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An online survey to assess parents' preferences for learning about child health research

Lisa Knisley[1,2] | Anne Le[1] | Shannon D. Scott[1] | the KidsCAN PERC Innovative Pediatric Clinical Trials initiative

[1]Faculty of Nursing, University of Alberta, Edmonton, AB, Canada

[2]Children's Hospital Research Institute of Manitoba, Winnipeg, MB, Canada

Correspondence
Shannon D. Scott, Faculty of Nursing, Level 3, Edmonton Clinic Health Academy, University of Alberta, 11405 87 Avenue, Edmonton, AB T6G 1C9, Canada.
Email: shannon.scott@ualberta.ca

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Abstract

Aim: Ethical and logistical issues often exacerbate recruitment problems in child health studies. This study aims: (a) to provide new knowledge on how parents want to hear about child health research and (b) to inform the KidsCAN PERC iPCT initiative's re-examination of recruitment and retention strategies for pediatric emergency department research studies.

Design: We employed a cross-sectional, survey design.

Methods: An online survey was distributed to participants (i.e., parents) through partner organizations' advisory group mailing lists. Frequencies and measures of central tendency guided data analysis.

Results: Parents are interested in hearing about child health research opportunities, particularly during general practitioner, pediatrician or walk-in clinic visits. Most parents wanted updates on the research team, progress and results and support to participate, such as reimbursement of travel and childcare costs. Results can inform research teams in the planning of communications to effectively share research opportunities, progress and results with parents.

KEYWORDS
acute care, child health, communication, emergency, patient engagement, pediatrics, research

1 | INTRODUCTION

Child health research is crucial to determining safe and effective treatments for children (Klassen et al., 2008; Modi et al., 2013). However, limitations in the availability of reliable pediatric data often forces healthcare providers to make treatment decisions for children based on evidence generated in adult patients (Klassen et al., 2008). A landmark report from the Council of Canadian Academies (2014) called for flexible and innovative approaches for child health research, including participant recruitment, to reduce inequities in health and improve the evidence base that informs pediatric medical practice. Participant recruitment is a crucial part of study design as research success often relies on having enough participants (Denhoff et al., 2015). Many studies have problems with recruitment, regardless of their setting and clinical field (Tracey et al., 2020), but ethical and practical issues often exacerbate these problems in child health (Caldwell et al., 2004; Council of Canadian Academies, 2014; Knox & Burkhart, 2007). Past regulations intended to protect children within research has led to difficulties in recruiting enough participants and/or reluctance to enroll children in studies

(Currie et al., 2010). Additionally, significant resources are needed to conduct child health research; for instance, participation from multiple health centres are usually required in order to recruit enough participants in a timely manner (Bialy, Plint, Freedman, et al., 2018). Identifying how best to recruit children into clinical trials in an efficient and ethical manner is a prerequisite for adequate and timely recruitment (Hartling et al., 2011).

Research nurses play a key role in the recruitment process, which can be particularly challenging when conducting research in acute care settings such as an emergency department (Kurt et al., 2017; Schandelmaier et al., 2016; Sully et al., 2013; Tracey et al., 2020). Patients tend to be there for a short time and may not live in the immediate area; there is usually no established relationship between the emergency clinician and potential research participants. The research process may feel rushed, and there are less opportunities for follow-up in comparison to a primary care centre or specialist clinic (Brierley & Larcher, 2011; Cofield et al., 2010; Tracey et al., 2020; Woolfall et al., 2014). Research in an emergency setting is also further complicated by the potential reluctance of a parent to hearing about a research study while their child is acutely ill or injured (Chamberlain et al., 2009). The KidsCAN (https://www.kidscantrials.ca) Pediatric Emergency Research Canada (PERC) (Bialy, Plint, Freedman, et al., 2018) 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 (Kelly et al., 2019). 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. An initial step in this process is learning more about how parents want to hear about child health research.

2 | BACKGROUND

There is a major gap in the evidence base on effective recruitment strategies for research studies (Bower et al., 2014) and successful recruitment requires a variety of approaches (Williams et al., 2018). Lack of awareness about research studies is one of many barriers to recruitment (Massett et al., 2017). Research is needed on how to communicate study information to potential and active participants and their families throughout the research process (Avins & Goldberg, 2007; Denhoff et al., 2015; Massett et al., 2017). Within child health, parents can be gatekeepers to their children's access to study information, and understanding their communication preferences can help to optimize recruitment and retention strategies (Coyne, 2010; Peay et al., 2018; Williams et al., 2018). Incorporating these preferences into research information and communication strategies may increase awareness of the importance of research and help parents make informed decisions about involving their child in research (Avins & Goldberg, 2007). A study that recruited adolescents in the emergency department optimized its recruitment by incorporating feedback from participants and families and developing a more flexible recruitment pathway that allowed participants to be recruited after discharge (Tracey et al., 2020). In a systematic review on determinants of parental decision-making in the context of pediatric clinical trials, the communication approach was an important decision-making factor (Wulf et al., 2012). Additionally, the review called for a broader approach to recruitment, beyond important legislative and regulation requirements, that considers the complexity of the process, including the needs of children and their families (Wulf et al., 2012).

