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Reconceptualizing Recruitment in Qualitative Research

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Abstract

Adequate participant recruitment is critical for any qualitative research project. Our research team experienced numerous difficulties when attempting to recruit young adults with type 1 diabetes to discuss their transition from pediatric to adult-focused care. Using our experience as a case study, we identify the activities involved in four phases of participant recruitment: (1) development of a recruitment plan, (2) implementation, (3) participant engagement post-data collection, and (4) post-recruitment assessment. We present a new definition of participant recruitment which better captures the range of activities involved. We discuss aspects impacting recruitment in our case: the influence of other stakeholders, the dynamic nature of recruitment, recruitment of specific populations, and the challenges of recruiting within a healthcare environment. Finally, we identify and consider four factors that impact participant recruitment: communication, participant interest/value, participant trust in the research project, and participant availability and consider potential strategies for overcoming barriers related to each factor. In the end, our case underscores the centrality and potential fluidity of participant recruitment within qualitative research.

Keywords

Qualitative research, recruitment, health services research, young adults, type 1 diabetes mellitus

What is Known?

Participant recruitment is an issue faced by all qualitative researchers, but it is a topic often not covered explicitly or in depth in qualitative methodological texts. There are few detailed cases available of the issues that can arise in recruiting participants for qualitative research, particularly with young adults in a health services research context.

What the Article Adds?

The article offers a new definition and presents the activities involved in four phases of participant recruitment. It provides a detailed account of some of the issues involved in recruiting young adults in qualitative research, including the impact of other stakeholders (e.g., funders and ethics boards) and the requirement to recruit through medical clinics can have on recruitment efforts. Finally, we present four factors for analyzing issues related to inadequate recruitment and highlight the critical role of participant recruitment within qualitative research.

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Introduction

Many qualitative researchers have struggled with issues related to participant recruitment (Hudson et al., 2017; James et al., 2014; Jessiman, 2013). Failure to recruit study participants can increase costs, create barriers to timely completion, and even threaten the viability of an entire project (Adams et al., 2015; James et al., 2014; Lovato et al., 1997; Tan et al., 2016). Issues with recruitment often only become apparent after considerable effort has already gone into planning a study. While recruitment is widely acknowledged as being critical for the success of research (Hendricks-Ferguson et al., 2013; James et al., 2014; McDonagh & Kelly, 2010; Poole & Peyton, 2013; Tan et al., 2016), it is often not directly or extensively discussed in many qualitative research methodology texts, which usually focus more on the issues of sampling and determining data saturation when discussing participant engagement (Creswell, 2012; Green & Thorogood, 2009; Morse, 2012; Patton, 2015). This omission may be due to earlier attempts to distinguish qualitative research from quantitative research and its concern with getting ample numbers of participants to improve statistical power. Recruitment may be seen as merely a procedure part of conducting research and be of less interest to academics focused on learning about a particular topic. Regardless, omitting recruitment from methodological discussions obscures the potential complexity and centrality of participant recruitment within qualitative research design.

In this article, we use a recent experience of attempting to recruit young adults with type 1 diabetes to explore the issue of participant recruitment. We present this examination for several reasons. First, we want to share the specific strategies we used in our recruitment plan and how we adjusted our approach to recruitment during the study. We hope that sharing our approach and difficulties in detail will foster greater discussion around how to ultimately improve participation in qualitative research. Given that we were unsuccessful in recruiting a sufficient number of participants, we reflect on how we may have been able to improve our recruitment efforts. In assessing our experience, we identify four phases of participant recruitment and the activities involved in each phase for our project. We then present a new definition of participant recruitment that better captures the range of activities involved and identify some of the lessons learned from our case. Finally, we use this case to conceptualize some of the dynamics of participant recruitment—which includes the elements of communication, participant interest/value, participant trust in the research project, and participant availability—and consider strategies for overcoming potential barriers.

Case: Type 1 Diabetes Transition Study

Our research study, *Improving Outcomes for Youth with Type 1 Diabetes in Transition to Adult Care Through Strengthening Integration with Primary Care*, was a multi-phase project that included both quantitative and qualitative components. The project explored ways to improve the experience of young adults with type 1 diabetes as they leave pediatric care and move into the adult-focused healthcare system. One component of the project was to have focus groups with young adults who recently transitioned into adult-focused care. The option of participating in a one-on-one interview was later added at the request of one of the ethics boards reviewing our project. We invited young adults who were (1) diagnosed with type 1 diabetes before 18 years of age and (2) their pediatric provider identified as having transferred to adult care in the last 5 years at one of the three pediatric diabetes programs in the Canadian provinces of Newfoundland and Labrador (NL) and Ontario (ON) to participate. Our recruitment plan used a combination of mailed invitation packages and telephone calls to potential participants who had been identified by the diabetes programs as eligible for the project.

