Practical and Ethical Issues in Conducting
Health Research with Refugees

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Abstract

Research is needed in Canada to understand refugees’ health challenges and barriers to accessing health services. There are practical and ethical challenges for engaging refugees as participants.

This study observed five recruitment methods and three informed consent strategies for four Government Assisted Refugee (GAR) language groups (Somali, Arabic, Karen and Farsi/Dari) in British Columbia. Demographic, attitudes and knowledge questionnaires were administered and language concordant focus groups explored participant perspectives on practical and ethical research issues.

Participants’ knowledge and experience with research was generally low particularly for groups with low formal education. Recruitment success was influenced by participants’ familiarity with the research team. Twenty-three variables impacting participants’ willingness to participate in research were identified. There were high rates of consent form signing which were even higher with implied consent options. Participants’ identified challenges and strategies for the informed consent process.

This research provides guidance for involving Canadian refugees in health research.

Keywords: Refugees; research; ethics; recruitment.
Dedication

This thesis is dedicated to the government assisted refugees who participated in this study with the hope that it would lead to improved health care services for future refugees coming to Canada.
Acknowledgements

I would like to acknowledge the Canadian Institutes for Health Research for a $10,000 Meetings, Planning and Dissemination Grant that funded this research project and the University of British Columbia Clinical Scholar Program and the TUTOR-PHC program for personal funding and support during my Master of Health Science.

I would like to thank the participants of the British Columbia Refugee Cohort Study Workshop in March 2010 for creating the impetus for this study, in particular to Dr Rolando Barios for his inspiration and support. I would like to acknowledge my supervisors Dr Nicole Berry and Dr Janusz Kaczorowski for their insightful guidance and feedback.

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<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>GAR</td>
<td>Government Assisted Refugee</td>
</tr>
<tr>
<td>BC</td>
<td>British Columbia</td>
</tr>
<tr>
<td>NCC</td>
<td>New Canadian Clinic</td>
</tr>
<tr>
<td>RA</td>
<td>Research Assistant</td>
</tr>
<tr>
<td>CIC</td>
<td>Citizenship and Immigration Canada</td>
</tr>
<tr>
<td>UNHCR</td>
<td>United Nations High Commission for Refugees</td>
</tr>
<tr>
<td>CIHR</td>
<td>Canadian Institutes for Health Research</td>
</tr>
<tr>
<td>IFH</td>
<td>Interim Federal Health Program</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Government Assisted Refugee</td>
<td>Government-assisted refugees are Convention Refugees Abroad whose initial resettlement in Canada is entirely supported by the Government of Canada or Quebec. This support is delivered by Citizenship and Immigration Canada supported non-governmental agencies.</td>
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1. **Introduction**

1.1. **Refugee health in Canada: The need for more research**

Canada is a multicultural nation and every year hundreds of thousands of individuals make Canada their new home. Canada settles over 200,000 economic immigrants and their families per year. Additionally, Canada resettles between 10,000 and 12,000 refugees annually from nearly 70 different nationalities. The three main classes of refugees include government assisted refugees (GARs), privately sponsored refugees and refugee claimants. Studying the health and healthcare needs of Canada’s newcomer populations is important. As a whole, there is some evidence to suggest that a “Healthy Immigrant Effect” exists where immigrants on average are healthier than their Canadian born counterparts. However, when refugees are analyzed separately, they have higher age standardized mortality rates than other immigrants.

Refugees have complex migration histories leading to health concerns prior to, during, and after settlement in their new host countries. Given the health challenges for refugees, timely access to appropriate health care is essential to both physical and mental wellness and the ability to settle successfully in Canada. Unfortunately, there are barriers to accessing health care for refugees at the health system, individual and provider level. These barriers often translate into decreased utilization of needed health care services and ultimately refugees experience a decline in health status after arrival in Canada.

Canada has an international reputation for its leadership in accepting refugees. The current government has been increasing refugee resettlement by about 20% per year and in 2013 plans to resettle up to 14,500 refugees and other vulnerable persons per year. Given Canada’s commitment to the resettlement of refugees and the known barriers faced by refugees in accessing health care, there is a surprising lack of
Canadian data on the health of refugees. Robust evidence is needed to assist policy makers in designing health policy, programs, and services for refugees. Designing, implementing and evaluating changes in refugee health care policy and changes to the healthcare system will continue to be difficult without readily available, reliable and valid data. For example, the lack of data on refugee health had practical implications in 2012 when the government instituted federal cuts to refugee health care benefits. Concerns expressed by health care practitioners across the country were motivated by the potential implications of these cuts. Tension between health care providers and Citizenship and Immigration Canada (CIC) has continued to date. Research on Canadian refugee health has been conspicuously absent from discussions on both ends, impairing the ability to engage in evidence based policy that would help to reorganize and improve health service delivery for this vulnerable population.

Recognizing this need for further research, the development of a longitudinal cohort study of GARs in British Columbia (BC), Canada has been proposed (Chapter 2). GARs are a subset of refugees that are selected abroad through the United Nations High Commission for Refugees (UNHCR) and receive permanent residency on arrival in Canada. About 2,000 to 3,000 GARs are settled in Canada yearly. These refugees often come from areas of prolonged conflict and many GARs have spent years in refugee camps with substandard housing, food, education and health care. Due to the predictable and documented arrival of this sub-group of refugees they are an easier group to study in a systematic manner. Understanding the health trajectories of this subset of vulnerable new Canadians is important to identify and address common health concerns and barriers to accessing care and improving health outcomes. While GARs do not reflect the overall diversity of all refugees in Canada, understanding the health of this population could provide insight into health issues for all refugees in Canada. Refugee claimants, while also an underserved and under-researched subset of refugees, arrive in Canada with less predictable patterns through various ports of entry making this population more difficult to enroll in longitudinal research and study using administrative databases.

The development of a longitudinal cohort study of GARs could lead to a wealth of high quality quantitative health data. This data would lead to novel understanding of changes in refugee health during the settlement process. Data from such research
would be a resource for health care providers, policy makers, advocacy groups, and the refugee community.

Stakeholders in BC support the need for a prospective, longitudinal cohort study of GARs, yet also perceive major barriers to carrying it out. This support was established during a one day workshop with key stakeholders in refugee health care held in BC in March 2010. This workshop was funded by a Canadian Institutes for Health Research (CIHR) Meetings, Planning and Dissemination Grant. Twenty-six academics, clinicians and community advocates attended the workshop. While there was strong support for the need for health research for the GAR populations in BC and for the methodological strengths of a cohort study, there were ethical and practical concerns about engaging newcomers in research activities shortly after arrival.

In particular, the proposed methodology for a longitudinal cohort study of GARs in BC would necessitate engaging GARs in the recruitment process while still residing centrally at the refugee settlement house in Vancouver before dispersing into the greater Vancouver area. This would require the first contact to take place within three weeks of arrival in Canada. Recruitment during this vulnerable phase could lead to lack of comprehension, involuntary participation and, ultimately, the possibility of harm to participants. On the other hand, fear and uncertainty may lead to low recruitment rates which would limit the ability to conduct research on a representative sample of newly arrived refugees. A better understanding of the practical and ethical issues of conducting research with refugees in Canada was needed. This research gap subsequently became the topic for this dissertation.

1.2. Research with refugees: Practical issues

Looking broadly at engaging ethnic minority populations in research, these populations can be more difficult to recruit for a host of reasons\(^1\). Ethnic minorities tend to be a more mobile and harder to reach population. There are also communication challenges due to language and cultural barriers\(^2\). For those with a history of trauma or injustice, fear and suspicion may make individuals wary of participation\(^3\). As a
consequence, ethnic minorities may not participate in research despite it being in their own best interest or the interest of their community.

Due to these practical barriers to engaging minority populations in research, many researchers have shown interest in understanding the effectiveness of different recruitment methods for minority populations\textsuperscript{14,17,18} and suggestions have been made\textsuperscript{17-19}. However, while some studies have clearly documented research and recruitment challenges that are particular to refugees\textsuperscript{20,21} for the most part, strategies for recruitment of refugees specifically are lacking.

The knowledge base for understanding research recruitment and participation strategies for minority populations generally and refugees specifically has mostly relied on researcher’s observations or hypotheses about refugee preferences in studies designed for other purposes. Studies designed specifically to assess recruitment strategies are sparse and almost all of them leave out the participant’s voice.

1.3. Research with refugees: Ethical issues

Current understanding of the ethical issues in research with refugees is imbedded within a broader context of the application of Western research bioethics to vulnerable populations\textsuperscript{22}. Western research bioethics is focused on beneficence and non-malfeasance of research for the participant, the participant’s own autonomy in relation to research, as well as the underlying issue of justice with respect to the balance of who contributes to research and who benefits\textsuperscript{23}. Within this paradigm, ensuring beneficence, non-malfeasance, autonomy and justice in research with vulnerable population relies heavily on the informed consent process.

While there is a growing body of literature contemplating research ethics with refugee populations\textsuperscript{24-27}, there has not been a study to date designed with the specific purpose of understanding how to ethically conduct research with refugees. Our understanding of the ethics of involving refugees in research has been limited to theory, speculation, conclusions extrapolated from research with other vulnerable populations, and researchers’ ad hoc commentary on ethical concerns arising in studies designed for
Recommendations for improving the informed consent process with refugees have been suggested based on this literature however the knowledge base from which these recommendations are drawn is lacking. In particular, the voice of refugees, their knowledge about research and their perspectives about the informed consent process are conspicuously absent from this discourse. Without this component, our ability to create culturally sensitive, effective informed consent processes is limited.

1.4. Research goals

Given the lack of understanding of the practical and ethical issues of recruiting refugees in Canada to engage in research, further work on the creation of a longitudinal cohort study of GARs in BC was suspended.

The goals of this research were to acquire new understanding of practical and ethical issues in conducting research with refugees. Specifically, we aimed to achieve this through two parallel research processes. The first was by designing a study specifically focused on examining and understanding practical and ethical issues in conducting research with refugees, not as an add-on element of a larger study. The second was to explore refugees’ perspectives about practical and ethical aspects of participating in health research. Overall, this study attempted to identify factors that influence refugees’ willingness to participate in research and factors that contribute to conducting research ethically.

The overriding objective in acquiring this knowledge was to aid in the creation of optimal and appropriate recruitment methods and ethical informed consent processes for research with refugees in Canada and beyond.

1.5. Research questions

Understanding the practical and ethical issues involved in conducting research with refugees and understanding refugees’ perspectives towards participating in health research involved several major areas of inquiry.
For assessing practical issues, we first sought to assess which study factors influenced whether or not refugees’ participated in our research. Secondly, we inquired directly about participants’ perspectives on factors that influenced refugees’ willingness to participate in research generally.

Similarly, we assessed ethical issues by observing the knowledge and misconceptions refugees had about the informed consent process and identified challenges and facilitators for conducting the informed consent process with refugees using a traditional Western bioethical framework. Secondly, we sought participants’ perspectives on research ethics to see if there was alignment in participants’ worldview with respect to research ethics or if new paradigms needed to be explored.

### 1.6. Research design

Recruitment of four different government assisted refugee language groups took place using five different planned and unplanned recruitment strategies and recruitment success rates were closely monitored. Informed consent took place using three different methods for documenting consent and participant choices were carefully observed. Lastly, four focus group sessions with language concordant research assistants explored participants’ perspectives on practical and ethical issues in health research.

The overall methodology and research procedures are explored in greater depth in chapter four which is devoted to methods.

### 1.7. Structure of thesis

The next chapter of this manuscript presents a more in depth review of health care issues for refugees in Canada and the case for new research. The chapter was written by Patricia Gabriel with input from four co-authors and was published in the Canadian Journal of Public Health in 2011.

Following this, a second background chapter, Chapter 3, reviews ethical issues for conducting research with refugees and other migrant populations. This chapter was
written with Dr Kevin Pottie and is in-press for publication in Migration and Health: A Research Methods Handbook.

Following these background chapters, chapter 4 discusses the research questions and methodological considerations guiding the study design and describes methods of data collection and analysis. Chapters 5 provides context for interpreting the results of this study by providing a detailed ethnographic description of the research team and the qualitative focus group sessions.

Chapters 6 through 9 focus on the results of this research. The topics for these chapters align with the research questions and are titled “Refugees knowledge about and experience with research”, “Practical Issues for conducting research with refugees: Comparing different recruitment strategies”, “Recruitment of refugees for health research: Adding refugees’ perspectives”, and “The Informed consent process for research involving refugee participants”. These chapters are designed to stand alone as publishable articles, each including a section for introduction, methods, results, discussion and conclusion.

This manuscript ends with chapter 10, a concluding chapter that ties the results together and proposes the next steps towards a fuller understanding of the practical and ethical challenges in research with GARs and refugees more generally.
2. Refugees and healthcare - the need for data: Understanding the health of government assisted refugees in Canada through a prospective longitudinal cohort study.

This chapter was written by Patricia Gabriel with four co-authors and was published in the Canadian Journal of Public Health in 2011\textsuperscript{12}. Permission has been granted for its use in this thesis.

2.1. Abstract

Canada is a country of immigrants and refugees. These populations face unique health challenges and barriers to accessing health care services. Amendments to the Canadian Immigration and Refugee Protection Act in 2002 have resulted in an increase in refugees with complex medical needs. However, little is known about health of refugees on arrival and their subsequent health care trajectories.

There is an urgent need for an improved understanding of refugee demographics and health status on arrival, changes in health status over time, utilization of health services, and characteristics associated with optimal health outcomes. This knowledge gap could be addressed through the creation of a longitudinal cohort study of government assisted refugees (GARs) in British Columbia (BC). The provision of services for GARs in BC lends itself readily to the creation of a prospective GAR cohort. This, combined with access to highly reliable, valid, and comprehensive administrative databases available through Population Data BC, would allow for longitudinal follow up, and insure low attrition rates.
Establishment of such a cohort would improve knowledge of refugee health and could guide health service providers and policy makers in providing optimal services to GARs.

2.2. There are a significant number of refugees in Canada

Canada resettles between 10,000 and 12,000 refugees annually from nearly 70 different nationalities. Of these, 2,000 to 3,000 are government assisted refugees (GARs). GARs are refugees selected abroad and are appointed as Permanent Residents on arrival in Canada. In June 2002, amendments were made to the Canadian Immigration and Refugee Protection Act (IRPA) in order to assist refugees in urgent need of protection. This resulted in the removal of pre-existing medical conditions as a barrier to settlement in Canada leading to new challenges for our health care system to meet the needs of incoming refugees.

2.3. There are unique health challenges for refugees

While there is some evidence to suggest that a “Healthy Immigrant Effect” exists when refugees are analyzed separately, they have higher age standardized mortality rates than other immigrants. This can be attributed to pre-migration experiences such as the stress of war and evacuation, physical abuse, sexual abuse, the challenges of life in a refugee camp, poor sanitation, poor nutrition, lack of access to health care and mental health concerns. On arrival, refugees have a high incidence of infectious diseases such as tuberculosis, syphilis, hepatitis B and gastrointestinal parasites and mental health concerns.

2.4. There are barriers to accessing health care for refugees

Given the health challenges of refugees, timely access to appropriate health care is essential to physical and mental wellness, and the ability to settle successfully in Canada. GARs are eligible for basic provincial health care coverage on arrival in
addition to one year of extended coverage through the Interim Federal Health (IFH) program\textsuperscript{35}. However there are often delays in securing provincial coverage and difficulties with accessing services through the IFH program\textsuperscript{32,36}. Individual-level barriers to accessing care such as difficulties with language, finances, transportation, mistrust of healthcare workers, perceived lack of access and lack of familiarity navigating the health system further compromise access to health care\textsuperscript{33,36-39}. At the provider level, feeling overwhelmed, insufficient reimbursement and time, lack of services, and lack of training to deliver culturally appropriate care are additional barriers\textsuperscript{32,33,40}.

