%).

Discussion

Our findings demonstrate that parents would like information about child health studies they might be eligible for, and they would like to be updated on the research teams, progress and results of the study their child is participating in. These findings mirror results from other studies and reviews that have shown parents are interested in learning about the research teams (12) and want to be informed of research results (13; 14). Despite this, most participants do not receive this information (15).

In our study, participants did not prefer to hear about new studies through a mailed pamphlet, but rather during a visit with their child's healthcare provider or through existing general practitioner (GP), school or community centre newsletters and bulletin boards, suggesting the importance of communicating efficiently through existing, trusted organizations. However, in a systematic review comparing participant

recruitment methods for randomized control trials (RCT), how or when the information was presented or who presented the information did not influence trial recruitment, but rather the information provided (16). Recruitment strategies that increase potential participants' awareness about the health problem being studied and its impact on their health appeared to be more effective (16).

The Health Research Authority (17) in the United Kingdom has recognized that printed media may not always be the best format and recommends exploring the usefulness of other media that may be more appropriate (e.g., videos, cartoons, animations, infographics, audio) for communicating trial information. Studies have shown that receiving study information via multimedia can have several benefits over written information sheets, including enhancing the understanding of complex information (12), and providing information in appropriate depth based on patient preferences (18). Yet, these approaches may require reasonably good computer skills and reliable internet access.

Social media was not a preferred source for receiving study information by participants in our survey. However, participants were already engaged with the healthcare system through participation in previous research or part of a patient/public advisory group. While research on the effectiveness of social media recruitment is still in its infancy, studies have shown effectiveness in using social media with populations that are historically hard-to-reach (19), including LGBT young adults (20) and young cancer survivors (21).

In our study, more purposeful recruitment strategies such as emails from a child's healthcare provider did not generate more support than passively using posters. Participants had mixed responses on whether they wanted to be informed of new studies for their child during an emergency department visit, highlighting the complexity of trial recruitment within this setting and the need for more research in this area. Our findings suggest that parents are more interested in hearing about research studies in non-urgent care settings (e.g. pediatrician/GP, walk-in clinic visits), which could be venues to promote awareness of emergency department research (e.g., poster on a GP waiting room bulletin board) prior to an emergency department visit.

Interpersonal interactions and relationships between potential trial participants and recruiters can be particularly important when people find their children in urgent, unfamiliar and potentially life-threatening situations (16). In a systematic review of methods to improve recruitment to clinical trials, promising strategies included telephone reminders to non-responders, opt-out strategies, and the use of open trial designs (22). Yet, telephone reminders to recruit participants are not practical for research that is conducted during an unexpected visit to the emergency department. Further research is needed to explore the use of opt-out strategies and open trial designs within an emergency department setting and the feasibility of these strategies during the emergency care of a child.

Much uncertainty remains in the literature regarding evidence-informed recruitment strategies for pediatric trials. Recruitment challenges will persist without the evaluation of alternative approaches to recruitment (23). Further research is needed on parents' experiences and preferences for informed decision-making in stressful situations such as an emergency department visit, and the use of prior

information and alternative formats for the consent process (24). Sully, Julios & Nicholl (25) suggest more advanced statistical methods should be considered by researchers during trial planning and analysis. In order to maximize trial participation within an emergency department setting, the KidsCAN PERC iPCT initiative is incorporating a novel preference-informed complementary trial design that allows caregivers to choose which of two simultaneous trials they wish their child to participate in (7). A qualitative exploration of the reasons behind the caregiver's decision is also being planned (7).

Lack of information on study progress and results have been cited as a top barrier to success in clinical trials (26). Since 2014, it has been a regulatory requirement of the European clinical trials database (27) to provide clinical trial results to participants in a clear, comprehensive, concise, relevant and understandable format. This is not a regulatory requirement in North America, but there is increasing recognition that providing these summaries should be considered the ethical norm (28, 14). Previous research has suggested the use of printed summaries to share study results to meet participant preference and to provide a physical demonstration of appreciation for their participation (15). In our study, participants preferred electronic communication via email to receive these results, aligning with the increasing expectation and preference of people to have information available online (17).

Conclusions

Parents are interested in hearing about opportunities to participate in child health research, particularly during visits to their GP/pediatrician or walk-in clinics. Most parents would like to receive updates on the progress, results, and researchers involved in studies their child has participated in. Parents would also like to be provided with support to participate in research studies (i.e., travel or child care). Our study was an initial step in the KidsCAN PERC iPCT initiative's re-examination of recruitment and retention methods that can inform researchers in planning child health studies. In order to involve a wider range of parents and children in current and future studies, there must be strong communication strategies in place, developed *with* parents, to effectively and respectfully share research opportunities, progress and results, and demonstrate that their participation matters.