Our recruitment plan had numerous strengths, including having been previously used successfully by members of the research team and being conducted by experienced researchers. Before we stated recruitment, our full plan was reviewed by a patient advisory committee, three different research ethics boards, and providers involved in the care of the patients we were trying to recruit. The research team included members who cared for patients at each of the clinics from which we tried to recruit participants (Sullivan-Bolyai et al., 2007). Contact with potential participants was made by a research nurse. This nurse had knowledge of all aspects of the project and previous experience interviewing young adults (Houghton et al., 2020). Our recruitment plan also allowed for multiple attempts to contact participants and was adjusted to try and improve recruitment during the process. Despite these efforts, we were only able to recruit 3 of the 48 people invited to participate in ON and none of the 40 people invited in NL after months of effort. Because of the low number of participants, the inability to get participants at all the sites after numerous attempts, difficulties in continuing recruitment, and the timeline for completing the entire project, we ultimately closed this component of the research project without completing it. In Appendix A, we provide a detailed description of the development of our entire recruitment plan and the changes we made to it over our research project.

What is Participant Recruitment?

Reflecting on our experience, we first recognized that participant recruitment can be seen as occurring over four phases. The first phase is the development of a recruitment plan. This phase includes everything from the initial planning of the project to the securing of the ethical and institutional approvals needed for the researchers to begin contacting potential participants. The second phase is the implementation of the recruitment plan. This phase includes everything from training recruiters to the decision to end recruitment. These first two phases encompass most of what people think of when they

Table 1. Activities in four phases of participant recruitment.

Phases of Recruitment	Activities
Phase 1: Development of the recruitment plan	Identifying study objectives
	Meeting funding requirements
	Involving patient advisors and incorporating their feedback
	Identifying eligible participants
	Determining the method of data collection
	Identifying data collection sites
	Considering participation of distinct populations
	Considering eligible participant population size
	Determining when to contact participants and when data collection would occur
	Determining what would be asked of participants
	Determining what participants would receive for their participation
	Determining how to contact participants, including the number of attempted contacts
	Determining who will contact participants
	Determining who would pay any costs involved in contacting participants
	Developing of recruitment instruments
	Planning in case there were too many potential participants
	Reviewing the appropriateness of the recruitment plan
	Applying for ethical and institutional approvals
	Adjusting the recruitment plan to meet ethics board requirements
	Securing ethical and institutional approvals to contact eligible participants
Phase 2: Implementing the recruitment plan	Training recruiters
	Reconsidering the timing for implementing the recruitment plan
	Negotiating with providers/clinic staff to carry out recruitment plan
	Securing contact information for potential participants
	Contacting potential participants
	Screening participants for eligibility
	Dealing with issues arising from contacting people not eligible for the study
	Arranging for data collection
	Explaining study aims, risks, and benefits
	Obtaining informed consent
	Monitoring recruitment
	Adjusting recruitment plan
	Submitting protocol amendments to ethic boards
	Conducting activities to further enhance recruitment
	Determining the end of recruitment
Phase 3: Maintaining participant engagement	Communicating any issues with the study to participants
	Providing updates to study participants
	Disseminating findings to participants
Phase 4: Post-recruitment assessment	Assessing recruitment process
	Disseminating lessons learned from recruitment assessment to the research community

consider recruitment. But there are two other phases that should be included when considering participant recruitment. The third phase of participant recruitment is maintaining participant engagement post-data collection, which should occur, even though we did not do it for our project. Given that participants have given their time and may have a direct interest in the results of a study, it is important to maintain contact with participants even after data collection is complete (Berger et al., 2009). This continued engagement will also allow researchers to communicate any issues with the study to participants if they arise post-data collection. A fourth phase is assessing the overall recruitment activities after they are completed to see what lessons can be learned. In most qualitative research studies, this fourth phase rarely explicitly occurs, but it is a useful practice to adopt so that recruitment can be improved and lessons about recruitment can be shared amongst researchers.

In analyzing recruitment in our study, we developed a detailed description of our recruitment activities (Appendix A). We then identified the specific activities and decisions we took during each of the four phases of recruitment for our project. We also include aspects of our project that impacted or influenced our recruitment efforts. Some of these activities are clearly part of what researchers consider as part of the recruitment process, for example, identifying eligible participants and contacting them to invite them to participate. Other authors have included activities such as consenting, screening participants, enrollment, and retention in their recruitment models (Berger et al.,

2009). As we assessed our poor recruitment results, we realized that a wider range of study activities had implications for our participant recruitment, including even selecting the original research objectives for the study. The list of activities involved in participant recruitment was also more extensive than has been presented by other authors (Table 1).