These barriers often translate into decreased utilization of needed health care services\textsuperscript{41}. Results from a pilot study in Canada indicated that recent refugees have a lower utilization rate for physicians and hospital services compared to other residents\textsuperscript{10}. Other studies worldwide support this underutilization pattern\textsuperscript{42,43}. This discrepancy between high health needs and low service utilization further underscores that access to health care services is a major obstacle for refugees. Recent data shows that ultimately, refugees experience a decline in health status after arrival in Canada\textsuperscript{6}.

### 2.5. There is a lack of quality data on refugee health care needs, health care utilization and barriers to accessing health care

Given Canada’s commitment to resettlement of refugees and the known barriers faced by refugees in accessing health care, there is a surprising lack of longitudinal Canadian data on health of refugees. Beiser and colleagues’ Refugee Resettlement Project, a decade long study of Southeast Asia refugees arriving in the early eighties, provided incredibly valuable data leading to an enhanced understanding of the settlement experience\textsuperscript{31}. Longitudinal data on more recent and more diverse waves of refugees is lacking. Additionally, there is a paucity of evaluation of the effectiveness of interventions designed to meet refugee health care needs\textsuperscript{11}. Most federal and provincial databases are inadequate to provide reliable, valid and comprehensive profiles of refugee health due to lack of detailed data on refugees\textsuperscript{36}. Much of the available research on refugee health employs cross-sectional assessment of refugees at the point of arrival.
with limited, if any, follow up. The available literature tends to be non-Canadian and usually examines only one specific ethnic population.

The most recent longitudinal data on refugees and health in Canada comes from Statistics Canada’s Longitudinal Survey of Immigrants to Canada (LSIC)\textsuperscript{34}. In this study, approximately 21,000 landed immigrants, including GARs, arriving between 2000 and 2001 were surveyed at 6 months, 2 years and 4 years after arrival. The surveys included socio-demographic, economic and health information data. While this data has been used for analysis of health related issues amongst refugees\textsuperscript{6,35}, limitations include that participants arrived prior to the 2002 IRPA amendment, follow up was only for four years, and measurements of health and health care utilization were self-reported.

### 2.6. Quality data is needed for policy makers to inform and evaluate health policy and services for refugees

High quality data is needed to assist policy makers in designing health policy, programs and services for refugees\textsuperscript{10,11,44}. The impact of any change in refugee health care policy or changes to the healthcare system will continue to be difficult to evaluate without appropriate data\textsuperscript{8,36}.

### 2.7. A prospective longitudinal cohort of refugees

The development of a prospective longitudinal cohort of refugees in Canada would address the need for high quality data post 2002. A well designed study would have the capacity to describe refugee demographics and health status on arrival, changes in health status over time, and utilization of health services. Secondarily, it would identify refugee characteristics associated with optimal health outcomes. See Table 2.1.

<table>
<thead>
<tr>
<th>Table 2.1. Primary research questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>What are the demographics and health status of government assisted refugees on arrival in British Columbia?</td>
</tr>
<tr>
<td>How does the health status of government assisted refugees change over time?</td>
</tr>
</tbody>
</table>
How are health services utilized by government assisted refugees?
What refugee characteristics are associated with positive or negative health outcomes?

2.8. Health care for refugees in British Columbia

British Columbia is ideally positioned to establish a longitudinal cohort. BC settles approximately 800 government assisted refugees annually\(^28\). About 100 additional GARs self-transfer from elsewhere in Canada to BC. Approximately ninety-nine percent of GARs in BC access services through the Immigrant Services Society (ISS) during their temporary residence at Welcome House in Vancouver.

During their stay at Welcome House, refugees in BC receive assistance in accessing primary health screening and have ongoing access to health care through Bridge Community Health Clinic\(^28\). The clinic, part of Vancouver Coastal Health, provides primary health care services with readily available interpretation\(^45\). GARs who settle quickly into the neighboring communities of Burnaby and Surrey may also access services at one of two New Canadian Clinics which provide similar services.

All three of these refugee health clinics have mandates to provide short term care during settlement with an aim to help refugees transition to accessing health care within the larger Canadian public system. Options for primary care include family doctor’s offices, community health care centres, walk in clinics and emergency departments. See Figure 2.1 for health care options for refugees in Canada.
Figure 2.1. *Health care options for refugees throughout the settlement process, with associated organizations and data sources*
The current structure of health care services for GARs in BC creates a unique opportunity to recruit and assess nearly the entire population of newly arrived GARs for the creation of a prospective cohort.

2.9. Data linkage through Population Data BC

Researchers in BC are privileged to have access to the services of Population Data BC. This multi-university data resource facilitates interdisciplinary research on the determinants of human health and well-being by integrating health service records, population health data and census statistics, making it possible to link de-identified administrative records at the individual level (See table 2.2).

<table>
<thead>
<tr>
<th>Table 2.2. Linkable datasets</th>
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</thead>
<tbody>
<tr>
<td>Population Data BC</td>
</tr>
<tr>
<td>Medical Services Plan (MSP) Payment Information File</td>
</tr>
<tr>
<td>PharmaCare</td>
</tr>
<tr>
<td>Discharge Abstract Database (Hospital Separations)</td>
</tr>
<tr>
<td>Home &amp; Community Care (Continuing Care)</td>
</tr>
<tr>
<td>Mental Health</td>
</tr>
<tr>
<td>BC Cancer Agency Incidence File</td>
</tr>
<tr>
<td>Canadian Community Health Survey (CCHS)</td>
</tr>
<tr>
<td>Vital Statistics Births</td>
</tr>
<tr>
<td>Vital Statistics Deaths</td>
</tr>
<tr>
<td>WorkSafeBC Injury Files</td>
</tr>
<tr>
<td>Consolidation File (MSP Registration &amp; Premium Billing)</td>
</tr>
<tr>
<td>Early Development Instrument</td>
</tr>
<tr>
<td>Other Data Sets</td>
</tr>
<tr>
<td>BC Centre for Disease Control</td>
</tr>
<tr>
<td>Center for Excellence in HIV/AIDS</td>
</tr>
<tr>
<td>Pathnet</td>
</tr>
<tr>
<td>PARIS (Primary Access Regional Information Systems)</td>
</tr>
</tbody>
</table>
After creation and initial assessment of a GAR cohort, utilizing virtual follow up data from existing databases through Population Data BC would enable longitudinal data collection that does not involve direct follow up with research participants and thus would not be affected by high attrition rates that usually characterize cohort studies. This is particularly relevant for GARs who are a highly mobile population. Additional longitudinal data could be collected directly through chart reviews from the three refugee health community clinics in Vancouver, Burnaby and Surrey.

2.10. Possible outcomes

Data from this study would be a resource for health care providers, policy makers, advocacy groups, and the refugee community. These results would aid in identifying opportunities for system level changes to improve the health of GARs. Any changes could be assessed through long term analysis of this refugee cohort or through the creation of a subsequent cohort.

2.11. Conclusion

Refugees have unique health care needs, they face numerous barriers to accessing health care, and there is a lack of Canadian data on refugee health. Consequently, the creation of a longitudinal cohort of refugees in Canada is needed. Creating such a cohort in British Columbia with GARs would provide data to complement existing databases and lead to a better understanding of the natural history of settlement of GARs in Canada in regards to health. This understanding could be extended to a biopsychosocial context by linking additional databases over time to examine settlement issues such as employment, income, education, and language acquisition.
Translation of knowledge garnered in this study could be disseminated broadly to government, service providers and the refugee community with a goal of reducing health inequities for refugees and improved settlement in Canada.
3. Ethical issues across the spectrum of migration and health research

This chapter is an excerpt from Migration and Health: A Research Methods Handbook, chapter XVI which was co-authored by Kevin Pottie and Patricia Gabriel. Permission for use of this chapter in this thesis has been granted by Kevin Pottie and the handbook editor.

3.1. Introduction

The search for ethics or answering the question “Is it right?” is complex when societies lack a shared story, or a collection of shared values, principles and beliefs. We all use stories, beliefs and rituals to create a sense of community, to enrich our experiences, and to sustain us during difficult times. Secular Western societies have created identities and stories from science and technology while traditional societies have stories based more on religion and community belonging. Stories also reflect how people of different cultures explain the cause of illness, the types of treatment they believe in, and to whom they will turn if they become ill.

Inequality of power can prevent the sharing of stories, opportunities and knowledge and can leave vulnerable members of a society dependent on the decisions of others. As migrant health researchers, we need to be aware of these inequalities of power and to be aware that in our engagement with migrant populations we will be entering into or creating forums for shared values. In this engagement process, we must be willing to allow variation and pluralism, and appreciate constraints of social position. Across different worlds of experience, we must be aware of the process of ethics, the process of building trust and accommodating and respecting peoples’ conscience, religion and beliefs. Indeed, a foundation of trust is an essential component for valid research results regardless of the methods being employed.
When researchers are faced with complex realities it is tempting to oversimplify “research ethics” and consider them to be a mere set of rules to follow when applying to research ethics boards. However, if we limit our attention to the process of acquiring ethic board approval we miss the opportunity to acquire an understanding and appreciation of the philosophical underpinnings of ethical approaches to research. Further, we are apt to take short cuts, miss opportunities for novel approaches and risk inadvertently causing harm to research participants. Ethical issues in research also emerge in setting up teams and developing partnerships, selecting research priorities, seeking funding, determining research design and approaches to analysis, selecting venues for presentation and publication, and supporting implementation equity and adaptation for local context (see Table 3.1). As an alternative, we favor an approach to research ethics that rigorously and honestly integrates ethical thinking into research across the continuum of knowledge creation and knowledge translation (implementation science).

Table 3.1. Research activities with ethical considerations along the continuum of research creation and translation

<table>
<thead>
<tr>
<th>Knowledge Creation</th>
<th>Knowledge translation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Setting up a research team</td>
<td>Publication and authorship</td>
</tr>
<tr>
<td>Partnerships with communities</td>
<td>Sustaining knowledge use (conflicts of interest)</td>
</tr>
<tr>
<td>Research design</td>
<td>Evaluation of application and barriers</td>
</tr>
<tr>
<td>Funding (public/private)</td>
<td>Equity in implementation</td>
</tr>
<tr>
<td>Ethics review board application</td>
<td>Adaptation of knowledge for local context</td>
</tr>
<tr>
<td>Informed consent process</td>
<td>Prioritizing topics for evidence reviews and summaries</td>
</tr>
<tr>
<td>Recruitment, data collection and analysis</td>
<td></td>
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</tbody>
</table>

When seeking ethical approaches to research with vulnerable populations, there are both theoretical and practical considerations. Theoretical considerations help us to understand the underlying values and principles that drive research ethics. Practical considerations in the research process help us to translate and utilize theories in the challenging realities of research on migration and health. This chapter will start by stepping back and reflecting on the values that inform research ethics generally and will engage with these theoretical concepts to consider how traditional theories apply to migrant populations. Secondly, it will take a practical look at the interface of ethics and
research processes to provide practical guidance on the implementation of ethical practices for research in migration and health. (The section on practical issues has not been excerpted for the purposes of this thesis).

3.2. Theoretical Issues

3.2.1. Research with vulnerable populations

The theoretical approach to research ethics with migrant populations is embedded within a larger framework of research ethics with vulnerable populations. Research conducted in Western countries has a dark history in regards to vulnerable populations and is wrought with examples of exploitation and injustice. There are inherent ethical and humanitarian concerns for research with disadvantaged groups due to often gross power imbalances between researchers and participants. This impacts the ability to acquire true informed consent, ensure participant autonomy and prevent mistreatment of participants\(^\text{22}\). Thus, research involving vulnerable populations such as migrant populations requires special consideration and quality assurance.

3.2.2. Why are migrants considered vulnerable?

Migrant populations are an example of a vulnerable population that requires scrupulous ethical consideration. Amongst migrants, vulnerability is variable between internally displaced persons, individuals in refugee detention camps, refugee claimants, government assisted refugees and immigrants. These vulnerabilities, as discussed elsewhere, are a result of pre-migration, migration, settlement and personal and social factors.

In regards to the interface of vulnerability and engaging in research, concerns can emerge from language and cultural barriers, lack of education, financial burdens, perceived lack of rights, dependency on host country governments, endemic hostility and a history of physical or emotional distress\(^\text{22}\). As a result, some migrants may be at risk of engaging in research without understanding the nature of the research, engaging
in research despite known risks due to a lack of perceived alternatives, or at worst, being coerced against their will to participate in research.

### 3.2.3. Western bioethics

Researchers have tended to look toward medical ethics as a scholarly framework to guide engagement with participants. For clinical research with human subjects, thirty-five specific principles are described in the World Medical Association’s Declaration of Helsinki, last updated in 2008\(^1\). The basic principles of ethical medical research are simplified in the Belmont Report and include beneficence, non-malfeasance, justice, and autonomy\(^{23}\). We will discuss each of these principles in relation to the conduct of research with migrant populations.

**Beneficence**

The hope that research will be beneficial to the population being studied is, or should be, the driving force motivating research. More often it is reasonable to expect long-term benefits to a population as a result of a subset of that population participating in research; for example, a subset of a population may participate in a qualitative study to determine access to care barriers. The knowledge gained from this study can potentially be translated into long term benefits to the migrant population en masse. The potential benefits include the emergence of a health care system that has improved understanding of their populations’ health care needs and improved delivery of health care services to their population. In fact, given the relative paucity of research on migrant populations, one may argue that there is an even greater need for research in this population.

Whether or not research benefits the study participants themselves over the short and long term is more difficult to ascertain. For individual migrant participants, while system level changes may primarily benefit new migrants on arrival, system changes may also benefit participants or their families in the future. There is a possibility that participants will gain new learning and relationships during the research process or will benefit from system changes that occur as a result of the actual research. In some studies, participants may benefit from tangible rewards in a study in the form of free medical assessment, treatment or material and financial compensation in the form of
honorariums. Given the uncertainty that participation in research will benefit the participant in the short term, and the potential for loss of time and resources to participants, tangible rewards often play an important role in ensuring benefits to migrant populations who face economic constraints.

Migrant participants may also benefit from the opportunity to share their stories, as described in studies of residents with limited access to health care in the United States and refugee detainees enthusiastically sharing their stories with researchers in the United Kingdom (UK)\textsuperscript{52,53}. In the focus group study of a vulnerable urban population by Grady et al. participants stated that they found participation valuable and appreciated the opportunity to be heard. Similarly, Bloom draws examples from a study of detainees in the UK who, despite their precarious status, elected to use their names and even photographs in a research study. In fact, “the majority of the interviewees responded with enthusiasm and commitment to the opportunity to publicly articulate their perspectives and experiences.” Participating in research, even for the vulnerable, can be empowering. Depending on the type of research study, participants may also benefit from engagement in social activities such as focus groups, or skill development and employment opportunities through participatory action research.

**Non-malfeasance**

The principle of non-malfeasance means to do no harm. There are many instances of research causing harm to participants. One has to only remember the research crimes committed in Nazi concentration camps brought to light during the Nuremberg trials or the notorious Tuskegee syphilis studies in the US that followed the natural course of syphilis in black males without offering treatment. The types of potential harm vary greatly with the type of research being done, varying from potential harms due to medical examinations, screening, investigations, or treatment, to the more subtle potential psychological harms from research questioning in the form of interviews, focus groups or surveys. The potential for harm increases with the power imbalance between researchers and participants, as the possibility for exploitation, loss of autonomy and inadequate informed consent become more likely\textsuperscript{22}.

Research with migrants has the same potential to cause harm as other forms of research, but in addition there are often population specific perils to consider. For
example, we must consider the human rights and political context of migrants\textsuperscript{54}. If research is done in countries where governments and institutions do not guarantee participant confidentiality or in recipient nations where a refugee’s legal status is perilous, researchers must consider the safety and privacy rights of participants to prevent research data and results from being used against participants\textsuperscript{22}. For example, misuse of information collected during research can result in exploitation, persecution or deportation of migrants.