List Of Abbreviations

HICCUP - Healthy Infants and Children Clinical Research Program

iPCT - Innovative Pediatric Clinical Trials

LGBT - Lesbian, Gay, Bisexual, Transgender

PERC - Pediatric Emergency Research Canada

SPOR - Strategy for Patient Orientated Research

Declarations

Ethics approval and consent to participate

The study was approved by the University of Alberta research ethics board (#Pro00081012) with survey completion serving as presumed consent.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request

Competing interests

The author(s) declare(s) that they have no competing interests.

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Authors' contributions

S.S. and L.K. contributed to the study design. A.L. contributed to data collection and analysis. All authors contributed to the interpretation of data. L.K. drafted the manuscript and S.S. and A.L. made substantive revisions to it.

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Table 1. Demographic Characteristics

Characteristic	n (%)
Sex	
Female	73 (94.8)
Male	4 (5.2)
Age	
20-30 years	8 (10.4)
31-40 years	40 (51.9)
41-50 years	23 (29.9)
51 years and older	6 (7.8)
Marital Status	
Married	68 (88.3)
Single	9 (11.7)
Education	
High school diploma	1 (1.3)
Some post-secondary	2 (2.6)
Post-secondary certificate/diploma	14 (18.2)
Post-secondary degree	22 (28.6)
Graduate degree	38 (49.4)
Gross annual household Income	
Less than \$25,000	3 (3.9)
\$25,000-\$74,000	7 (9.1)
\$75,000-\$99,000	12 (15.6)
\$100,000-\$149,000	23 (29.9)
\$150,000 and over	29 (37.7)
Number of Children in the Family	
1	21 (27.3)
2	37 (48.1)
3	15 (19.5)
4	4 (5.2)

Table 2. Parents' Information Preferences

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I am interested in hearing about opportunities to participate in child health research studies:	54 (70.1)	22 (28.6)	1 (1.3)	0 (0.0)	0 (0.0)
· During my child's pediatrician/GP appointment	36 (46.8)	32 (41.6)	6 (7.8)	2 (2.6)	1 (1.3)
· During a visit to the emergency department	15 (19.5)	29 (37.7)	13 (16.9)	14 (18.2)	15 (19.5)
· During a walk-in clinic visit	21 (27.3)	35 (45.5)	12 (15.6)	8 (10.4)	1 (1.3)
· In a community centre newsletter	36 (46.8)	29 (37.7)	9 (11.7)	3 (3.9)	0 (0.0)
· In my child's school newsletter	34 (44.2)	33 (42.9)	5 (6.5)	5 (6.5)	0 (0.0)
· In an email from my child's health care provider	35 (45.5)	31 (40.3)	8 (10.4)	1 (1.3)	2 (2.6)
· In a poster on a school or community centre bulletin board	28 (36.4)	25 (32.5)	15 (19.5)	8 (10.4)	1 (1.3)
· In a poster on a clinic waiting room bulletin board	33 (42.9)	33 (42.9)	7 (9.1)	3 (3.9)	1 (1.3)
· In advertisements on Facebook and other social media	16 (20.8)	24 (31.2)	16 (20.8)	16 (20.8)	5 (6.5)
· In a radio advertisement	9 (11.7)	14 (18.2)	27 (35.1)	19 (24.7)	8 (10.4)
· In a TV advertisement	9 (11.7)	13 (16.9)	25 (32.5)	19 (24.7)	11 (14.3)
· From a pamphlet mailed to me	20 (26.0)	27 (35.1)	7 (9.1)	15 (19.5)	8 (10.4)

Table 3: Parents' Information Needs

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I would like to receive information about studies my child has participated in	56 (72.7)	18 (23.4)	3 (3.9)	0 (0.0)	0 (0.0)
I would like to receive information about:					
· Progress	38 (49.4)	23 (29.9)	7 (9.1)	8 (10.4)	1 (1.3)
· Results	62 (80.5)	15 (19.5)	0 (0.0)	0 (0.0)	0 (0.0)
· Researchers involved	27 (35.1)	26 (33.8)	21 (27.3)	3 (3.9)	0 (0.0)
I would like to receive this information:					
· In an email newsletter	50 (64.9)	21 (27.3)	6 (7.8)	0 (0.0)	0 (0.0)
· In a newsletter mailed to me	12 (15.6)	15 (19.5)	22 (28.6)	20 (26.0)	8 (10.4)
· In an email that includes a link to online information	41 (53.2)	29 (37.7)	3 (3.9)	3 (3.9)	1 (1.3)
· In a text that includes a link to online information	15 (19.5)	21 (27.3)	14 (18.2)	21 (27.3)	6 (7.8)
· Through a Facebook page	6 (7.8)	14 (18.2)	21 (27.3)	21 (27.3)	14 (18.2)
· Through Instagram updates	2 (2.6)	5 (6.5)	23 (29.9)	20 (26.0)	27 (35.1)
· From Twitter updates	2 (2.6)	4 (5.2)	22 (28.6)	24 (31.2)	25 (32.5)