Surprisingly, we found few definitions of participant recruitment provided in the academic literature. Given defines participant recruitment as "the process whereby the researcher identifies and invites (recruits) participants to join the study" (Given, 2012). Based on the range of activities we identify in our case, we propose a wider definition of participant recruitment as including *all the activities that impact the planning and engagement of participants in and after data collection, including any assessment of a study's recruitment activities*. In short, participant recruitment includes most of what you plan and do with participants next to data collection. Our definition is even more broad because it includes the phases of the study that impact on participant recruitment that may be often seen as distinct from recruitment, for example, identifying research objectives. As we discuss below, it is not that these activities are solely about recruitment, but they do impact how recruitment will occur and their potential impact on recruitment should be considered when these activities are being carried out. Looking at participant recruitment from the perspective of all the activities involved highlights its central role in any research project. It should also not be surprising given the list above that researchers may spent as much time on recruitment than they do on data collection and analysis.

Aspects of Recruitment

Our analysis identified some aspects that may be useful for researchers to consider when planning their own recruitment activities. We discuss four of them here: the influence of other stakeholders on recruitment, the dynamic nature of recruitment, recruiting specific populations, and the challenges of recruiting within a healthcare environment.

Stakeholders' Influence on Recruitment

Researchers may think of a recruitment plan as something the research team develops on its own as part of its original research protocol. We found numerous stakeholders influenced our recruitment efforts and that a recruitment plan involves a level of negotiation with other stakeholders, especially in contexts where implementation is dependent on other professionals. The conditions set by the research funders led to the project being conducted in multiple centers. This multi-center approach resulted in the project going through three different ethics reviews, with the ethics review boards influencing the timing of recruitment, the level of information about potential participants that was shared with the research team, and the methods of data collection. The funding requirement that there be a patient advisory committee led to its creation and it also provided input on our recruitment efforts. Because the participants were being identified through healthcare programs, the research team had to negotiate its recruitment plans with providers and clinical administrative staff at different centers. It is not that any of these stakeholders are responsible for the poor results of our recruitment efforts. In fact, it is likely that their input helped our overall recruitment plan. Researchers should be cognizant, however, of the extent to which other stakeholders are involved and can influence their participant recruitment.

The Dynamic Nature of Recruitment

Researchers may also think of a recruitment plan as something that they develop only at the beginning of a research project. But recruitment is dynamic and recruitment plans often have to evolve throughout a research study. Over our project, we made changes to the timing of recruitment and data collection, the methods of data collection used, how participants were to be contacted, and their level of compensation. Changes to our recruitment plan continued to occur almost to the end of data collection. These changes were either requested by stakeholders or adjustments made given the context and our low levels of recruitment. Our recruitment plans for NL and ON were the same at the beginning of the project. By the end, given the changes made, recruitment was being carried out differently between the two provinces.

Difficulties in Engaging in Young Adults

Different populations raise unique issues for participant recruitment. In our case, engaging young adults with type 1 diabetes raised issues related to their moving back and forth to university/training programs and the contact information on their medical file still being for their parents. One of the main difficulties related to the transition of young adults into the adult-focused health care is that this is a period of flux in many young adults' lives, which makes it difficult for them to maintain a connection to the healthcare system. These factors can also make recruitment difficult and add addition time to the recruitment period. Sequeira et al. (2015) were unable to analyze the control arm of their trial of a structured transition program for young adults with type 1 diabetes because a large number of people had either changed contact information or lost interest in participating in the study within a 12-month period. Some of the issues identified in our study may be, therefore, an indicator of suboptimal transition experiences, including the lack of accurate contact information and the overall poor response rates. Our research team considered when to start recruitment and data collection given the timeline of university semesters. Because we were focused on a small population who attended specific diabetes programs and we had their contact information, we did not feel that a wider engagement through social media was required, which may have been a mistake. Regardless, further examination and

sharing of research experiences to determine best practices for recruiting distinct populations, like young adults, would be helpful to qualitative researchers (Ellard-Gray et al., 2015; Spratling, 2013). Special attention must also be given to ensuring unique populations are also not biased against during recruitment (Bamidele et al., 2019; Banas et al., 2019).