This challenge is highlighted by Bernhard et al in their research with refuges with precarious status in Canada. They were unable to promise participants complete confidentiality as the Canadian legal framework only permitted the maintenance of confidentiality to the ‘fullest extent possible by law’ which may have actually permitted research records to be used in court. The possibility for ‘policing of knowledge production’ requires further exploration but should be considered in all migrant research.

Many migrants, especially refugees, have a history of physical and sexual abuse\textsuperscript{55}. Inappropriate questioning on these topics, especially when there may be background issues such as post-traumatic stress, can lead to psychological harm\textsuperscript{56}. Lack of measures to ensure that participants are well informed as to the nature of the study may lead to confusion, fear and uncertainty. Risk factors for research studies that may cause harm include research studies that provide material or financial incentives and those that offer a lower standard of care for participants. These are often mediated by participant poverty, leading to a lack of other options\textsuperscript{22}.

**Justice**

Considering justice when designing and conducting research helps to ensure equality in who benefits from research and who bears the burden. Justice requires that we as researchers assess, on the one hand, which individuals will potentially bear the burdens or accrue the benefits of being research participants and, on the other hand, which populations will potentially suffer or benefit due to the outcome of research findings.

Using equality as a lens and assuming that, overall, research benefits society justice supports including migrant populations in research so that they have the
opportunity to benefit from the fruits of research. In fact, given the relative paucity of research on migrant populations, one may argue that there is an even greater need for research in this population. On the other hand, considerations of justice make us aware of the need to assess the burden on research participants as well. For some researchers this leads to the question of whether or not research should be done with vulnerable populations such as migrants at all. Such concerns are raised due to the often unequal power relations between participants and researchers, which can be further accentuated with migrant populations. In studying refugees, for example, research may inadvertently contribute to human rights abuses and the worsening of conditions for refugees. Advocates for research with vulnerable populations argue that scientific investigation is needed to help end inhuman and cruel conditions and they further argue that denying these populations the right to participate in research is paternalistic. Within this debate, a balance is proposed which articulates the need to recognize that research is necessary, but that we must be aware of the ethical pitfalls and devise new research tools and approaches to ameliorate potential harms.

When considering migrant research, justice reminds us to determine if our approach to migrant research maintains the same rights for participants as research with other populations. This is not to be confused with doing things the exact same way, for treating people justly is not always the same as treating them equally. For example, research ethics boards often require written consent from participants. The purpose of this is to help ensure that participants have been appropriately informed about the study and are participating voluntarily. However, some migrant populations have high illiteracy rates, and requiring participants to read and sign a consent form to participate may be inherently unjust. Stepping back and considering the underlying values guiding research ethics may result in different approaches to migrant populations in order to maintain equality. We must always consider the inequalities between populations in our approach to research and try to make adjustments to account for these differences.

**Autonomy (respect for person)**

Ensuring autonomy in research entails that individuals are capable of deliberation and can act under their own direction without obstruction. The Declaration of Helsinki discusses elements of autonomy in at least nine of its thirty-six principles (11, 22, 24-29,
articulating the need for participants to be adequately informed of the aims, methods, risks and benefits of the research and their right to refuse participation. Additionally, it requires that participants act voluntarily and provide informed consent, preferably in writing.

Maintaining autonomy in medical research is facilitated through the process of informed consent. For research involving migrant populations, there are numerous reasons to suspect that the standard Western informed consent processes are inadequate for maintaining autonomy for non-western populations. For these populations there is a higher risk of individuals consenting without understanding their rights or refusing to participate due to a lack of understanding the value of the proposed research.

The major principles of informed consent are disclosure, comprehension, capacity, voluntariness and consent. At each step, there is potential for inefficacy when being applied in the context of research with migrants. Disclosure, that is, insuring that participants are adequately informed, is often complicated by language barriers and by insufficiently trained research assistants. Inappropriate translation of research material and lack of professional interpretation of verbal interactions can result in the inaccurate exchange of information. Research personnel who lack appropriate cultural competency or familiarity with endemic concepts of health and research may be unable to convey information appropriately or accurately to participants, thus preventing them from being truly informed.

Comprehension refers to a participant’s ability to understand the purpose of the research and the implications of participating in the research. Comprehension can be compromised in migrant populations. On the one hand, participants may struggle with understanding due to illiteracy, lack of education and lack of familiarity with research. On the other hand, as with any population, comprehension becomes increasingly challenging with the complexity of the research. Assessing comprehension in vulnerable populations where there is often a power differential may also be difficult if participants are unwilling or unable to disclose a lack of understanding due to fear, embarrassment or a desire to please.
Capacity broadly implies an individual’s ability to reason and make his or her own decisions. Capacity in migrants, as with any population, can be affected by age and mental capacity. With certain vulnerable migrants capacity can also be impacted by real or perceived extraneous cultural or political circumstances that may limit an individual’s liberty.

Voluntariness means that an individual agrees to participate in research under conditions that are free of undue influence and coercion. In migrant research, voluntariness can be impacted by a power imbalance between researchers and participants and contextual issues such as a desire to please, threats of harm or promises of reward that might lead to coercion.

The final step in ensuring the principle of autonomy involves the act of actually giving consent. This is a culmination of all of the aforementioned issues and refers to the step where an individual indicates that they are willing to participate. This can take the form of written, oral or implied consent. This step can be impacted by all of the issues outlined above. Additionally, it can be negatively impacted by a participants’ literacy level in the case of written consent or by their suspiciousness of signing authoritative documents.

In summary, the theoretical considerations in research ethics include assessing the potential benefits and harms to participants, considering justice by reflecting on equity in the distribution or research efforts, and ensuring the protection of participant autonomy throughout the informed consent process. General principles must be considered for migrant research in addition to population specific measures reflective of potential vulnerabilities, due to political, linguistic and cultural variations.
4. Methods

The purpose of this chapter is to clearly state the research questions to be answered in this thesis, to discuss the methodological considerations guiding the research paradigm, to provide background information on the study population, to justify the research design and to describe methods of data collection and analysis for this body of work.

4.1. Research questions

Understanding the practical and ethical issues involved in conducting research with refugees and comprehending refugees’ perspectives towards participating in health research involves five major areas of inquiry:

Knowledge and experience of GARs
What is the knowledge of and experience with research and informed consent for refugees in British Columbia?

Practical research issues
What recruitment factors influence refugees’ participation in research? What factors do refugees’ perceive will impact refugees’ willingness to participate in research?

Ethical research issues
What are the challenges and facilitators in conducting the informed consent process with refugees? What are refugees’ perspectives on the informed consent process?
4.2. Methodological considerations

This study was uniquely designed to address questions about practical and ethical issues for engaging refugees in health research, not as an add-on element of a larger research study as has been done previously. The methodology guiding this study was shaped by the nature of the research questions outlined above. However, some questions epistemologically lend themselves to positivist approaches, such as assessing recruitment factors that influence research participation, and others to relativist approaches, such as understanding refugees’ perspectives on research ethics.

The overarching methodology selected for this research was a relativist paradigm, played out through the selection of qualitative focus group methods. This decision arose from a belief that the most pressing knowledge deficits with respect to engaging in research ethically and practically with refugees stemmed from a lack of knowledge about participant perspectives. Asking research questions about social phenomenon, such as a culture’s view on research, requires a view of knowledge acquisition that allows for individual subjective viewpoints and multiple truths. Further, it necessitates an analytical approach where the investigator must recognized themselves as an instrument of knowledge inquiry and adopt a careful reflexive approach to finding meaning in their data. A qualitative methodology was also needed given paucity of previous studies on refugees’ perspectives about research. This necessitated methods that would facilitate inductive exploration. Inductive reasoning allows for the analysis of specific facts, such as participant comments, and analyzes these in an attempt to seek an overarching rule or pattern.

Following logically from the decision to use a qualitative methodological approach, focus group methods were selected for this research. Focus groups allow for refugee’s own voices to be the focal data source. Focus groups were selected over one-on-one interviews as it was felt that the group process would facilitate participant comfort, allow for dynamic interactions and group brainstorming, and allow for the emergence of shared sociocultural characteristics.

Focus groups with culturally and linguistically diverse populations have notable challenges, reviewed and summarized in a 2007 literature review on the topic 63. This
research study considered the suggestions put forth in this review and utilized such strategies as hiring members of the target community as part of the research team, engaging in multiple recruitment techniques, selecting appropriate venues, providing reimbursement, food and childcare, making culturally sensitive modifications to data collection, providing multiple options for documenting informed consent and allowing extra time in the focus group session for questions and clarifications to ensure comprehension.

While the overall research design is that of a qualitative focus group study, additional data was collected in what appears to be a more traditional positivist approach. Positivist approaches view the acquisition of knowledge as seeking one fixed truth that can be discovered by an objective observer using quantitative measures to identify relationships between variables. Traditional methods include quantitative measures of objective data. Indeed, this study does use quantitative measures of participant demographics and participant choices with respect to participation and documentation of consent. There are also two questionnaires which are summarized using descriptive statistics. However, these measures are really quantitative summaries of primarily qualitative data. Keeping in mind that the division between quantitative and qualitative methodology is truly a false dichotomy and the methodological approaches fall across an epistemological spectrum, this study can be best described as a qualitative study supported by simple descriptive statistics of qualitative and quantitative data.

### 4.3. Methods overview

The overall research design was built around four language based focus group sessions with Arabic, Farsi/Dari, Karen and Somali speaking government assisted refugees (GARs). There were two key elements to the study design.

Firstly, recruitment and the informed consent processes for these focus groups were closely observed to assess practical and ethical issues in conducting research with GARs. Five different recruitment strategies and three different methods for obtaining and documenting consent were utilized to allow opportunities for different strategies to
be observed and compared. Recruitment patterns and participants’ choices about giving or documenting consent were carefully noted.

Secondly, the four focus groups with language-concordant research assistants explored participants’ perspectives on health research, research ethics and the informed consent process. Data from the focus group sessions was supplemented with quantitative and qualitative data from three questionnaires about participants’ demographics, knowledge and opinions.

4.4. Research setting

4.4.1. Background information on the study population

In 2010 the five most prevalent source countries for GARs in British Columbia (BC) were Myanmar (Karen people), Afghanistan, Iran, Iraq and Somalia. As a result, the four language groups selected for our study were Karen, Farsi/Dari, Arabic and Somali. The migration histories for these populations are summarized below as they are helpful in understanding the context of this research.

Arabic

The majority of Arabic speaking GARs in BC at the time of this study were from Iraq. The Iraqi GAR resettlement to Canada started in 1996, with a sharp increase in resettlement since 2008. Most Iraqi GARs came to Canada from camps in Syria and Jordan after fleeing the Sunni-Shi’a conflict in Iraq. The dominant language is Arabic. Most Iraqi GARs are Muslim including both Sunni and Shi’a Muslims, but some are Christian. Most Iraqi GARs are literate in their first language and many hold university degrees. English language skills are variable. Many Iraqi GARs have experienced physical and emotional trauma as a result of the Iraqi war and many families that arrive are not intact. There is limited pre-existing Iraqi community support in BC.

Farsi/Dari

All of the Farsi/Dari speaking participants in our group were initially from Afghanistan. Afghanistan has had four decades of conflict. There are approximately
450,000 internally displaced people in Afghanistan and over 2.5 million refugees originating from Afghanistan. After fleeing their country, many Afghans settle in Iran, Pakistan, Russia, or India. Many Afghan refugees have waited for decades in these countries in settings of ongoing conflict and safety concerns. Many settings lack access to adequate health care, education, income earning opportunities and other basic needs. Most Afghans are Muslim. Families that settle in BC are often composed of single mothers with an average of six children. Low literacy as a result of limited formal education is common and makes learning a new language and the overall settlement process slower. The two main Afghan languages Dari and Pashto are in the same language family as Farsi which is spoken in Iran.

Karen

The Karen speaking GARs in BC primarily originate from Myanmar (Burma). Most GARs from Myanmar are from a minority ethnic group called Karen. Myanmar’s human rights abuses to the Karen population led to many people fleeing to the borders of Thailand. Approximately 140,000 Karen refugees have lived in remote jungle refugee camps for the past 20 years. Most Karen speak S’gaw or Pwo. Literacy is relatively low due to lack of educational opportunities in the camps. Most Karen people are Christian. The United Nations High Commissioner for Refugees (UNHCR) recognized Karen refugees as a distinct group with particular protection needs and recommend resettlement. Karen resettlement to Canada began in 2006. In BC the Karen GARs tend to live in concentrated neighbourhoods to support each other.

Somali

All of the Somali speaking group participants in this research study were from Somalia. Somalia’s years of conflict since 1991 have resulted in violence, human rights violations and insecurity throughout the country. Somalis have fled to Ethiopia, Djibouti and Kenya. Refugee camps in these settings have had ongoing struggles with violence, drought and scarcity of resources. Ethnically and culturally, Somalia is one of the most homogeneous countries in Africa. Most Somalis speak Somali and are Muslim. In BC, between 2005 and 2009, 175 Somali refugees settled in Surrey and Burnaby. The majority of Somali GAR families are composed of single mothers with 4 to 9 children or single young Somalis arriving alone from Turkey and the Middle East.
4.4.2. **Institutional research sites**

Just outside of Vancouver BC, in the municipalities of Surrey and Burnaby, there are two community health care centres called The New Canadian Clinics (NCC) that specialize in providing health care services to refugees. They are staffed by a nurse, a nurse practitioner, a physician, a medical office assistant and professional medical interpreters. They provide care from the first few months after arrival to several years into settlement. These were the primary locations for institutional recruitment of participants.

The two most prevalent groups seen at the NCC in Surrey were Karen and Somali speaking GARs and at the NCC in Burnaby were Farsi/Dari and Arabic speaking GARs. Thus, recruitment for the Karen and Somali speaking focus groups took place in Surrey and for the Farsi/Dari and Arabic speaking groups in Burnaby. The focus group sessions took place at nearby community resource centres. In Burnaby the groups were hosted at MOSAIC, a multilingual non-profit organization dedicated to addressing issues that affect immigrants and refugees, and in Surrey at DIVERSEcity, a non-profit agency offering a wide range of services and programs to culturally diverse communities around Vancouver.

4.5. **Research methods**

4.5.1. **Research assistants**

Recruitment was facilitated by hiring four research assistants (RA), one from each language group. The RAs attended four training sessions on research, recruitment and focus group facilitation. These sessions were one to two hours in length and facilitated by the lead researcher. The RAs prepared for the first session by reading the research proposal for the study. During the session RAs practiced explaining the study in their own words. RAs were asked to journal following this session and articulate their own hypotheses about the research questions. The second session on recruitment included hands-on practice with filling out data collection sheets and practicing recruitment through mock phone calls with potential participants. A second recruitment meeting was held at the Burnaby NCC with clinic staff. This allowed RAs to make
personal contact with the NCC staff and allow for training of the NCC staff with respect to their role in recruitment. For the fourth training session on focus group facilitation two additional experienced researchers were invited to provide expert guidance. The RAs were given resources to read in preparation and there was opportunity during the session for each RA to practice asking questions and facilitate group discussion.

The RAs key responsibilities in the study included recruitment and focus group facilitation. For recruitment, RAs were responsible for translating the recruitment information sheet, giving oral in-person or telephone invitations within their personal circles of GAR contacts, liaising with community GAR service organizations, liaising with NCC staff and making follow up phone calls with individuals who were identified at the clinic and community organizations.

RAs were also responsible for facilitating the focus groups. The RAs were given a semi-structured focus group script to study for several weeks prior to their focus groups sessions. Additionally, the same four RAs translated and transcribed the focus group audiotapes and assisted in coding and thematic analysis.

4.5.2. Recruitment

Four planned recruitment methods and one unintended recruitment method were used to invite participants to the focus group sessions.