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 (Bialy, Plint, Zemek, et al., 2018). Designing recruitment and retention strategies that are responsive to parents' communication preferences requires the engagement of parents in the study design (Liabo & Roberts, 2019). Public and patient engagement organizations such as the Strategy for Patient Oriented Research (SPOR, 2021) and the International Association for Public Participation (IAP2, 2018) see patient and public involvement in health research as existing on a spectrum. This study sought feedback from parents on (a) how they would like to learn about potential child health research studies that their child might be eligible for; (b) whether they would like to learn more about the research studies they are participating in; and (c) how they would like to receive information about studies they are participating in. This study is at the consultation level of the engagement spectrum (IAP2, 2018), and the results will inform the KidsCAN PERC iPCT initiative's larger re-examination of recruitment and retention strategies for pediatric emergency department research studies.

3 | THE STUDY

3.1 | Design and participants

We employed a cross-sectional, survey design. Participants needed to be a parent or guardian of a child and able to read English. An initial email, followed by a reminder email approximately two weeks later, was sent to 261 potential parents from research or patient/public advisory group 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.

3.2 | Method

The study was conducted at the University of Alberta and leveraged our partner organizations' existing parent/public advisory groups within the Canadian provinces of Alberta and Manitoba. An online

survey was determined to be the most appropriate method for this consultation phase (IAP2, 2018) to meet study timelines, decrease administrative costs and facilitate data collection across multiple geographical areas. No existing survey was identified that was relevant to the study purpose. As such, the survey questions were developed by the study team and in consultation with the KidsCAN PERC iPCT research team, including experts in patient/public engagement. The survey format was guided by the Public and Patient Engagement Evaluation Tool (Abelson & the PPEET Research-Practice Collaborative, 2015). Face validity was determined through team discussions and pilot testing with two colleagues from our partner organizations.

The survey consisted of 29 multiple choice research questions (5-point Likert scale) and seven demographics questions and took approximately 5–10 min to complete. It 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 were asked to complete the demographic questions, including their sex, age, marital status, education, household income, and number of children in the family. Following these questions, participants were asked to rate their preferences on the Likert scale (from Strongly Agree to Strongly Disagree) for (a) hearing about opportunities for their child to participate in child health research; (b) receiving information about studies their child has participated in; and (c) the importance of providing supports needed to participate in a research study (e.g. travel, child care). Additionally, parents were asked to answer "yes" or "no" to whether their child had participated in a research study. Participants who answered "yes" were asked an additional question on whether they were informed of the study results. 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.

The survey was distributed through our partner organizations' research or patient/public advisory group electronic mailing lists, which included the (a) Alberta Strategy for Patient Orientated Research (SPOR) SUPPORT Unit Patient Engagement Panel, (b) University of Alberta - Edmonton Pediatric Parent Advisory Group, (c) George & Fay Yee Centre for Healthcare Innovation Patient and Public Advisory Group, (d) Translating Emergency Knowledge for Kids -Winnipeg Parent Advisory Group, and; (e) 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.

3.3 | Analysis

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.24 (IBM, 2016). Cleaning involved removing variables automatically generated by SimpleSurveys, such as survey access date, time of first answer, time of last answer, time of submission and survey status (i.e. "submitted", "in progress"). Surveys that were accessed but not started were removed during data screening. Analysis included descriptive statistics and calculating frequencies for each survey item and corresponding Likert scale options.

3.4 | Ethics

The study was approved by the University of Alberta research ethics board (#Pro00081012) with survey completion serving as presumed consent. Participation was voluntary. The data collected were self-reported and anonymous and could not be traced back to any individual.

4 | RESULTS

We received 77 responses out of a potential 261 participants (30% response rate), which is low but fairly typical for healthcare surveys (Ammentorp et al., 2007). There were no missing data. All respondents answered each question on the survey apart from one 'no response' (Table 1) and the last question, which was a follow-up question about receiving study results. This question was only for those respondents who had answered "yes" to their child previously participating in a research study.