Unique Issues for Qualitative Health Services Researchers

Health services research examines ways to improve the effectiveness and efficiency of our health systems by analyzing the numerous factors that impact care delivery (Canadian Institutes of Health Research, 2014). Because it is often conducted within hospitals and other healthcare institutions, qualitative health services researchers can face additional challenges regarding participant recruitment (Broyles et al., 2011). As we found, ethical concerns and legal restrictions surrounding confidentiality meant that potential participants had to be invited to participate directly by their care providers, limiting the possible recruitment strategies open to researchers who are outside patients' circles of care (Nguyen et al., 2014; Sullivan-Bolyai et al., 2007). Studies that focus on exploring patient experience with a specific medical program have a restricted patient pool from which to recruit (James et al., 2014; Poole & Peyton, 2013) and a limited number of providers and clinic staff to help recruit participants (Ellard-Grey et al., 2015). There are other logistic barriers to participating in interviews and focus groups within the healthcare setting that can hamper recruitment efforts, such as arranging a suitable time to conduct interviews and finding a suitable location (Hendricks-Ferguson et al., 2013; Lovato et al., 1997; Walders-Abramson & Larkin, 2017; Wdowik et al., 1997). More research and guidance around how to address specific issues of qualitative recruitment in specialized contexts, for example, within a healthcare context, would also be helpful to qualitative health researchers.

Assessing Participant Recruitment

Participant recruitment is, at its core, about reaching outside the research team and making a connection with a person who has a relevant experience and them agreeing to share their experience. When we reflect on the actions we took to try to bring about this connection, we found that there was four factors that we tried to influence. First, we enacted a communication strategy to let potential participants know about the study and how they could become involved. The communication back from potential participants showed us the extent to which our efforts were being successful. But potential participants do not only need to know about a study in order to participate. They must be interested or see value in participating (Kristensen & Ravn, 2015). Potential participants also need to be able to trust that the study is credible

Table 2. Advantages and potential issues with recruitment plan and implementation across four factors.

Communication	Participant interest/value	Participant trust in research project	Participant availability
Advantages			
Invitation packages Calls to participants Recruitment calls made at various times a day Toll-free phone number provided to contact research team Project described by nurse practitioner (NL) Research coordinator attending clinics (NL)	Project reviewed by young adults with type 1 diabetes and diabetes providers Offered gift card (NL)	Information packages sent from clinic they attended Invitation packages addressed directly to participants Contact information for a research team provided Communication on University letterhead Research ethics board approvals communicated to potential participants	Flexibility in timing of focus groups Availability of telephone interviews Recruitment calls made at various times a day
Potential issues			
Uncertain whether potential participants received invitation package or telephone call	Patient advisory committee not large or diverse enough Research topic chosen before involvement of the patient advisory committee Participants have competing life commitments Potential participants not interested in research topic Not enough emphasis on the benefits of the project to diabetes care	Telephone calls came from NL, which may have been unfamiliar number for participants in ON Participants unfamiliar with members of the research team Young adults may not be comfortable with participating in health research	Competing life commitments Relatively small population from which to recruit

(Ellard-Grey et al., 2015). Finally, they need to be available or able to participate. These elements can all influence the success of the recruitment plan. We found it useful to assess what we did and potential issues that may have arose in terms of these four factors (Table 2).

Assessing recruitment from these four perspectives can also highlight issues that should be addressed. Future recruitment may improve by emphasizing the benefits of research to diabetes care (Hendricks-Ferguson et al., 2013; Poole & Peyton, 2013). McDonagh and Kelly have noted that involving young people in study design helps ensure study relevance and achievable outcomes (McDonagh & Kelly, 2010); this begins with the identification of a research question that will engage the population needed for successful recruitment. While the patient advisory committee was involved in the recruitment strategy, they could have been consulted on the research topic using their experience to assess its relevance to emerging adults living with diabetes. The panel could have been more involved in the development of the information material communicated to potential participants, rather than just being requested to review the completed material.

While we discuss four key factors that we saw as impacting our recruitment issues, there are clearly other factors that should be considered when developing a recruitment plan for a qualitative research study. Houghton et al. (2020) recently completed a comprehensive review of the factors that impact recruitment within randomized healthcare trials. Although the context is different, many of the factors that they identified—for example, the level of perceived risk and gain to participants, study features, the type of communication, and encouragement of other people—are also relevant to recruitment in the qualitative research context. Their review also highlights the fact that there is no perfect recruitment strategy and that making the decision to include certain features may be viewed positively by some potential participants and negatively by others. Lessons from other reviews of interventions to improve randomized trials could also be tried and evaluated by qualitative researchers (Gardner et al., 2020; Treweek et al., 2018; van den Brink et al., 2020).