- New Canadian Clinic on-site recruitment
- New Canadian Clinic direct phone calls
- Invitation through a community organization
- Invitation by the research assistant to a personal contact
- Invitation by a potential participant

The primary method of recruitment was through the NCCs. A recruitment meeting was held with NCC nurses and physicians and the RAs prior to the onset of the study. The clinicians were all very keen to participate. The recruitment plan started with
medical and administrative staff at each clinic, including nurses, physicians, medical office assistants and interpreters, giving verbal participation invitations to patients. A brief description of the focus groups was provided through the aid of onsite interpreters who were provided with a language concordant template for giving a verbal description of the study along with a language concordant written information sheet (See Appendix A). Interested participants gave oral permission to be contacted by phone for further details. The staff were informed to be very clear in informing patients that they did not have to participate in the research and whether or not they participated would not affect their ability to continue using the clinic. Staff documented each encounter with a participant and indicated if the participant was willing to receive a phone call or not, and if not, why not (See Appendix B and C).

For the follow up phone calls the RAs contacted interested patients by phone to provide more details. The RAs were given a list of items to cover when explaining the research study during each follow up phone call. This information was given to the RAs in English to allow for ad lib oral interpretation to account for flexibility and nuance of speech as suggested by previous studies (See Appendix D). The encounter, including participant questions and concerns, was documented by the RA in a spreadsheet template (See Appendix E). For those who were interested in participating, the RAs made one reminder phone call leading up to the day of the focus group.

The second recruitment method was unplanned and only occurred in one language group. Several days prior to the Somali focus group study there were very few confirmed participants. Unaware that we did not have ethical approval for this method of recruitment, NCC staff gave the RA the phone numbers of patients who they thought might be interested in participating in the study but whom had not been contacted by an NCC staff member first. The RA called these individuals directly and the proceeded as with the follow-up phone call described above. The research ethics boards at the University of British Columbia and the Fraser Health Authority were notified of this deviation and post-hoc ethical approval was received. No identifiable harm occurred due to this strategy and participants contacted through this method expressed gratitude generally to have been involved in the study.
Previous research with refugees suggests that recruitment may be more effective with word-of-mouth and face-to-face communication\textsuperscript{26}. Thus the third recruitment method involved encouraging RAs to contact community organizations that might be relevant to their language group. Once contact had been made with representatives of the community organizations the RA instructed them on how to invite participants to receive follow-up phone calls from the RA as above.

For the fourth recruitment method, RAs were asked to consider their own personal contacts to see if anybody they knew met the inclusion criteria for the study. If they were comfortable with doing so, they were encouraged to contact the individual to invite them to participate following the same telephone procedure outlined above.

Lastly, when the RA spoke with a potential participant from the NCC, from the community or the RA’s personal social network, the RA was encouraged to ask if the individual knew of anybody else who might be interested in participating. They requested that the individual invite their family or friends to participate and contact the RA for further details.

The goal was to invite 25 participants to each focus group so that after accounting for the possibility of half of confirmed participants not attending we would have 10-12 participants at each session.

Data on the recruitment process was collected through field notes and detailed documentation of each in person or telephone contact with potential participants by NCC staff and the RAs (See Appendices B, C and E). A follow up discussion with the RAs on the recruitment process was audiotaped and analyzed. Retrospective guided journals were collected from all RAs.

\textbf{4.5.3. Inclusion and exclusion criteria}

Participants had to be a GAR in Canada for five years or less. This time frame was selected as practical and ethical issues were hypothesized to be most concerning during early resettlement and we wanted to explore participant perspectives during this window of time. Because each focus group was conducted in one of four different
languages, participants had to speak one of the targeted languages: Arabic, Farsi/Dari, Karen, or Somali.

**Exclusion criteria included**

1. Age < 19 years old
2. In Canada for longer than five years and
3. Participants who did not speak one of the targeted languages.

**4.5.4. Focus groups**

The focus groups were approximately two hour sessions. The groups were facilitated by the language concordant RA with the lead researcher observing. Lunch, childcare, transportation reimbursement of $5 and a $20 honorarium were provided for each participant. The focus groups were audio-recorded and transcribed.

**4.5.5. Questionnaires**

Each participant was asked to fill out three questionnaires. The first consisted of seven true or false questions about informed consent (appendix G). The second questionnaire was four Likert scale questions about participants' attitudes, knowledge, experience and willingness to participate in health research (appendix H). A few key facts describing medical research were given to participants before answering these questionnaires to ensure a basic understanding of the topic.

The third questionnaire asked information about participant demographics and included their age, country of origin, languages spoken, and duration of time in Canada (appendix I). Participants could optionally include their name. This option was intentional as it created an opportunity to indirectly assess participants' comfort with disclosing personal information. Assistance was provided to those participants who were illiterate.
4.5.6. **Informed consent process**

Given that one purpose of this research was to better understand the informed consent process for refugees, special attention was given to the informed consent process for this study. Three variations for obtaining and documenting informed consent were offered.

We were also aware that the informed consent demonstrated in this study could strongly influence our results. To address this, clear instructions were given to each RA for a uniform informed consent process for each group. The aim of our informed consent process was to ensure that all five elements of informed consent were met.

Our informed consent process consisted of five parts:

**Disclosure**: Information about the purpose and methods of the research study were given by the NCC staff, by the RA during the two telephone calls and during the focus group session. Printed colored images were used to assist the RA with a presentation about the research during the focus group session.

**Comprehension**: Participants were given time to ask clarifying questions and the RAs were instructed in their focus group guide to assess for comprehension by asking clarifying questions to participants.

**Capacity**: Capacity based on age was addressed by the exclusion criteria. Informal screening for developmental or mental impairments that would impact capacity was done during recruitment by NCC staff superficially. The NCC staff were aware of participants’ health status and did not invite those with known developmental or mental impairments.

**Voluntariness**: NCC staff and RAs were instructed to clearly state that participation was voluntary and that declining the invitation would not impact one’s ability to receive health care at the NCCs. The follow up phone call included a specific reminder to inform participants that participation was not mandatory. After the lunch that preceded the formal onset of the focus group session, participants were invited to leave if they did not wish to participate further. They were still entitled to the honorarium. At
the end of the study participants were told that they could choose whether or not to fill in their questionnaire and/or hand in their questionnaire.

Consent form: The consent form was a simple two page language concordant consent form (appendix F). The key principles of the consent form were conveyed orally during the RAs phone conversations with potential participants. During the focus group session each participant was given a copy of the consent form while the RA summarized the content out loud. After this was done, participants were invited to express their consent to participate by signing the consent form. For participants who would rather not sign the consent form, they were given other options for conveying their consent for each component of the study. See table 4.1.

**Table 4.1. Options for conveying consent to participate**

<table>
<thead>
<tr>
<th>Component of Study</th>
<th>Consent</th>
<th>No Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole study</td>
<td>Signed consent form</td>
<td>Did not sign consent form AND left/did not participate in focus group session AND did not hand in questionnaire.</td>
</tr>
<tr>
<td>Focus group discussions</td>
<td>Implied by participation in focus group conversation.</td>
<td>Left or chose not to speak during focus group session.</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Handed in signed or unsigned questionnaire.</td>
<td>Did not hand in questionnaire.</td>
</tr>
</tbody>
</table>

For the focus group session participants were told that they could indicate their consent by choosing to stay and participate in the session. Participants were told that those who did not wish to consent could leave, or, alternatively, stay but not participate in the conversation.

For the questionnaire participants could express their consent by handing in their signed or unsigned questionnaire. Those who did not consent were invited to keep their questionnaires and not hand them in or hand in a blank questionnaire.

Of note, the informed consent process took place at the beginning of the study after the knowledge questionnaire had been administered and the Likert questionnaires were filled out, but before the demographic questionnaire and before any questionnaires were handed in. This was done because we anticipated that the informed consent
process, in particular the question and answer period, would provide participants with new information about research that might influence their answers on the knowledge questionnaire.

4.5.7. Focus group discussion

The four focus groups explored participants’ perspectives on health research, research ethics and the informed consent process. The focus groups were led by the language-concordant RA using a semi-structured interview guide (appendix J). The focus groups session started with questions about participants’ knowledge of research, previous experience with research, attitudes towards research, and willingness to participate in research. It then moved to a case study to stimulate discussion around issues of recruitment and informed consent. It finished with a few specific questions around the concept of a cohort study with linked databases, participatory action research and inquiry about what topics participants would prioritize in health research.

The case study was an example of a research assistant approaching a refugee to participate in a health related research study. Prepared questions were used to stimulate participation. Elements of the case study, such as characteristics of the refugee, the research study, the research assistant, and the information provided, were changed in order to stimulate further contributions. The types of questions in the section were designed to elicit data to answer the four major research questions.

4.5.8. Data collection

The research activities described above were each associated with different means of data collection.

Recruitment process

The NCC staff and RAs recorded observations of each in-person and telephone encounter with potential participants. Observations were documented with recruitment data templates (appendices B and C), telephone data template (appendix E), field notes during recruitment, through guided journaling, and though an audiotaped discussion with the RAs at the conclusion of the study.
Participant reflections on the recruitment process were documented through transcription and translation of tape recorded session.

The outcome of the recruitment process was measured by recruitment and participation rates.

**The informed consent process**

The lead researcher recorded observations of the informed consent process during focus group session and the RAs shared their observations during a focus group discussion at the end of the study and through guided journaling.

Participant reflections on the informed consent process were documented through transcription and translation of tape recorded focus group session.

The outcome of the informed consent process was measured by rates of participant’s engagements in each informed consent option.

**Responses to the questionnaire**

Participants’ responses to questionnaires were collected and entered into Excel software for analysis.

**Focus group discussions**

Participants’ discussions were documented through transcription and translation of tape recorded sessions.

**4.5.9. Ethics**

This project received ethical approval from the UBC Behavioural Research Ethics Board and the Fraser Health Research Ethics Board.

**4.5.10. Analysis**

Data from the questionnaires, including demographic information about participants and their answers to questions about their knowledge and attitudes towards research, was summarized using descriptive statistics. Quantitative data were analyzed
to determine recruitment rates from the initial invitation received through the various steps that culminated in a participant attending the focus group and then signing the consent form. See figure 4.1.

**Figure 4.1.** Conceptual image for assessing recruitment rates at each stage in the recruitment and informed consent process.

Qualitative data from focus group transcripts, RA journals and field notes were analyzed. This data was analyzed through coding and thematic analysis. The lead researcher was primarily responsible for coding the transcripts. A list of anticipated themes was created prior to reading the transcripts. These themes were derived from the literature and a priori discussions with the research team. Then, the four transcripts were read once and new codes were added with each new transcript. At the end of the first review the codes were assembled thematically. The transcripts were read a second time and were recoded and new codes were added. At the end of the second review the codes were reassembled thematically. This process was repeated a third time. Coding
was facilitated through the use of WeftQDA software. Input on coding was collected from each of the RAs for their own focus group after the second read through.
5. A detailed description of the research team and focus group setting

5.1. The research team

Due to the multilingual nature of this research study, the research team was made up of a unilingual English speaking lead researcher and four multi-lingual research assistants (RAs).

The Somali speaking RA was a young male initially from Somalia. He grew up in a refugee camp in Kenya and came to British Columbia (BC) for post-secondary education on a scholarship. He was fluent in Somali and English, recently finished an undergraduate degree and had experience in research and teaching.

The Arabic speaking RA was a family physician initially from Iraq. He practiced in Iraq during the recent conflict and recently came to Canada with his family as a GAR. He had extensive experience in clinical care, health care administration and teaching.

The Karen speaking RA was initially from Burma. She spent most of her life living in a refugee camp in Thailand before moving to Canada with her family as a GAR. She had informal training as a teacher and a nurse when living in Thailand and was working as a student support worker for Karen children in the local school district.

The Farsi speaking RA was a young female initially from Iran who immigrated to Canada with her family as a teenager. She had recently finished her undergraduate studies in sciences. She was fluent in Farsi and English and had previous experience in qualitative research. Of note, her focus group participants were primarily from Afghanistan and spoke Dari, which is similar to Farsi.

The research assistants were asked if they identified as being part of the same community as the focus group participants. The Arabic and Karen speaking RAs
strongly agreed that they were while the Farsi speaking RA was certain that she was not. While they shared a language, their migration histories and socio-demographic characteristics were different. The Somali research assistant felt in some ways that he was part of his focus groups community, given that they had some common past experiences in Somalia and Kenya, however given that he was much younger and well educated, he felt that he was also a bit of an outsider.

As discussed in the methods section, the RAs were responsible for translating the recruitment information sheet, conducting in-person or telephone invitations within their personal circles of GAR contacts, liaising with community GAR service organizations, liaising with NCC staff and making follow up phone calls with individuals who were identified at the clinic and community organizations. The RAs were also responsible for organizing and facilitating the focus groups. They had a two hour session on focus group facilitation and an opportunity to practice with feedback from the lead researcher and two local researchers with experience in qualitative research. The RAs were provided with a semi-structured focus group script to study several weeks prior to their focus groups sessions. The RAs came very well prepared for facilitating their focus group sessions. They proceeded confidently and made participants appear to be comfortable and were successful at engaging most participants in discussion and maintaining a friendly environment.

The lead researcher for this study was a Caucasian female family physician born in Canada. She was present at all focus group sessions and, along with the RA she arrived early to set up the room and the food. The lead researcher and RA jointly welcomed each participant. The lead research only spoke English, thus said hello and welcome to each participant in English and often shook hands. She helped participants to find seats and gestured to them to help themselves to food. With some of the English speaking participants they had brief friendly conversations during lunch. At the start of the focus group she handed out the questionnaires and consent forms and set up the audio recording equipment. The RA introduced her as the lead researcher and a family doctor. After that, for the most part, she sat quietly and took notes on her computer. Occasionally the RA would turn to her and ask clarification questions in English or translate a brief piece of the dialogue, particularly if something humorous had occurred. Recognizing the importance of the researcher as a research tool in qualitative research,
a reflective essay was written called “To Wear a Hijab” which can be found in Appendix K.

In the Somali and Farsi group the lead researcher’s role also included walking around the room during the questionnaire period to help orient participants to the page and line that was being discussed as many of the participants were illiterate and had a difficult time following written material. In the Farsi group her role also doubled as child minder making sure that the two children were quiet and content.

5.2. The research setting

The Farsi/Dari and Arabic speaking focus groups were held at a community organization called MOSAIC which provides settlement assistance for new immigrants and refugees. It is located across the street from the New Canadian Clinic (NCC) in Burnaby where participant recruitment occurred. The Karen and Somali speaking focus groups took place at a community organization DiverseCity which also provides settlement assistance. It is located down the hall from the NCC in Surrey. At both locations the focus groups took place in small classrooms that tightly fit about fifteen people. They were well lit rooms with white boards at the front. Tables and chairs were arranged in a circle with the research assistant at the front of the room by the white board. The lead research sat either within the circle or at the edge of the room. The tape recorder was at the front of the room with the research assistant.

5.2.1. Childcare

For three of the four groups we were able to provide childcare for the two to seven children that attended with their parents. The child minder took the children to a second classroom (at DiverseCity) or across the street to the library (at MOSAIC). The child minders were bilingual and found through the help of the research assistant. One was an RA’s partner, one was an RA’s daughter and the third was a participant’s daughter. Childcare providers were paid $25 for their services. In the Farsi group we were unable to provide a child minder so the two elementary school aged children sat at the back of the room where we had provided colouring and crafts to occupy them.
5.2.2. **Timing**

The four focus groups were initially going to be held within a two week period at the end of July 2011. The group order was Somali, Arabic, Karen then Farsi/Dari. The Farsi/Dari group had to be rescheduled due to an initial lack of participants for the first scheduled time. Due to the occurrence of Ramadan in August we decided to reschedule the last group for early September. The groups started at 12:30 in the afternoon. Lunch was served and the focus groups ran on average from about 2:00 till 4:00.