Demographic data (Table 2) were obtained in order to understand the population sample that responded to our questionnaire. The majority of participant 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 3) 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

TABLE 1 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 no response, n = 1	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)
It is important to provide the supports I need to participate in a research study (e.g. travel, child care, etc.)	36 (46.8)	28 (36.4)	10 (13.0)	2 (2.6)	1 (1.3)
	Yes			No	
My child has participated in a research study	60 (77.9)			17 (22.1)	
If yes, I was informed of the study results	22 (28.6)			44 (57.1)	

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, 26% of respondents either disagreed or strongly disagreed with this approach.

Parents were interested in receiving information about studies their child had participated in (72.7%) (Table 1). 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%).

5 | 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 (Martin-Kerry et al., 2019) and want to be informed of research results (Fernandez et al., 2009; Shalowitz & Miller, 2008). Despite this, most participants do not receive this information (Hallinan & Getz, 2014), which was also reflected in our results.

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. This communication approach has been supported in other research studies (Cruz et al., 2014; Harrigan et al., 2014; Peay et al., 2018; Tracey et al., 2020; Williams et al., 2018). Research nurses and team members need time to build relationships with healthcare professionals, who can be gatekeepers to patient recruitment (Hernon et al., 2020), as well as to identify and connect with relevant educational and community organizations to share study purpose and communication materials. 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 (Caldwell et al., 2010). Recruitment strategies that increase potential participants' awareness about the health problem being studied and its

TABLE 2 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–$74,999	10 (13.0)
$75,000–$99,999	12 (15.6)
$100,000–$149,999	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)

impact on their health appeared to be more effective (Caldwell et al., 2010). Additionally, removing logistical barriers to study recruitment must be considered by research teams (Leiter et al., 2015), such as providing the necessary support (i.e. travel and child care) to participate.

The Health Research Authority (2017) 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 (Martin-Kerry et al., 2019) and providing information in appropriate depth based on patient preferences (Antoniou et al., 2011). 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 adolescents (Schwinn et al., 2017) and populations that are historically hard-to-reach (Gelinas et al., 2017), including LGBT young adults (Guillory et al., 2018) and young cancer survivors (Gorman et al., 2014). 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 (Price et al., 2020; Wulf et al., 2012) 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. However, these venues may already be saturated with posters, and it is time consuming for practitioners to discuss studies with patients (Phoenix et al., 2020). The research team would need to invest time in connecting with GPs and other community partners to determine what would work best in each setting.

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 (Caldwell et al., 2010; Price et al., 2020). 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 (Treweek et al., 2013). 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 (Treweek et al., 2018). 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 (Jansen-van der Weide et al., 2015). Sully et al. (2013) 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 (Kelly et al., 2019). A qualitative exploration of the reasons behind the caregiver's decision is also being planned (Kelly et al., 2019).

TABLE 3 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)	6 (7.8)
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 healthcare 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)

Lack of information on study progress and results have been cited as a top barrier to success in clinical trials (Carroll et al., 2016). Since 2014, it has been a regulatory requirement of the European clinical trials database (The European Parliament & the Council of the European Union, 2014) 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 (Fernandez et al., 2009; Partridge & Winer, 2002). Wulf et al. (2012) argue that providing patients and their families with study results is a crucial part of empowering children and their parents within the research process. 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 (Hallinan & Getz, 2014). 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 (Health Research Authority, 2017).

6 | LIMITATIONS

Our survey was limited to people who could read English and had the technology to access the survey online. Participants self-identified as parents. Although we used our partner organizations' research or patient/public advisory group electronic mailing lists to share the survey with parents, we cannot verify whether the participants were indeed parents. Participants did not receive any incentive (e.g. gift card) to complete the survey, which may have contributed to a lower response rate (Dillman et al., 2014). Participants were already engaged with the health system as parent/public advisory group members or research participants and therefore not representative of people who may experience barriers to accessing the healthcare system or refuse to engage with it. Despite using established relationships to distribute the survey (Dillman et al., 2014) the sample size was small and limited to two provinces within Canada, and reflective of a highly select sub-group of the population in terms of higher levels of household income and education, as well as predominately married and female participants (Table 2). Our study focused on parents and did not explore the preferences of children and youth participating in clinical trials.

7 | CONCLUSION

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 childcare). This 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. It provides new knowledge for nurses working within research, primary care, schools or community organizations, on how parents prefer to hear about child health studies. In order to involve a wider range of parents and children in current and future studies, research teams must have strong communication strategies in place, developed *with* parents and healthcare providers, to effectively and respectively share research opportunities, progress and results and to clearly share with parents that their involvement matters.

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CONFLICT OF INTEREST

The author(s) declare(s) that they have no conflict of interest.

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.

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.

DATA AVAILABILITY STATEMENT

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

ORCID

Lisa Knisley https://orcid.org/0000-0003-1056-3790

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