Our case study and assessment have several limitations. First, it was not initially planned as a case study. We also did not conduct a formal evaluation of our recruitment strategy nor were we able to interview any of the people who did not participate in the study. In another part of our study, we were conducting interviews with healthcare providers. For that part of the study, our study coordinator completed 9 interviews out of the 17 people asked to participate, using a similar recruitment approach. Because it was beyond the scope of our project, we did not follow up with participants to evaluate why our recruitment in one part of the study appeared to work much better than the other.

Conclusion

Our study highlights the problems that can arise for recruitment in qualitative research. Participant recruitment is not just something researchers need to consider when developing their research protocol but includes all the activities required to get participants to participate in data collection. It is clear then that recruitment can be, as it was with our study, a central and dynamic aspect of qualitative research design. While we devoted a lot of attention to our recruitment strategy, we ultimately failed to recruit enough participants for our project in two different jurisdictions. We identify four factors from which to assess potential issues with recruitment. Researchers need to carefully consider the design of their recruitment plan but should also be prepared to revise it during the study if necessary. We hope that other researchers can learn from our experience when recruiting participants in future qualitative research projects and that this case will help foster greater discussion around this topic.

Appendix A

Description of the Recruitment Strategy of Young Adults for the Type 1 Diabetes Transition Study

In this appendix, we provide a detailed account of the development of our recruitment plan for engaging young adults with diabetes in a series of focus groups, its implementation, and the changes to our recruitment efforts made over the course of our research project.

Phase 1: Development of the Recruitment Plan. Our research study, *Improving Outcomes for Youth with Type 1 Diabetes in Transition to Adult Care Through Strengthening Integration with Primary Care*, focused on improving the experiences of young adults with type 1 diabetes as they leave pediatric care and move into the adult-focused healthcare system. The overall study objectives were (1) to identify the best model of diabetes transition care for different jurisdictions and (2) to enhance the role of primary care providers in supporting young adults with type 1 diabetes (Bhawra et al., 2016; Chafe et al., 2019). The project was conducted in two Canadian provinces: Newfoundland and Labrador (NL) and Ontario (ON). It was a multi-phase project comprised both quantitative and qualitative components, with one component being planned focus groups with young adults with diabetes.

The study was supported by a grant from the Canadian Institutes of Health Research, specifically their Strategy for Patient Oriented Research's (SPOR) Quick Strikes in Primary and Integrated Health Care Innovations program. This grant had several requirements that impacted on the study design and participant recruitment. The Quick Strike program aims to fund research that could rapidly impact the healthcare system, be completed within 1 year, and had a focus on primary care. The program required that the work be conducted in more than

one Canadian province and that research teams include researchers, providers, and relevant healthcare decision makers. Finally, the research teams had to allow for patient and stakeholder contributions on how the research was conducted, which we did primarily through a small patient advisory panel consisting of two young adults with type 1 diabetes and a parent of one of the young adults.

Garvey et al. (2014) used a series of focus groups to study the experience of emerging adults with type 1 diabetes who all attended the same diabetes transition program. We planned to employ a similar approach for engaging study participants. In terms of recruitment, Garvey et al. reported getting 26 people to participate in one of 5 focus groups, with recruitment consisting of an initial call from the diabetes clinic staff and a follow-up letter about the focus group. In order to get perspectives in each province, rather than focus on only one clinic as Garvey et al. did, we planned to conduct focus groups for diabetes programs in three different cities: Markham, ON; Toronto, ON; and St. John's, NL. These centers were chosen because they all have relatively large numbers of patients with type 1 diabetes transferring from pediatric care every year, they represent various models of transition care, and the research team had a connection with the pediatric diabetes program at each center.

Emerging adults who were (1) diagnosed with type 1 diabetes before 18 years of age and (2) identified by a pediatric provider at one of the three centers as having transferred to adult care in the last 5 years were to be contacted by mail and invited to participate in the study. The invitation was to be sent directly to prospective participants from the pediatric diabetes program from which they transitioned. We considered having the program also conduct follow-up calls to potential participants, as used in the Garvey study, but providers connected to the three centers felt that this would add to the duties of already busy administrative staff. Members of the research team also had prior experience with using just an invitation package as a recruitment strategy without any previous issues. While we recognized that young adults can be a difficult population to recruit, we felt that having their contact information and the fact that all participants would be contacted from a diabetes program that they had a connection with would be able to overcome these barriers.

The research team developed invitation packages to be sent to potential participants. These packages contained a letter addressed directly to the patient inviting them to participate in the study (Appendix B), a list of the topics to be discussed in the focus group, and a copy of the study's consent form. The introduction letter contained all the elements required by the NL research ethics board. Contact information for the study coordinator and the principal investigator was provided in the letter with instructions for participants to contact her if they were interested in attending the focus group or wanted more information. This approach allowed us to invite patients to participate in the study without having their contact information directly shared with the research team. While somewhat cumbersome, this approach for reducing the amount of personal health information shared with the research team had been used by members of the research team before and it had in the past been required by one of the local research ethics review boards.