5.2.3. **The focus groups**

Prior to starting the focus group, lunch was served from the small kitchen area outside the classroom at MOSAIC or from within the classroom at DiverseCity. The RAs ordered food that they thought would be appropriate for each group, considering dietary preferences such as providing Halal food for Muslim participants. Some participants were late but most groups insisted on waiting for everyone to arrive before starting. There was food for the children too. Some participants choose to keep some of their food to take back for their family. In all four groups there was leftover food that participants could package and take home.

Participants ate lunch in the classroom with the research team. Participants spoke quietly to each other and to the RA. Some participants spoke English and chatted with the lead research. In all four groups lunch time had a relaxed social ambiance and it became clear that many participants knew each other and engaged in friendly conversations.

The RA started the session after lunch by introducing the research team then going around the circle and having participants give their name, where they were from and how long they had been in Canada. In the Somali group, just after introductions had started, it was noted by one participant that it was time for daily prayer for the Muslim participants. The session was paused for about fifteen minutes and the female participants used the classroom for prayers while the male participants and the research team left the room.
The next step in the session was administering the three questionnaires. The RA read each line out loud and directed participants to answer each question independently. Despite this, participants would often answer out loud, look at their neighbour’s response or help the person next to them answer questions. Some participants even circled questions for their neighbours. The request for independent answers was restated and in most groups participants then followed these instructions. These behaviours were most notable in the Somali group and least frequent in the Arabic group. The length of time for this step varied greatly due to literacy levels. The Somali groups took over thirty minutes to complete these three short questionnaires due to the need for line-by-line reading and pointing for several participants. In the Arabic group, on the other hand, many participants had finished filling out the questionnaires long before the RA had finished his explanation.

This section was followed by a didactic presentation by the RA explaining health research and informed consent. The RA used some printed pictures to aid in the discussion. These were used to varying degrees by the RAs and were largely unnecessary. Participants comfortably asked questions during this phase. Each participant had a copy of the two paged language concordant informed consent form in front of them during this presentation. Some participants read the form while the RA presented. At the end, participants were invited to sign the form if they wanted to and place it in a large envelope for submission. The questionnaires were also placed inside the envelope. The writing of one’s name on the questionnaires was voluntary. Participants were invited to submit their envelopes, but were also informed that they could choose not to. All participants submitted their envelopes except for one envelope in the Farsi/Dari group. Participants were informed that a conversation would soon begin, and consent would be implied by participation, whether or not they had signed the consent form. Participants were also informed that they could leave. No participants left.

The discussion began with asking participants general questions about attitudes, knowledge and willingness to participate in research and then moved on to the case-based discussions. Throughout the discussion many participant contributed spontaneously. In the Arabic group, the RA encouraged everyone’s participation by asking each member in the group systematically around the circle to respond to
questions. In each group there were some participants who spoke frequently and some who spoke rarely or not at all. Most participants displayed signs of interest and engagement while some displayed signs of boredom. The Karen group was notable for short answers that tended towards agreement while the Somali and Arabic groups were the most verbose. There were no major points of tension observed, but people did politely voice their opposition to others ideas. There was often laughter.

At the end of each session participants were invited to sign up to be contacted for future studies. A thank you card and the reimbursements, in cash, were distributed. Many participants lingered after the study to talk to each other or to the RA or myself. After the Somali group, three women gave us each a hug. After the Farsi/Dari group, one woman stayed to ask the lead researcher personal medical questions for about ten minutes. After all of the groups most participants came up to the RA and lead researcher to shake hands and conveyed thankfulness for the experience.
6. **Refugees knowledge about and experience with research**

6.1. **Introduction**

Ensuring that individual participation in health research is voluntary is integral to conducting research ethically\(^{23,51,66}\). The autonomous and voluntary nature of participation is facilitated in western bioethics through the informed consent process. This process consists of disclosure, comprehension, voluntariness, capacity and documentation of consent\(^{25}\). These steps are particularly important when conducting research with vulnerable populations\(^{22}\) such as refugees. This population requires even further ethical considerations due to challenges arising due to language and cultural barriers\(^{24}\).

When we focus on informed consent in research with refugees and the challenges arising due to language and cultural barriers, the importance of ensuring a participant’s comprehension of the research process becomes clear. We can assume that an individual’s comprehension of any process is likely to be enhanced if they have previous knowledge or experience in that domain. Thus, knowledge about refugee populations’ previous experience with research and knowledge about research can aid researchers in assessing what might be needed to facilitate comprehension in a given refugee population prior to their participation in research.

This study assesses four refugee populations living in British Columbia (BC), Canada for their previous experience with research and their knowledge and confusions about research and the informed consent process. It reveals the diversity in participant experience and suggests that participant education level may be predictive of key knowledge gaps that must be addressed by researchers to create ethical research processes.
6.2. Methods

The data for this paper was collected as part of a larger Canadian qualitative focus group study of Arabic (Iraqi), Farsi/Dari (Afghani), Karen (Burmese) and Somali (Somalian) speaking government assisted refugees (GARs). This study used five different recruitment methods and three different informed consent options to observe practical and ethical issues for research with refugees. It also included language concordant focus groups that examined participant perspectives on practical and ethical issues of conducting research with refugees. Participants were asked to fill out three questionnaires (on demographics, knowledge and attitudes) during the focus group session. Four language concordant research assistants (RAs) were hired to aid in recruitment and to conduct focus group sessions. Institutional recruitment was centred at two health clinics in Greater Vancouver called the New Canadian Clinics (NCCs) and focus groups were hosted at nearby community centres (MOSAIC and DIVERSEcity).

Data to address refugees’ knowledge and confusion about health research and the informed consent process comes from multiple sources including all three questionnaires, researcher field notes and thematic analysis of the focus group sessions.

The primary data source comes from a seven true or false questions questionnaire on the informed consent process that was administered during the focus group (appendix G). The seven true or false questions each explored a different domain of the informed consent process. The questions addressed voluntariness (questions 1 and 6), confidentiality (2), financial incentives (3), comprehension and disclosure (4), consent forms (5), and ethics boards (7) respectively. These questions were administered prior to the informed consent process in order to assess a priori knowledge.

Additional data comes from a question about previous education found on the demographic questionnaire (appendix I). The options for previous education included none, primary, secondary, or post-secondary education. Data also comes from two questions on the Attitudes, Knowledge, Experience and Willingness Likert Questionnaire (appendix H). The first stated “I have a lot of experience with research in the past” and
the second “I have a lot of knowledge about research”. There were five options for responding ranging from disagree strongly to agree strongly.

Supporting data about participants` knowledge and confusions also came from researcher field notes and coding and thematic analysis of the focus groups.

6.3. Results

The total number of participants attending our focus groups was 48, with 14 Arabic speaking participants, 10 Farsi/Dari speaking participants, 13 Karen speaking participants and 11 Somali speaking participants.

6.3.1. Education level

The highest level of education obtained for participants varied tremendously, with the least amount of secondary or post-secondary education in the Somali group and the highest in the Arabic group. In the Somali speaking group, eight of the ten participants who responded to this question had no primary education and or primary education only. Only two participants, 20%, had secondary education and nobody had post-secondary education.

In the Karen speaking group, of thirteen participants, three had no education, seven had primary education, and two had secondary education. A total of 13% had secondary education. Nobody had post-secondary education.

In the Farsi/Dari speaking group, of ten participants, three had no education, one had primary education, three had secondary education and two had post-secondary education. A total of 56% of participants had secondary or post-secondary education.

In the Arabic speaking group, of fourteen participants, two had primary education, five had secondary education and seven had post-secondary education. A total of 86% of participants had secondary or post-secondary education.
6.3.2. **Self-reported experience with research**

In regards to participants’ self-reported experience with research in the past, the Somali group reported the least experience with research and the Karen group reported the most experience with research. In the Somali group seven members disagreed strongly with having previous experience with research, two answers could not be interpreted and the two youngest participants agreed strongly. Thus, only 22% agreed or strongly agreed with having experience with research in the past. In the Arabic group 36% agreed or strongly agreed with having experience with research in the past. In the Farsi speaking group 44% agreed or strongly agreed with having experience with research in the past. In the Karen group, unexpectedly, all participants stated that they had experience with research in the past and 100% agreed or strongly agreed with the statement.

6.3.3. **Self-reported knowledge about research**

In regards to participants’ self-reported knowledge about research, group responses aligned closely with experience with research. Again, the Somali group reported the least knowledge about research and no participants (0%) agreed or strongly agreed with having knowledge about research. In the Farsi/Dari group 22% of participants and in the Arabic group 43% of participants agreed or strongly agreed about having knowledge about research. In the Karen group again all participants (100%) agreed or strongly agreed with this statement.

6.3.4. **True or false questions**

The first question was “People can be forced to participate in research.” Thirty-five out of 47 responding participants (74%) correctly chose false. The second question was “Personal information about people who participate in research is kept a secret.” Thirty-seven out of 47 responding participants (79%) correctly chose true. The third question was “People who participate in research always get paid.” Forty-nine percent of the participants stated that they did not know the answer. Eleven out of 47 responding participants (23%) correctly chose false. The fourth question was “People who participate in research should understand the purpose of the research.” Forty out of
43 responding participants (93%) correctly chose true. The fifth question was “People who participate in research have to sign a form saying that they agree to participate.” Only five correctly chose false (11%). Thirty-five out of 45 responding participant chose true. The sixth question was “Once someone starts participating in a research study, they are not allowed to quit.” Only 19 out of 46 responding participants correctly chose false (44%). The final question was “Researchers need to get permission to do research.” Forty-two out of 46 correctly chose true (91%). Group variation in answers can be seen in figure 6.1.
Figure 6.1. True of false answers by focus group.
Figure Note:
T=True, F=False.

People who participate in research have to sign a form saying that they agree to participate

Once someone starts participating in a research study, they are not allowed to quit

Researchers need to get permission to do research
For all seven questions combined, the average for all four language groups 59% of answers were correct, 27% incorrect and 14% answered with “I don’t know”. The variability between groups in correct responses overall ranged from 52% correct in the Arabic group to 67% correct in the Farsi/Dari group. The percentage of responses stating “I don’t know” ranged the most, with the Farsi/Dari group only choosing this for 3% of responses overall and the Arabic group for 25%. Incorrect responses for all groups were Arabic 22%, Somali 27%, Farsi/Dari 30% and Karen 31%.

### 6.3.5. Research assistant field notes

Prior to conducting the focus groups session, the four RAs were asked to answer the question “How much will refugees in your language group know about research?”

The Farsi speaking RA noted:

*I anticipate that most refugees in my language group be familiar with research and appreciate its importance. Iranian TV has many programs to educate the public about health research and recent technological advances. However, I think most of them understand research to take place in labs using microscopes and various tools.*

The Somali speaking RA wrote:

*The Somali community has been afflicted with civil war. As a result of life in camps and daily struggle to raise kids, the Somali adults, especially parents, have not had the opportunity to gain any formal education. As new immigrants to Canada, they bring a high level of illiteracy. Consequently, I will assume that Somali refugees have little to no knowledge about research.*

The Arabic speaking RA thought:

*Most people who came from big cities may know what research means, however the majority have not participated in a research before. Some may think that research are just show work for media and political purposes.*

And the Karen speaking RA said:

*About 30% of refugees in my own language know about research. One thing we have to explain them carefully until they understand it.*
6.3.6. **Focus group themes**

There were three major categories of participant statements from the focus groups that pertained to education and knowledge about research. These thematic categories were ‘confusion about research’, ‘well-informed about research’ and ‘experience with research’.

There were fifteen statements across three of the four focus groups that demonstrated confusion about research. Five of these quotes were from the Somali group and nine were from the Karen group. The major confusion identified was that some participants were confused between health education and research.

*Karen Female-* We live in refugee camp and we have a health care worker called CHE they have a home visit and teach us how to keep the food safe and not to get diarrhea and sick and they also teach us hygiene. We have to eat hot meal. We are an important mother. There are many people and many different kinds of diseases. The health care worker doing a research and teach us for prevention.

*Karen Male-* Because of doing a research we understand and we have more knowledge about how to take care of our health.

*Somali Female:* There are different kinds of research. There is research that educates us on diseases and how to prevent them. There is cleanliness and hygiene. How to cook food. How to avoid mosquitoes. Mothers are involved in research because they want to save lives. They use mosquito nets, they clothe their children.

*Somali Female:* In this kind of research we can benefit from it because it can help us to know how some diseases come about and how we can protect ourselves from it because these are things that we do not know due to our lack of being informed. So there is a chance that we can learn and then pass on this knowledge to others.

There were seven statements from three of the four focus groups where participants demonstrated a clear understanding of health research.

*Arabic Female:* Yes, it (research) is important. Because even with a failure there will be other research to explain why has this failure occurred.

*Somali Male:* The way I understand it, is the way the girl mentioned, like, that illness that happened, trying to figure out how future generations can be saved from it. We have to find out the cure for it.
Finally, there were six statements from two of the four focus groups, with four statements coming from the Arabic focus group, demonstrating previous experience with research.

Arabic Male: *I had some research at university related to my field but not after my graduation.*

Arabic Female: *The same just at university time.*

Arabic Male: *Only academic research during my university study.*

Somali Male: *Mine (experience with research) had to do with cancer. How it happens to a person and how it reaches a person, and all that.*

6.4. Discussion

In our study, refugees’ knowledge about health research and experience with research was overall low and varied by language group. In general, knowledge and experience were highest in the Arabic speaking group, and lowest in the Somali and Karen speaking groups. The Farsi/Dari group had members with variable levels of knowledge and experience.

These conclusions are supported by self-reported knowledge about research being clearly highest in the Arabic group at 43% and then Farsi/Dari group at 22%. Additionally there were more comments in the Arabic and Farsi/Dari focus groups demonstrating an understanding of health research. The RA journal comments prior to the focus group correctly anticipated that these groups would have more familiarity with health research.

The Somali had the lowest levels of knowledge about health research. This was supported by nobody in the Somali group self-reporting that they had a lot of knowledge about health research. In the focus group, there was clear confusion about the meaning of health research, with many participants revealing from their comments that they believed health research was in fact public health education. The Somali RA noted that there was not a good term for translating the word ‘research’ and he used the expression ‘knowledge search”. This might have contributed to the confusion. Two participants in the Somali group did have clear understanding of health research, but they were
demographically quite different than the rest of the group, being the only two males, being younger and having had secondary education.

In the Karen group, 100% of all participants unexpectedly self-reported high agreement with having knowledge about health research. In context, however, many members of this group also demonstrated confusion about the meaning of health research during the focus groups. After discussion with the Karen RA and analysis of the focus group transcript, it is likely that Karen participants were in fact thinking about health education. As such, we would categorize the Karen language group as having low levels of knowledge about health research along with the Somali group. These findings were also correctly anticipated by the two RAs for these groups.

In regards to experience with health research, as with the self-reports of having knowledge about research, the Arabic and Farsi/Dari group had the highest rates at 36% and 44% and the Somali group the lowest at 22%. Again, the Karen group unexpectedly reported high rates of agreement with having experience with health research, but given the overall pattern of confusion, we again infer that in fact the group had low levels of experience along with the Somali group.

If we look at knowledge about informed consent specifically, the overall frequency of correct answers was 59%. We felt that participants should be able to correctly answer the questions about voluntariness (1,6), confidentiality (2) and disclosure/comprehension (4) in order for informed consent to be effective. The questions about confidentiality and disclosure/comprehension were answered correctly by 79%, and 73% of participants respectively. This could be interpreted as reassuring, but in reality, these 100% of participants should be aware of these basic ethical tenants prior to engaging in research. For the two questions about voluntariness, the correct responses were chosen by only 74% and 40% of participants. This is an area of concern. Alarmingly, seven participants thought that people could be forced to participate in research and twenty-two participants thought that once someone starts participating in a research study, they are not allowed to quit. Voluntariness of research participation was clearly not appreciated. Of note, by protocol, every participant had been contacted by phone by an RA and was clearly told that their participation was optional.
Ensuring that participants know the answers to the three remaining questions about financial reimbursement, consent forms and the need for researchers to obtain approval for research is not imperative to achieving informed consent. Rather, these questions were asked in order to understand participants’ expectations about research. In regards to whether or not all participants get paid to participate in research, most participants 49% stated that they did not know the answer, and for those who answered opinion was divided equally. Almost all (91%) of participants stated correctly that researchers need to get permission to do research. In regards to the need to sign a consent form, 78% of participants thought this was always necessary.