The research team were to provide each of the three programs with envelopes containing all components of the invitation package except the introduction letter. An electronic copy of the letter was shared with each program. The administrative staff and a clinician at each program were then to identify patients who met our inclusion criteria at their center, address a copy of the introduction letter to each patient, print and put the addressed introduction letter into an invitation package, printed a label with the patient's name and mailing address which the clinic had on file, attached the label to the invitation package, and mailed the invitation package. Because of the small number of invitation packages being sent and some complications in arranging to pay the diabetes programs from our research grant account, postage was ultimately paid by the three diabetes programs as an in-kind contribution to the project.

Once receiving the invitation package, if the patient was interested in participating in a focus group, they would call the study coordinator to register. We planned to include the first 10 willing respondents at each center, with a goal of having 6–10 people per focus group. To meet this recruitment goal, our plan was to initially send out 20 invitation packages per center. A list of individuals who indicated that they were willing to participate in a focus group but who were not in the first 10 to respond was to be kept by the study coordinator in case subsequent focus groups were deemed necessary.

All materials and our overall recruitment plan were reviewed and approved by our patient advisory panel, with only some small revisions being suggested to the wording of introduction letter and the focus group questions. We then prepared ethics applications in order to get approvals to conduct the focus groups.

Ethics Approvals. The first revisions to our recruitment plan occurred due to changes requested by the various health research ethics boards from which approvals were required. We required ethics approvals from each of the centers where we planned to hold focus groups. NL has a single ethics board, the *Newfoundland and Labrador Health Research Ethics Authority* (HREA, n.d.), which is responsible for all health ethics reviews in the province. In Ontario, we were required to get ethics approvals from the hospital ethics boards at Markham Stouffville Hospital and the Hospital for Sick Children. Although we originally submitted the same recruitment strategy to all three ethics boards, the boards required changes in our applications which resulted in different recruitment processes being used in ON and NL.

The ethics boards at Markham Stouffville Hospital and the Hospital for Sick Children both suggested and later approved an opt-out recruitment approach. This approach allowed the

diabetes programs at both ON sites to send information packages to people with type 1 diabetes who met our study inclusion criteria. Potential participants were provided a toll-free number in the information package with instructions for those who wanted to request not to be contacted by the study team. The contact information that the pediatric clinic had for the patients to whom packages were sent was then shared with our study coordinator. After a 2-week period to give people the opportunity to opt out of being contacted, our research coordinator called to invite each person to one of two focus group sessions we were planning in the Toronto area.

The ethics board at the Hospital for Sick Children also requested that all participants be given the option of doing a telephone interview if they wanted to participate in the study but were unable to attend either of the focus group sessions. Although the inclusion of a new method of data collection can be a significant change to a qualitative research project's design, the research team felt that adding interviews could help us reach more participants. To be fair to potential participants, we decided to offer this option at each of the three centers even though it was only requested by one ethics board.

In NL, the ethics board required that recruitment for the focus groups be conducted through the diabetes program that patients attended and that no patient contact information was to be provided by the clinics to the research team. This approach was in keeping with the original recruitment strategy that we developed.

Because it was required to establish the financial account for the grant, we applied for ethics approval in NL as soon as we were awarded the grant. Ethics approval for the project in NL was granted on May 18th, 2016. We submitted ethics applications just for the focus groups at the ON centers in early 2017, but because of the length of the review process and the conditions placed on by one of the ethics board that a data sharing agreement be in place between the universities and healthcare institutions involved before the focus group proceed, ethics approvals for the two centers in ON were not in place until September, 2017.

Phase 2: Implementing the Recruitment Plan. Our study coordinator, who had a background in nursing and previous experience in recruiting participants for medical research projects, was responsible for overseeing recruitment for the focus groups. She had been involved with the project from the start, including in the development of the entire recruitment plan, so that she did not require any additional training before starting recruitment.

A lot of consideration was given by the research team around the best timing to start recruitment and to hold focus groups. We were mindful that many of the people we were trying to recruit were likely engaged in university or in other training programs. Many may have also been away from the family home during this educational/training period. Delays in getting all the required administrative approvals meant that we could not start recruitment until the middle of October 2017. Because participants were going to be in contact with our study coordinator to indicate their interest in the study, we decided to have several potential dates for the focus groups, both before and after the holiday season. We would confirm the date and time of the focus groups based on the potential availability of the people who indicated their willingness to attend. This flexibility was intended to best accommodate those willing to participate and maximize the number of participants who could be part of the study.

Study Recruitment in Ontario. In Ontario, information packages were sent from the pediatric diabetes program at Markham Stouffville Hospital on November 20th, 2017, to 24 potential recruits identified as having recently transferred to adult care from either Markham Stouffville Hospital or the Hospital for Sick Children. We did not receive any requests not to contact potential participant within 2-week period after sending out the information packages.

The ON diabetes programs shared the contact information of whom they sent invitation packages with the study coordinator, who began calling potential participants in early December 2017. We were unable to contact many individuals for various reasons: no answer, had phone numbers that were no longer in service, or the phone number on file at their pediatric diabetes program belonged to their parents. One parent who was contacted got somewhat agitated because we called to talk to their child who no longer lived with them. The study coordinator was in St. John's. Potential participants in Ontario may not have answered the call because the caller IDs displayed a NL area code that would have been unfamiliar to them. Two of the people we talked to about the study mentioned the strange area code. Of those who were contacted, most reported that they had not received an information package, even though a package were mailed to their address which was on file at the pediatric diabetes clinic. Calls to this list of 24 people were made again over the holiday period when we thought that individuals might be more available. Recruitment was poor despite efforts to make calls on weekends, in the evening, and at different times of the day. Of the 24 people contacted in the first round of recruitment in ON, only two people agreed to participate in the study.

Following the poor initial level of recruitment, a second wave of 24 packages was sent on March 5th, 2018, to another 24 potential participants. Recruitment calls were made between mid-March and early April. Recruitment was again poor, with people reporting not having received the information package, said that they were too busy to participate, no answer at the phone number, or the phone numbers on file being out of service. As with the previous round of recruitment, potential participants were provided with a toll-free number to call if they did not want to be contacted by the study coordinator. One person called and left a message saying that they wanted to participate in the study, but he could not be reached after numerous follow-up attempts. Ultimately, only 1 individual in the second group of 24 potential participants

agreed to participate. A focus group was proposed to three people in Ontario who agreed to participate in the study, but all opted to do an individual interview, which were all conducted by telephone within 2 days after the person agreed to be interviewed.

Study Recruitment in NL. In 2017, a new young adult diabetes program was started in St. John's. While we originally planned to recruit through the pediatric program that patients had attended, we were advised by local providers before we started recruitment that this young adult program was now the most appropriate program to distribute the information packages to potential participants. The arrangement was for patients to be briefly told about the study by their nurse practitioner at their next regular clinic visit and be given a study information package. Participants were directed to call the study coordinator if they were interested in participating in a focus group or to get more information about the study. An amendment was made to our ethics application to approve this change in our recruitment strategy.

In mid-October 2017, information packages were handed out by a nurse practitioner to the first 20 patients who were eligible for our study as they came to the young adult diabetes clinic. Our study coordinator attended the clinics, waiting in the waiting room, to answer any questions potential participants had about the study. None of the potential participants asked the study coordinator any questions as they left the clinic sessions she attended. Those given information packages had to call the study coordinator to indicate their interest in participating in the study. No calls were received from any of the patients following the first round of invitations.

Members of the research team in NL then met to discuss the problem of young adult recruitment in St. John's. One member of the patient advisory committee also attended the meeting. After meeting with members of both the pediatric and adult clinics involved, we made some changes to our recruitment strategy for the next round of invitations. First, providers from both the adult diabetes clinic and the patients' previous pediatric clinic now felt that patients may have a better connection with their previous pediatric program given that they would have attended that program for a longer time. We revised the information letters and arranged for them to be sent directly from the pediatric clinic to 20 patients who had transferred into adult care in the last 3 years. Second, members of our research team had previous success in recruitment by offering a small remuneration for participation. Both the research team and the patient advisory member felt that a $20 gift card for a local supermarket would be appropriate. We revised the information package to indicate that all participants were to receive a $20 gift card for groceries. Finally, based on experience in ON, we ask people just to participate in an interview, which we now thought would be easier for participants than attending a focus group at a specified date. In order to make these changes, we had to submit another amendment to our original ethics application, which was approved on February 26th, 2018.

The second round of information packages were sent from the pediatric clinic on March 8th, 2018. The packages had the patient's name and address on the envelope and a letter addressed to them inside the envelope. Ultimately, none of the people who were invited in this second round of invitations contacted the study coordinator to indicate their willingness to participate.