Lastly, we were curious to see if educational level could be used as a proxy to anticipate refugees’ knowledge about health research and experience with research. The educational experience of our participants varied quite dramatically. Two of our focus groups, the Somali and Karen speaking groups, were for the most part made up of individuals who no education or primary education only. In these groups, only 20% and 13% of all participants had secondary education and nobody had post-secondary education. On the other hand, in the Arabic group, 86% of participants had secondary or post-secondary education. The Farsi/Dari group was the most heterogeneous group with about half of participants having secondary or post-secondary education and half having no education or primary education only.

Thus, if we consider that the two groups with the least formal education were the Somali and Karen group, this corresponds with the Somali group having the lowest self-reported knowledge and experience and the high levels of confusion in both the Karen and Somali focus groups. However, there was no clear pattern by language group for correct (range of 52%-67%) and incorrect (range and 22%-31%) responses to the true and false questions about informed consent. Thus, for knowledge about informed consent, we did not see any obvious pattern related to educational obtainment between groups and our study was not designed to look for patterns between individuals.

There are several limitations to these results. Our first two questions about knowledge and experience were both limited by being self-reported. This was clearly a concern with the Karen group where we suspect misunderstanding led to invalid responses. For the true and false questions we are also limited in our ability to state that
correct responses correspond to true knowledge about this topic as rates of guessing are unclear. Certainly, some groups were much more apt to choose “I don’t know”. Given that the Arabic group, which was the most knowledgeable group based on self-report and education level, had the highest number of “I don’t know” responses, we hypothesize that there may have been a lot of guessing in other groups rather than stating “I don’t know”. Also worth noting is that during the administration of the questionnaires, despite instructions to answer the questions independently, we observed that many individuals in the Farsi/Dari and Somali groups were quick to help their neighbours and share an answer out loud and had to be instructed several times to work alone. Due to high levels of illiteracy in the Somali, Karen and Farsi/Dari group, each question had to be read out loud and the RA and lead researcher had to help orient participants to where to document their answers. Illiterate participants had difficulty orienting themselves to the concept of the Likert scale, however this was facilitated by pictographic representations and slow clear instructions by the RAs. Overall, each of these limitations can be mediated by triangulation for our various data sources.

6.5. Conclusion

When assessed as a whole, our data show a clear picture. Refugees from situations with limited educational opportunities, such as countries where individuals have spent most of their lives in refugee camps such as Somalia and Burma, had limited experience with research, limited knowledge about research and high levels of confusion about research. Refugees from situations where they had more educational opportunities such as those from Iraq had more knowledge and experience with respect to research.

In regards to the informed consent process specifically, most, but not all, refugees were knowledgeable about the need for disclosure and comprehension and the maintenance of confidentiality. However, knowledge about the voluntariness of research was alarmingly low. These finding are important to note as it puts this group as risk of coercion and involuntary participation. The need to educate potential participants on the nature of research and their rights as participants is paramount to the conduction of research ethically.
7. Practical issues for conducting research with refugees: Comparing different recruitment strategies

7.1. Introduction

There are numerous reasons to suspect that standard Western recruitment strategies for health research are less appropriate with refugee populations and must be modified. Recruitment for health research projects, from qualitative studies and participatory action research to surveys and clinical trials, is often conducted through advertising with posters or letters, discussions at clinical encounters, making phone calls, utilizing online spaces or through word of mouth. This process can be facilitated though incentives such as gifts, financial reimbursement, or enhanced medical services. For many refugee populations there may be obvious challenges associated with these recruitment methods due to communication difficulties as a result of language and cultural barriers\textsuperscript{15}. Additionally, refugees like other minority populations may be more difficult to recruit due to being a highly mobile and harder to reach population\textsuperscript{67}. For those with a history of trauma or injustice, attitudes of fear and suspicion may be more prevalent and make individuals unduly wary of participation\textsuperscript{16}. As a consequence refugee populations may not participate in research despite the fact that doing so is in their own best interest or the interest of their community.

There is an awareness of the difficulties of recruiting minority populations in general, and refugees more specifically, for research. Indeed, many researchers have reflected on how to best recruit for research in minority populations\textsuperscript{14,17,18} but only a few studies have clearly documented research and recruitment challenges that are particular to refugees\textsuperscript{20,21} or made suggestions for improvement\textsuperscript{17-19}.

However, there is a paucity of studies directly designed to investigate the appropriateness and effectiveness of recruitment strategies for minority groups, and
instead these studies have relied on assessing studies designed for other purposes for findings relating to recruitment. For example, in an informative 2011 systematic review, Ndumele searched all peer-reviewed focus group studies with minority populations (Black and Hispanic) and attempted to quantify the relative effectiveness of various recruitment strategies for focus group research. However, of 45 studies, only 21 reported any metric of recruitment success, and of these, no discernible trend was found. The authors articulated the need for increased rigor in describing methodology of recruitment in literature in order to better understand recruitment patterns in minority research.

To address the research gap, this study seeks to further our understanding of the appropriateness of recruitment strategies among refugee populations. This was not a hypothesis driven experiment comparing recruitment methods. Rather, it was designed to allow for the evaluation of various planned recruitment strategies and other naturally emerging recruitment strategies by clearly documenting recruitment processes and evaluating the effectiveness of each method utilized for a qualitative focus group study with government assisted refugees (GARs). This study also allowed for the assessment of the impact of researcher-participant familiarity that has been previously identified as a variable influencing recruitment success in minority and vulnerable population research. This was done by observing the different successes and challenges faced by each of four research assistants who had varying degrees of familiarity and demographic homogeneity with their target refugee subgroup. In this study our experience emphasized the impact of familiarity on successful recruitment among this population.

7.2. Methods

To allow for comparisons of the appropriateness and effectiveness of different strategies, we analyzed five different recruitment methods used to recruit GAR participants from four language groups (Arabic, Farsi/Dari, Karen and Somali; corresponding to four GAR refugee groups from Iraq, Afghanistan, Burma and Somalia) for a series of four focus groups. The data was collected as part of a larger Canadian focus group study that examined participant perspectives on the practical and ethical issues in conducting research with GARs.
Inclusion criteria for the focus groups included GARs in Canada for less than five years who were older than 19 and who spoke one of the focus group languages. The goal was to invite 25 participants to each focus group so that, after accounting for hypothesized attendance rates, we would have 10-12 participants at each session. Participants were offered lunch, childcare, transportation reimbursement of 5$, and an honorarium of $20.

7.2.1. **Recruitment strategies**

Recruitment of refugees was facilitated by hiring four language concordant research assistants (RAs). The RAs attended three training sessions on research, recruitment and focus group facilitation. The Arabic speaking RA was a physician and also a GAR from the target population in Iraq. The Karen speaking RA was a school support worker and also a GAR from the target population in Burma. Both the Arabic and Karen speaking RAs considered themselves part of their respective communities of interest. While the Somali speaking RA was a refugee from Somalia, his migration history was different as he was a university student who came to Canada on a scholarship. He considered himself partially connected with the community of interest. The Farsi speaking RA was a university student and an immigrant from Iran and spoke Farsi while the population of interest was from Afghanistan and spoke the related but different language Dari. Besides having a shared language, she did not consider herself to be part of the community of interest.

Four planned recruitment methods and one unintended recruitment method were used to invite participants to the focus group sessions. The first, and perhaps most traditional, recruitment strategy was based at two clinics that specialize in refugee care called The New Canadian Clinics (NCC), just outside of Vancouver British Columbia, which provide care from the first few months after arrival to several years into settlement. Study personnel met with NCC nurses and physicians who were all very keen to participate. Medical and administrative staff at each clinic, including nurses, physicians, medical office assistants and interpreters, were asked to verbally invite patients to participate in the study. A brief description of the focus groups was provided through the aid of onsite interpreters along with a language concordant written information sheet (See Appendix A). Interested participants gave oral permission to be contacted by
phone by the language concordant research assistant for further details. When recruiting, the staff were very clear that patients did not have to participate in the research and that their ability to continue using the clinic in no way hinged on their participation. Staff documented each encounter with a participant and indicated if the participant was willing to receive a phone call or not, and if not, why not (See Appendix B and C).

Patients who were interested then received follow-up phone calls from an RA, where more detail was provided. A list of items to cover in these calls was given to the RAs in English to allow for ad lib oral interpretation facilitating flexibility and nuance of speech as suggested by previous studies (See Appendix D). The encounter, including a potential participant’s questions and concerns, was documented by the RA in a spreadsheet template (See Appendix E). For those who agreed to participate, the RAs made one reminder phone call leading up to the day of the focus group.

The second recruitment method was unintended and only occurred in one language group. Several days prior to the Somali focus group study there were very few confirmed participants. Unaware that we did not have ethical approval for this method of recruitment, NCC staff gave the RA the phone numbers of patients who they thought might be interested in participating in the study but who had not been contacted by an NCC staff member first. The RA called these individuals directly and then proceeded with the follow-up phone call described above. Post-hoc ethical approval for this recruitment method was obtained.

The third recruitment method involved encouraging RAs to contact community organizations that might be relevant to their refugee group. Once contact had been made with representatives of the community organizations the RA instructed them on how to invite participants to receive follow-up phone calls from the RA as described above.

For the fourth recruitment method, RAs were asked to consider their own personal contacts to see if anybody they knew met the inclusion criteria for the study. If they were comfortable with doing so, they were encouraged to contact the individual to invite them to participate following the same telephone procedure outlined above.
Lastly, when the RA spoke with a potential participant from the NCC, from the community or the RA’s personal social network, the RA was encouraged to ask if the individual knew of anybody else who might be interested in participating. They requested that the individual invite their family or friends to participate and contact the RA for further details.

A follow up discussion with the RAs on the recruitment process was audiotaped and analyzed. Retrospective guided journals were collected from all RAs.

7.2.2. Analysis

The primary analysis involved calculation of ‘participation rates’ where the total number of people who attended each focus group was divided by the total number of individuals contacted for each group or for each recruitment strategy. We also engaged with the qualitative data from RA follow up discussion, RA journals, and RA and researcher field notes to support the analysis of the recruitment rates.

7.3. Results

7.3.1. Description of recruitment process

See figure 7.1 for a diagram of the recruitment process.
Figure 7.1. Recruitment diagrams for all four focus groups with percent attendance for each language group.
Iraqi group

Recruitment for the Iraqi group was slow due to low numbers of Iraqi patients attending the NCC at that time. Only four contacts were collected. Three agreed to come and did attend. Two also brought their spouses. The fourth, a male, considered coming with his wife but the cost of public transit for his family of seven children was a barrier to participation.

Beyond the NCC, the RA contacted a female friend to invite her to participate. This friend brought her husband and gave the names of two other friends. One passed on the invitation to a family of six. Of the seventeen people contacted by the RA, fifteen people committed to coming. All attended, however one was late, so fourteen participated in the focus group. A total of 82% of those invited participated the focus group.

When asked why participants did and did not attend the RA wrote:

Most participants agreed to come because they thought that the research title touch an important issue. Most of them had some problems with medical care services and they might think that this research would answer some of their questions about the health system in Canada.

When asked about any underlying reasons that people might have attended, the RA thought that recruitment by a health clinic and the affiliation of the research with a university were very important features in participants’ willingness to attend. He believed the association with government institutions helped with building trust and the association with individuals in a position of authority helped them believe that the results of the research could be meaningful and have the potential to impact the health system.

Somali Group

Due to low recruitment at the NCC, the RA was given a list of twelve names directly by the NCC staff. In total, sixteen people were contacted and all sixteen agreed to come. The morning of the focus group three men called to cancel due to last minute work. That afternoon, two women did not show up. One additional participant came with a friend however she did not meet the inclusion criteria. A total of eleven people, 69% of the sixteen people we invited, participated in the focus group.
When asked why participants attended the RA wrote:

*They had the time and were excited about the opportunity to be listened to and be part of the study. It actually resonated with them and they had strong feelings about the health sector because all of them were vulnerable government assisted refugees. Some of them were using it as an opportunity to socialize with their friends and attend the focus group. There was incentive at the end, lunch and a small monetary token. A factor that made a difference as they felt like they are being compensated for their time.*

When asked why people choose not to attend the focus group the RA wrote:

*Most the ladies I contacted showed up whereas the guys did not. On the day of the focus group discussion, there was a new temporary job in town that opened up at the blueberry farms and most of the guys went to work in the fields to make money.*

**Karen Group**

For the Karen group, the NCC spoke with twelve patients. The staff reported that there was a high volume of Karen people attending the clinic at that time.

Beyond the NCC, the RA was well connected with the community personally and occupationally. She directly phoned seven people. She chose to call people who she thought would be interested in the project and confident about sharing their opinions. In total 20 people were contacted. Seven could not attend, five due to work or a conflicting appointment. On the day of the focus group thirteen people had committed to coming and all thirteen attended. Thus, a total 67% of the twenty people invited participated in the focus group.

When asked why participants did and did not attend she wrote:

*People who choose to attend focus group because they would like to share their experience and want the service to be better. They were also interesting in focus group. People that choose that not to attend the focus group because they are not interesting and shy to speak out and did not want to share their experience.*

The RA additionally added her opinion on underlying reasons why participants agreed to come. She felt that people she knew trusted her and might have had a desire
to please her. Many of them were also confused about the idea of research and believe in part that the research focus group would provide them with an opportunity to learn about health issues.

**Farsi/Dari Group**

The Farsi/Dari group was postponed due to low recruitment rates and due to the initial date occurring during Ramadan. The NCC spoke with four people who all agreed to be contacted further. Of these, only one agreed to attend but did not show up. To address the low recruitment rates the RA contacted a local community organization that worked with Afghani refugees. Two of the Afghani staff at the centre, one of whom was a physician in Afghanistan, were very helpful and invited 11 people to attend and gave their contact information to the RA. Of these, two numbers were not in service. Eight of the other nine contacts agreed to participate and did come to the focus group along with two friends. A total of ten people out of the twenty people contacted, 50%, participated the focus group.

When asked why she believed participants’ attended the RA noted several reasons including “joining other fellow Afghans”, (the) “event sounded like a fun community event where participants would enjoy some food and join other Afghans to discuss their experiences”, “recruited by an Afghan community worker, trust between recruiter and participant”, “feeling well-informed about the study and its objectives” and “trust between researcher and participant”.

When asked her opinion about why some people did not participate, the RA mentioned schedule conflict and not feeling comfortable in interviews and discussions.

**7.3.2. Descriptive statistics**

At the New Canadian Clinics nurses and physicians spoke with twenty-three patients and wrote down twenty three names of patients who were willing to be contacted by a research assistant with further information. Everybody who was asked by an NCC staff member if they were willing to receive a follow up phone call agreed. Of these 23, 14 agreed to participate. Of these 14, 12 attended the focus group. See figure 7.2.
Figure 7.2. Recruitment flow chart for the New Canadian Clinics

- 12 Attended Focus Group Session
- 13 Yes, 0 No, 0 Maybe, 1 Not Contacted
- 4 Yes, 2 No, 3 Not Contacted
- 19 Yes, 6 No
- 25 People Contacted by Research Assistant
- 25 Names Collected
- Health Clinic
- Agreed to come at phone call #1
- Agreed to come at phone call #2
- Received Call
For the other four recruitment methods, fifty potential participants were contacted by an RA through other means including through the NCC providing direct contact information of patients (n=8), through community organizations (n=9), through direct personal contacts of the RA (n=8), or through invitation by another potential participant (n=25).