On April 23, 2018, the research team discussed the participant recruitment issues with the focus group component of the project. We discussed a number of considerations including the likelihood that further efforts would not result in greater participation, the willingness of clinic staff to further assist with contacting potential participants, and the timeline for completing the entire project. Based on these factors, we decided not to attempt a third round of participant recruitment and to close this component of the study (Table A1).

Appendix B

Example Invitation Letter

[Institutional Letterhead]

[Date]

Dear [Patient's Name],

We are conducting a research study to find out about the experiences of young adults with type 1 diabetes during their transition to adult care. The name of the study is *Improving Outcomes for Youth with Type 1 Diabetes in Transition to Adult Care Through Strengthening Integration with Primary Care.*

We hope to learn about any gaps in services and other issues patients like you had during their move into adult care. We also want to hear your ideas on how we could improve this transition for other patients in the future, and about the potential role family physicians could play in supporting young adults with type 1 diabetes.

To help with our study, we are asking you, as someone who has recently made this transition into adult care, to participate in a telephone interview. A list of the questions you will be asked to discuss is attached with this letter. Also included is a copy of the consent form we will review with you before the start of the interview. The interview should take around 30 minutes. Your interview will be audio-recorded and transcribed. In appreciation of your participation in our study, you will be provided at $20 Sobeys gift card.

Before agreeing to participate in this research, we encourage you to read the following explanation of this study. It describes the purpose and procedures of the study. It also explains that you can stop participating in the study at any time. This study has been approved by *the Newfoundland and Labrador Health Research Ethics Authority.*

Table A1. Recruitment Process Timeline.

Event	Date
Grant awarded	March 11th, 2016
Ethics approval in NL	May 18th, 2016
Ethical approval in ON	September, 2017
Information packages given in the clinic to the first 20 eligible young adult patients in NL	Mid-October, 2017
First round of information packages are sent from Markham Stouffville Hospital to 24 potential participants in ON	November 20th, 2017
Phone call follow up begins for the first wave of 24 young adults in ON	Mid-December 2017
Revised ethics approval in NL including the $20 gift card	February 26th, 2018
Second round of information packages are sent to 24 more potential participants in ON	March 5th, 2018
Information packages and letters sent to 20 patients who had transferred to adult care in the last 3 years with the promise of a $20 gift card	March 8th, 2018
Phone call follow up begins for the second wave 24 young adults in ON	Mid-March–April, 2018
Decision to end recruitment for focus groups	April 23rd, 2018

Explanation of Procedures. We are looking at experiences of young adults with type 1 diabetes during their transition to adult care in order to identify ways to improve the transition for patients and reduce any adverse health outcomes. One of the focuses of the study is on the role that family physicians can play in better supporting patients. Participating in the study means participating in an interview that asks about your experience in moving from the child health to the adult health environment, any issues that you faced, and recommendations you have for making the transition better.

Before the start of the interview, you will be asked to review a consent form (a copy of which is included with this letter) indicating that you understand the nature of your involvement in the study and are freely agreeing to participate in this study. Additionally, you understand that you are free to refuse to answer any question and to withdraw from the study at any time.

Risks and Discomforts. There are no risks expected from your participation in the study. Thinking about your negative healthcare experiences may make you uncomfortable.

Benefits. Hopefully, participation means the chance to talk about your thoughts and concerns about your healthcare. We hope that by understanding the concerns of young adults like you, we will be able to make improvements in care for future patients.

Confidentiality. During this project, only the researchers will have access to the study information. The results of the research may be printed in a professional health journal or presented at professional meetings, but these descriptions of the project will not identify the names of people who participated. The information from this study will help to guide healthcare professionals to be more effective in providing adolescent and young adult friendly healthcare.

Withdrawal without Prejudice. Participation in this study is completely voluntary. You are free to refuse to participate or to stop participating at any time. You are also free to refuse to answer any question during the interview that you do not want to.

Further Questions. If you are interested in participating in this study, please contact [Suppressed] at [Suppressed] to register for the interview. She is the study research coordinator who will be conducting the interview with you.

The project is being led by Dr. Roger Chafe. Please contact him at [Suppressed] if you have any questions.

Thank you for considering our project.

Sincerely,

Acknowledgments

Thank you to the diabetes clinics at the Janeway Children's Health and Rehabilitation Centre (St. John's, NL), Major's Path (St. John's, NL), Markham Stouffville Hospital (Markham, ON), and SickKids Hospital (Toronto, ON) for their assistance in recruiting the patients for this study.

Declaration of conflicting interests

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Ethical approval

Ethics Approvals for this study were granted by the Newfoundland and Labrador Health Research Ethics Authority and the hospital research ethics board of the Hospital for Sick Children and of Markham Stouffville Hospital (Markham, Ontario).

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