In total, 73 people were invited to attend, 55 people agreed to attend, 49 people showed up and 48 people participated in the four focus groups. There were 48 participants for the Arabic (n=14), Farsi/Dari (n=10), Karen (n=13) and Somali (n=11) speaking focus groups. The average age was 42 (range 19 to 65). Seventy-six percent were female. About half reported speaking some English, with the rest having no English language skills. Half had no formal education or primary education only. Eight-nine percent of participants had been in Canada for less than three years and twenty percent for less than one year (table 7.1).

**Table 7.1. Demographic information about focus group participants**

<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
<th>Average Age</th>
<th>Female (%)</th>
<th>Also speak English (%)</th>
<th>No education or primary education only (%)</th>
<th>In Canada for less than 1 year (%)</th>
<th>In Canada for less than 3 years (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somali</td>
<td>11</td>
<td>38</td>
<td>82</td>
<td>27</td>
<td>80</td>
<td>20</td>
<td>100</td>
</tr>
<tr>
<td>Arabic</td>
<td>14</td>
<td>43</td>
<td>64</td>
<td>79</td>
<td>14</td>
<td>17</td>
<td>100</td>
</tr>
<tr>
<td>Karen</td>
<td>13</td>
<td>47</td>
<td>67</td>
<td>46</td>
<td>77</td>
<td>8</td>
<td>69</td>
</tr>
<tr>
<td>Farsi/Dari</td>
<td>10</td>
<td>39</td>
<td>90</td>
<td>22</td>
<td>44</td>
<td>44</td>
<td>89</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>42</td>
<td>74</td>
<td>46</td>
<td>50</td>
<td>20</td>
<td>89</td>
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</table>
In terms of variability between groups, the Farsi/Dari and Somali groups were predominantly female while the Arabic and Karen groups were more gender balanced. The Arabic group had the most English speakers, with 79% speaking some English. The Karen and Somali group had the least amount of formal education and the Arabic the most. The Somali and Arabic groups were the ‘newest’ and the Karen had on average been in Canada the longest.

The percentage of people who agreed to attend and who actually attended varied by language group and on how each person was recruited. See tables 7.2 and 7.3.

**Table 7.2. Recruitment rates by language group**

<table>
<thead>
<tr>
<th>Arabic</th>
<th>Invited</th>
<th>Agreed</th>
<th>Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Canadian Clinic</td>
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<td>3</td>
<td>3</td>
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<tr>
<td>New Canadian Clinic Direct</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Friend of a Participant</td>
<td>12</td>
<td>11</td>
<td>10</td>
</tr>
<tr>
<td>Friend of Research Assistant</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Community Contact</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>17</td>
<td>15</td>
<td>14</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Farsi/Dari</th>
<th>Invited</th>
<th>Agreed</th>
<th>Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Canadian Clinic</td>
<td>4</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>New Canadian Clinic Direct</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Friend of a Participant</td>
<td>7</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Friend of Research Assistant</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Community Contact</td>
<td>9</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Invited</td>
<td>Agreed</td>
<td>Attended</td>
</tr>
<tr>
<td>-------</td>
<td>---------</td>
<td>--------</td>
<td>----------</td>
</tr>
<tr>
<td>Karen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Canadian Clinic</td>
<td>12</td>
<td>7</td>
<td>7</td>
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<tr>
<td>New Canadian Clinic Direct</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Friend of a Participant</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Friend of Research Assistant</td>
<td>7</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Community Contact</td>
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<td>0</td>
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<tr>
<td>Total</td>
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<table>
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<th></th>
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<th>Agreed</th>
<th>Attended</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somali</td>
<td></td>
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<td></td>
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<td>2</td>
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<tr>
<td>New Canadian Clinic Direct</td>
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<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Friend of a Participant</td>
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<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Friend of Research Assistant</td>
<td>0</td>
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<table>
<thead>
<tr>
<th>Totals</th>
<th>Invited</th>
<th>Agreed</th>
<th>Percent Agreed</th>
<th>Attended</th>
<th>Percent Attended</th>
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<tbody>
<tr>
<td>Arabic</td>
<td>17</td>
<td>15</td>
<td>88</td>
<td>14</td>
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<tr>
<td>Farsi/Dari</td>
<td>20</td>
<td>11</td>
<td>55</td>
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<tr>
<td>Karen</td>
<td>20</td>
<td>13</td>
<td>65</td>
<td>13</td>
<td>65</td>
</tr>
</tbody>
</table>
Table 7.3. Recruitment rates by method of recruitment

<table>
<thead>
<tr>
<th>Method</th>
<th>Invited</th>
<th>Agreed</th>
<th>Percent Agreed</th>
<th>Attended</th>
<th>Percent Attended</th>
</tr>
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<tbody>
<tr>
<td>New Canadian Clinic</td>
<td>23</td>
<td>14</td>
<td>61</td>
<td>12</td>
<td>52</td>
</tr>
<tr>
<td>New Canadian Clinic Direct</td>
<td>8</td>
<td>8</td>
<td>100</td>
<td>5</td>
<td>62</td>
</tr>
<tr>
<td>Friend of a Participant</td>
<td>25</td>
<td>19</td>
<td>76</td>
<td>17</td>
<td>68</td>
</tr>
<tr>
<td>Friend of Research Assistant</td>
<td>8</td>
<td>6</td>
<td>75</td>
<td>6</td>
<td>75</td>
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7.4. Discussion

The overall recruitment rate for this study was 66%, consistent with a 2011 systematic literature review of recruitment strategies of focus group research with minority populations in the United States which showed recruitment rates ranging from 43% to 87% across 21 studies\textsuperscript{14}. Ndulemele’s review showed that there were no clear patterns to the effectiveness of recruitment strategies, with respect to overall recruitment rates or the ability to recruit a representative sample, in large part due to poor documentation of recruitment methods. The attention to documentation of the recruitment process in this study adds to this body of literature and could serve as a model for future research practice.

The most striking pattern in our data is the effectiveness of familiarity on recruitment success. The most effective recruitment strategy was being invited by somebody in a familiar community organization (89%), by an RA who was already a friend or acquaintance (75%) or by somebody who was already planning on participating (68%). These rates were higher than the two recruitment rates at the NCC by health
care practitioners; recruitment while attending an appointment (52%) and direct phone calls by the RA to NCC clients (62%). This finding suggests that being invited to participate by a familiar contact might increase the likelihood of participation and recruitment through health care workers or a health care clinic might decrease the likelihood of participation.

Furthermore, the language groups with the most effective recruitment rates utilized RAs that shared similar demographic characteristics to the target population. In this study, the highest recruitment rate was 82% in the Arabic group where the RA was a GAR from the same country as participants. He was also a physician in his home country which is considered a position of respect and authority. The next highest recruitment rates were in the Somali and Karen groups at 69% and 65% respectively. Both RAs were refugees with a shared language and culture with the focus group participants. The language group with the lowest recruitment rate was the Farsi/Dari group at 50%. As noted previously, the Farsi speaking RA was an immigrant from Iran while her focus group was primarily composed of refugees from Afghanistan. This finding suggests that research team members with shared demographic features to the target population may have higher recruitment rates.

From these two key findings, we can see that familiarity is correlated to recruitment rates. Familiarity has been explored as a factor influencing recruitment with minority populations and this research supports previous findings indicating a positive correlation. However, there is no specific “familiarity recruitment strategy”. Familiarity between a participant and a research team may manifest through pre-existing personal relationships, pre-existing contact through a community or health care organization, or a shared language or culture. It can also manifest when a participant is invited by somebody already planning to attend a research event. Thus, for researchers considering the role of familiarity in their recruitment strategies, one should consider the specific context of the research and newcomer environment.

The role of trust as a variable mediating the impact of familiarity is suggested by the RA journaling where three of the RAs mention the role of trust as a key factor influencing recruitment success. Trust between researcher and participant has been explored in the minority research recruitment and was further explored with our own
participants during the focus group sessions. Results pertaining to participant perspectives and trust are reported elsewhere (Chapter 8).

Lastly, we must note that this research only supports the effectiveness of familiarity on recruitment. It does not assess the ethical appropriateness. On one hand, familiarity might be helping interested but otherwise fearful potential participants to engage in the opportunity of partaking in research. Alternatively, researchers must consider the potential that familiarity can lead to coercion or feelings of obligation, both impacting voluntariness. Further, we must consider the impact on the community members serving as members of the research team and the ethical dilemmas that they might face\textsuperscript{69}. A further assessment of the ethical implications of familiarity is found in Chapter 9.

These findings are limited in that only a few recruitment strategies were assessed. The sample size was small and may not be representative of the larger GAR community for each language group. In particular, comparing the demographics of our study population to the larger GAR populations in BC\textsuperscript{28,64} suggests that our groups were over represented by women. Additionally, due to the organic nature of word-of-mouth recruitment, perfect documentation of all individuals contacted cannot be assured and thus participation rates through this method may be inaccurately high.

7.5. Conclusion

In conclusion, this study was unique in that it was explicitly designed to look at recruitment strategies with refugees. It found that recruitment rates varied by refugee group, by research assistant demographics and by method of recruitment. We hypothesize that these differences were due to variable familiarity with the research team member or individual who invited them to participate with increased familiarity being associated with higher recruitment rates. This finding suggests that researchers engaged in refugee health research should be intentional in their recruitment strategies and consider the role of familiarity based on their specific research context.

There are still unanswered questions about how utilize the impact of familiarity on recruitment strategy in an appropriate way. Ethical implications with respect to familiarity
and trust in recruitment need to be further considered. While further research is needed in this area, results from this study should be considered in the recruitment of refugees for future health research.
8. Recruitment of refugees for participation in health research: Adding refugees’ perspectives

8.1. Introduction

Engaging ethnic minority participants in research studies can be challenging due to a number of barriers for researchers or participants alike. To date, understanding of these barriers has focused primarily on obstacles perceived by researchers and identified as part of studies designed for other purposes. Commonly cited barriers include language barriers, adapting recruitment material, finding and contacting potential participants, and obtaining informed consent.

As far as we know, only three studies to date directly sought the opinions of minority groups on barriers and enablers to participation in research. A 2012 German study assessed the willingness of individuals with Turkish migration backgrounds to participate in health research studies. Using focus group methodology eight potential reasons for lower participation rates were identified including the different role of women, lack of knowledge, lack of interest, German-Turkish interactions, mistrust, anxiety, data privacy protection and lack of benefits of the study. A 2005 Canadian focus group study asked migrant women to review research materials for a separate study and this group made recommendations about consent processes, interpretation procedures, development of trust in research, approaches to sensitive topics, and reimbursement of participants. A 2003 American study of African American, Latino and Chinese American perspectives on research found that willingness to participate was decreased if there was distrust, fear of stigma, fear of loss of services, fear of loss of confidentiality, fear of safety, or schedule conflicts, and increased if participants valued the research, wanted to share their stories, contribute to efforts that might help others, and were assured of confidentiality. These studies, by adding participants’ voices, have resulted
in greater understanding of minority participants’ willingness to engage in research and suggestions have been made for culturally appropriate research designs for minority participant involvement\textsuperscript{16,17,19,67}.

However, with respect to refugees as a specific minority group, there is a paucity of research. To date, some additional challenges have been identified by researchers, such as those due to higher rates of illiteracy\textsuperscript{71} distrust, fear, and suspicion\textsuperscript{26}, being ‘socially invisible’\textsuperscript{21}, potential power imbalances, institutional discrimination, and trauma associated with pre-migration, migration, and settlement experiences\textsuperscript{20}. Based on these observations, thoughtful suggestions for improving the efficacy and effectiveness of research with refugees have been made\textsuperscript{20,21,26}. However, the knowledge base for recommendations on improving research with refugees still lacks input directly from refugee participants.

Without refugees’ perspectives, our understanding of the factors that impact willingness to participate in research will remain limited in depth and breadth. The current study seeks to clearly document refugee participants’ opinions on factors that may impact refugees’ willingness to participate in health research.

8.2. Methods

Focus group sessions hosted by language-concordant research assistants (RAs) were held in British Columbia (BC) Canada in 2011 with the four most locally prevalent government assisted refugee (GAR) language groups (and country of origin) at that time; Arabic (Iraq), Farsi/Dari (Afghanistan), Karen (Burma) and Somali (Somalia). GARs were selected as a subgroup of refugees due to the higher prevalence of this subgroup at the recruitment clinic sites and due to a better understanding of the study population locally due to the carefully documented and monitored arrival of GARs.

The main recruitment sites for this study were two community health care centres that serve refugees near Vancouver BC called The New Canadian Clinics (NCCs). Four additional recruitment strategies were used including cold calls to NCC patients, invitations to personal contacts of the research assistants, recruitment at refugee focused community centres and snowball sampling. These strategies and their
effectiveness have been documented elsewhere (see Chapter 6). Inclusion criteria for
the focus groups included GARs in Canada for less than five years who were older than
19 and who spoke one of the focus group languages. Participants were offered lunch,
childcare, transportation reimbursement of 5$, and an honorarium of $20.

Four language concordant research assistants (RAs) were hired to aid in
recruitment and to facilitate focus group sessions. During the focus groups, RAs utilized
a semi-structured interview guide to inquire about participants’ attitudes towards
research, knowledge about research, experience with research and willingness to
participate in research. A case-study was presented involving a research assistant
approaching a newly arrived refugee to participate in a health related research study.
Prepared questions were used to stimulate discussion of the case study. Participants
were then invited to consider alternative iterations of the case study where elements,
such as characteristics of the refugee, the type of research study, the identity of the
research assistant, and the information provided were different from the original.

The focus group sessions were audiotaped and transcribed. Results were
analyzed using coding and thematic analysis by the lead researcher with input from the
four RAs.

8.3. Results

The total number of participants attending our focus groups was 48, with 14
Arabic speaking participants, 10 Farsi/Dari speaking participants, 13 Karen speaking
participants and 11 Somali speaking participants. The average age across the four
groups was 42. The youngest participant was 19 and the eldest 65. Seventy-six
percent were female. About half reported speaking some English, with the rest having
no English language skills. Half of participants had no formal education or primary
education only. Eight-nine percent of participants had been in Canada for less than
three years including twenty percent who were in Canada for less than one year.
Comparing the demographics of our study population to the larger GAR populations in
BC (Immigrant Services Society of British Columbia 2007, Immigrant Services Society
2010) suggests that our groups shared similar characteristics to the larger population however, our groups were over represented by women.

Several themes about willingness to engage in research emerged within the focus groups. These themes are categorized into general areas that influenced refugees’ willingness to participate in research: factors related to research design and factors related to individual characteristics of the research participants.

8.3.1. Research design factors

Research design factors related to: recruitment, the research team, and the research study.

Recruitment

The way in which a participant was invited to participate in a study influenced their willingness to participate. There were five sub-themes identified that pertained to research recruitment. These were incentives, timing, language, informed consent, and perception of mandatory participation.

Incentives

Providing a financial incentive was reported as being a motivating factor but many participants were clear to indicate that money alone would not have been sufficient if they were not willing to participate for other reasons. Reflecting on the honorarium in our study, one Somali participant indicated that the honorarium was insulting, but many other participants indicated appreciation.

Karen Female. If I am not interested in the study even if you pay me $100 I am not going to participate in it.

Somali Female: No. When you called me and told me about the money, I got mad. I interpreted it as if there is no money involved, then they will not come. I see it as belittling. That's what the Arabs call it- belittling. It's as if I asked you a favor and I followed it up with I'll pay you for it. When you do that, you take away the brotherhood and sisterhood. Then people won't even help each other without being paid for it. But people are not the same.
**Timing**

The timing of recruitment with respect to how long a refugee had been in Canada emerged as an important theme in all of the focus groups. If recruitment took place in the first few days or even the first month in Canada participants felt an individual would be unable to think clearly about participation. They may participate without fully understanding due to fear or a perceived sense of obligation. Alternatively they may decline due to suspicion or fatigue. The impact of a longer duration of time in Canada was not uniform, however, most participants indicated that they would be more likely to participate after having spent some time in Canada. Importantly, they felt that after a longer duration of time they would be more likely to understand and engage willingly, rather than out of a perceived sense of obligation.

*Arabic male:* As a newcomer, everything would be new, he might be confused. I think he would refuse to participate.

*Karen Male:* When he first came he is confused and he does not want to participate.

*Somali Female:* For me if a researcher came on my first day with an interpreter, I would probably cooperate more. But after a week, chances are people have told me so many things, and they have warned me a lot and planted so much fear in me that I will not cooperate.

*Farsi/Dari Female:* Bit by bit as time goes on, she talks to one, two or other people and interacts with the environment and starts feeling satisfied with her home. After all this she is then ready to participate in a project in order to learn something.

*Somali Male:* After one week, his eyes will be more open. By then people from the community have come and visited him and told him how things work. He’s also told them some of his issues and concerns. So at this point he is more willing to deal with foreigners.

**Language**

Language was identified as an important factor in recruitment. Unanimously, participants favored engagement in their mother tongue. Where this was not possible, most participants were comfortable using a bilingual research assistant or an English speaker with an interpreter. However, in the Somali group an unexpected finding was that some participants were suspicious of interpreters.

*Farsi/Dari Female:* Everyone is more comfortable with someone who speaks their language.
Karen Female: In our opinion if we have the person who speaks the same language is better and we feel more comfortable.

Farsi/Dari Female: And since there is a Dari or Farsi translator and I could understand what he is saying and asking, I don’t think there would be a problem. I would participate.

Somali Male: Since (he) is new, and this man is an interpreter, he can’t really tell the interpreter hey I’m not satisfied with you. And he can’t express his concerns to the researcher either, since he doesn’t know the language... And the interpreter is getting into other business that is not related to the research and Ali can tell based on the body language, so he is automatically suspicious of the interpreter.

**Informed consent**

Part of the informed consent process involves disclosure and comprehension. These two aspects of appropriate communication about the research study were brought up by participants and were associated with increased likelihood of participation.

Somali Male: The most important thing to make Ali comfortable, is to do what you did. To explain to us everything in a good manner and make us feel at ease. If he has any questions or private concerns, they should be answered and addressed. So once he is fully informed and convinced that this is not something shady, then he will participate.

Farsi/Dari Female: I have to know why is he asking me. I will not answer him.

Arabic Female: if I didn’t understand anything about the research, I would say no.

**Perception of mandatory participation**

Participants commented that times refugees’ may perceive involvement in research studies to be mandatory. This sense of obligation was associated with increased likelihood of participation.

Farsi/Dari Female: And I would find if it is necessary by the government to participate, if it is necessary, then I would participate.

Arabic Female: I have the same experience. A person came to me at Welcome House (with an interpreter).she said that she represents some governmental organization and she asked me to participate. It wasn’t a nice way ...I was confused and exhausted after a long trip. The recruitment was like an order to obey. I couldn’t say no.
Research team

The demographics of the RA or researcher emerged as factors influencing participation. In regards to the gender of the researcher, some participants felt that it was irrelevant, while others felt it may influence participation. The importance may be mediated by the nature of the research questions, with more participants preferring the same gender for more sensitive topics.

Farsi/Dari Female: One is more comfortable with women.
Somali Female: Some men are shy around women.
Arabic Female: Whether it was a man or a woman, it depends on how she or he approaches… how to invite participation.
Somali Male: Culturally and religiously speaking, I think it would be best if a woman gets a woman and a man gets man.

The impact of the nationality or ethnicity of the researcher was not unanimous. While more participants expressed a desire for a researcher from their own background, one participant expressed some suspicion of somebody from their own country being involved in the research. Insight from the Arabic RA revealed that suspicion of RAs from one’s own country may exist if refugees are from a region where politics or conflict may have made them suspicious of fellow citizens.

Somali Female: When I first came, I had young children with me. So any Caucasian who I saw, I was afraid they would take away my children. That’s what I used to hear from other people.
Farsi/Dari Female: If this person is Afghan, then we are more comfortable.
Arabic Female: I am afraid of people speak Arabic in a foreign country….and at the first week!!!

Personally knowing the RA was reported as factor that would influence disclosure of personal information and willingness to participate. Other qualities of the researcher, such as their affiliations, occupation or personal qualities were reported as being influential. In particular, if a researcher was affiliated with a hospital or settlement centre they would be more likely to participate. If the researcher was also a doctor, several participants also suggested that this would persuade them to participate.
Farsi/Dari Female: If it is someone responsible who asks me, like if you ask me, then I will tell you about my job and income, but if it is another person who asks us, then what have we got to say?

Farsi/Dari Female: It is in my nature that if I like the person then I would allow it.

Arabic Female: I would agree if I found him a good guy. He might help me in my situation.

Arabic Female: if the researcher is one of the hospital staff, I will participate.

Arabic Female: I knew (the research assistant). He was my counselor at welcome house.

Arabic RA: so if the researcher comes through this person, you will agree?

Arabic Female: yes, that will make a difference.

Karen Female: When we first came anything that the doctor asking us to do a test, we are always do it. Even now we are doing it.

Research study

Three sub-themes emerged under research study factors that participants identified as impacting willingness to participate in research including: the expected outcomes of the study, logistical factors, and safety concerns.

Expected outcomes

Individuals were motivated to participate if they expected a personal benefit from participating.

Somali female: Ali might be a man with a strong background. He might have been born into a very educated family. So he will take part for his own good. He probably knows that these people are here to welcome him and help him out.

Farsi/Dari Female: How is the research that you’re doing right now going to help us? How is it going to benefit us?

Frequently, and in all groups, to opportunity to gain knowledge was a strong motivator for participation. Curiosity and a general knowledge were mentioned, with specific interests in the topics of health and Canada.

Arabic Female: Maybe it is the curiosity. As I am new in this country I want to know everything.
Somali Female: In this kind of research we can benefit from it because it can help us to know how some diseases come about and how we can protect ourselves from it because these are things that we do not know due to our lack of being informed. So there is a chance that we can learn and then pass on this knowledge to others.

Arabic Female: I have some problem with my family doctor. Therefore; I thought it may be helpful to participate to understand the health system here.

Farsi/Dari Female: He has to participate. So that when they ask him something, he would know what to say. He can find out how things are in Canada and how he should behave and what Canadians are like and how to interact with other people.

Altruistic motivations were clearly influential with strong statements of support for research that might benefit other people, particularly other refugees, in the future.

Farsi/Dari Female: I would contact the person and find out about the purpose of the study and learn about whether it helps others. Does it help people in the future? Even one person? Would they benefit from my experiences? If so, then I will participate.

Somali Female: So we can help our fellow brothers and sisters who will come and are new to this country.

The topic and the purpose of the research were also important, where participants were more willing to participate in research with topics that were interesting and personally relevant and in projects that had the potential for meaningful outcomes that would contribute to positive change.

Karen Female: If he is interested in it he will participate, if not he won’t participate.

Arabic Female: For instance, I wouldn’t be interested if the research topic was about weather. On the other hand, anything related to health or medicine would

Farsi/Dari Female: Does your study have the power to change the law and help or not?...So let’s say you have that privilege, are you actually able to change things?

Logistic factors

Logistically, the location of recruitment and research could impact willingness due to practical reasons but also due to associations with the location. In the Farsi/Dari and Arabic groups location was discussed at length. Several participants indicated that
a familiar place may make them more likely to participate, although some suggested this was irrelevant. In the Arabic group there was also a discussion of the impact of hosting research activities in a religious setting such as a mosque. Participants did not feel that a religious setting would alter their decision to participate.

Karen Female: We need some people to assist us to go to that place.

Arabic Female: When recruitment comes from the clinic, like in Surrey or here in Burnaby… it would be very persuasive.

Arabic Male: I would agree if it was at Welcome House.

Farsi/Dari Female: We have to know where we are going. If we have no relations, then we aren’t going to answer the question.

Arabic Male: Place will not change my decision.

Other logistical factor included childcare and time constraints.

Somali Female: And sometimes there is the issue about children for mothers. Who will take care of their kids? Will they be ok while we are away?

Arabic Male: The time is another reason. If I don’t have time, I will not participate.

Safety concerns

When discussing different types of health research, safety concerns did become an issue of concern for participants. As would be expected, individuals were less willing to participate in research that might put their health at risk.

Farsi/Dari Female: Maybe it is harmful, so he won’t participate.

Farsi/Dari Female: Yeah, like, for example, the government now has a new medication, and no one has tried this medication, they ask you, do you want to take this medication? Because it helps human health. Yes or no? Will you accept or not?

Farsi/Dari Female: Well, we are not mice.

8.3.2. Individual factors

Refugee participants’ perspectives on one’s willingness to participate in research revealed numerous individual participant factors that might influence one’s decision: participants’ demographics, participants’ attitudes and participants’ knowledge or experience with research previously.
Participant demographics

In several focus groups, participants initially indicated that a low education level would likely mean that a refugee in Canada would be less likely to participate in research. However, other group members differed, and felt that regardless of education level any refugee could participate in research.

Farsi/Dari Female: I am illiterate. In Afghanistan the circumstances did not allow me to get an education. There was war and I moved around and was a stranger and I don’t know what to decide and what to do. I will think to myself why should I go? I’m illiterate. I can’t answer questions. I don’t understand. I understand nothing. What am I gonna say when I go there?

Farsi/Dari Female: They can answer. The most illiterate people of Afghanistan have knowledge, you would ask them 0, 2, 3, even though they can’t sum it up, their understanding is high.

Somali Female: Sure, because you still have a brain, and if you put your mind to it you can change something

Previous exposure to war was mentioned by just a few individuals, but in all cases it was felt to decrease willingness to participate in research.

Farsi/Dari Female: Even if there is a translator, if I’m … illiterate and just arrived from Afghanistan, have no language skills and have lived through war conditions where there were guns and rockets, and there were times we couldn’t get a dried piece of bread to eat, my head doesn’t work, I have no business there. I won’t participate.

Similarly, lack of proficiency in the local language (in this case English) was unanimously felt to be a barrier to participation. The presence of an interpreter was a facilitating factor, but some participants still felt the lack of English skills might prevent participation.

Arabic Male: Some might feel shy because he afraid of making mistakes in language or in behavior.

Karen Female: It is necessary to do more research and our people were not being shy and have courage to participate more. I can say only yes and no. For example: If I can speak English like (name) I am not shy I am going to participate more and I am not shy.

Karen Female: If that person can speak English then he would be participating.
In only one instance did a participant comment that her religion might make it difficult to participate in research studies. Other participant comments indicated that in general refugees in our study did not see religion as being a factor influencing participation.

**Somali Female:** If some Somali girls see her with Caucasian people, they might assume that she has abandoned the religion, and that she wants to assimilate to what they are.

**Farsi/Dari Female:** It has to do with the research project. It has nothing to do with being a Muslim or Christian.

The impact of a participant’s gender on likelihood of participation was mixed. In the Somali group, there was an uncontested impression that women may be less likely to participate due to shyness and shame. In the Karen group, gender was felt to be irrelevant. In the Arabic group too, there was passing mention that gender would not be influential and the discussion moved on.

**Somali Female:** We don’t know, there is something different in everyone’s heart. Some people are very shy, they have a lot of shame and others are not shy.

**Karen Female:** Doesn’t matter It is a male or a female. If he or she interesting in and he/she is going to participate.

In the Farsi/Dari group some too thought that gender was irrelevant, while a group of female participants thought that women were more likely to participate because the issues were more important to them. A male participant agreed, but felt that the reason that fewer men participated was due to their occupational roles and their financial obligations.

**Farsi/Dari Female:** My personal opinion of course is that when it comes to problems, there is no difference between a man and woman. It might be a single man or a single woman. Or it might be a family including a man and a woman. I think that when they arrive here form another environment, their problems are the same when they come here. Over time, bit by bit the problems of women differentiate from that of the men.

**Farsi/Dari Female:** In my opinion, women are more likely to participate in events that they are invited to.

**Farsi/Dari Male:** In my opinion, in my case for example, sometimes I study and think to myself, but my dad is not here and then I think to myself, I should work and take care of my father and my brother, I am the
youngest one and have to take care of things. I may not get to anywhere, yes, that's right, but they'll get somewhere. I have to take care of the others.

Attitudes towards research

Participants generally had very positive attitudes towards research. There were twenty-five comments coded under general positive attitudes. Several comments directly linked a positive attitude to an increased likelihood of participation.

Arabic Female: I like research. Whenever they told me about any research, I would participate.

Karen Male: On behalf of us we are very happy to participate in this research study and thank you for doing a research and we would like you to do more research study in the future.

As for negative attitudes, these were subcategorized into fear and suspicion generally about research, fear of loss of confidentiality and fear of consequences of not participating. The level of suspicion and fear appeared to be highest in the Farsi/Dari speaking and Somali groups, with almost no mention of these concerns in the Karen and Arabic groups.

Farsi/Dari Female: Fear sometimes causes you not to participate in things.

Farsi/Dari Female: Like, you have doubts, who is this person? Where did he come from? And why exactly is he doing this? If he doubts, then he won't participate at all. But if the objectives are clear then that person would definitely participate.

Somali Male: Like I said they're afraid. I told some guys that I was taking part in a research and I asked them if they wanted to benefit along with me, but they said no because they think their information will be stolen. Some of the people who are new are afraid of being tricked or something.

Somali Female: The person already had negative experience in this. Chances are that they already shared their concerns with someone back home and they are still regretting it. So they do not want to repeat the same mistake, and this time they will not share anything. Research Assistant: They will die with it. Somali Female: Yes. They will die with it.

Somali Male: He might take part, because he fears that if he doesn't, they will not help him. So he might even sign the papers without knowing what he is signing.
Knowledge about research and previous experience with research

Participant comments directly and indirectly revealed a diversity in individual participant’s knowledge about research and previous experience with research, but there did not appear to be a link one way or the other with increased or decreased willingness to participate in research.

The twenty-three variables mentioned here and their impact on refugees’ willingness to participate in research are summarized in table 8.1.

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<tr>
<th>Research design factors</th>
<th>Individual factors</th>
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<td><strong>Recruitment factors</strong></td>
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<td>Exposure to war</td>
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<td>Language</td>
<td>Lack of local language</td>
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<td>Informed consent</td>
<td>Religious beliefs</td>
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<tr>
<td>Perception of mandatory participation</td>
<td>Gender of participant</td>
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<table>
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<tr>
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<th>Participant attitudes</th>
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<td>The gender of the researcher generally doesn’t matter but some participants prefer same gender researchers, particularly for sensitive topics.</td>
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<tr>
<td>Nationality of the researcher</td>
<td>The nationality of the researcher generally doesn’t matter but may for refugees with certain political contexts.</td>
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<td>Personal qualities of the researcher</td>
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<td><strong>Research study factors</strong></td>
<td><strong>Participant knowledge and experience with research</strong></td>
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<tr>
<td>Safety concerns</td>
<td>Any research that puts participants at risk decreases the likelihood of participation.</td>
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</table>

*Table 8.1. Factors influencing willingness to participate in research*
8.4. Discussion

Our study of refugees’ perspectives on factors influencing refugees’ willingness to engage in research identified twenty-three variables important to consider in research. There are no other studies that we are aware of with refugees’ perspectives on research engagement with which to compare our results. Of note, our research findings about refugees are in line with previous findings about the perspectives of ethnic minorities more generally. However, this study also elicited seven unique variables including enablers such as participant demographics (higher education level), participants’ desire to acquire knowledge, and the personal qualities of the researcher (same gender, good personal qualities, and affiliations with settlement or health services). A new barrier discovered was previous exposure to war.

Most importantly, this study unearthed three important factors that enhanced the efficacy of recruitment but with ethical concerns. Firstly, if refugees are being recruited into a research study shortly after arrival in their host country participants predicted that this would result in either lower participation rates due to confusion, fear, and feeling overwhelmed or higher participation rates due to misconceptions about participation being obligatory or fear of refusal. In both circumstances, there are ethical concerns due to the risk of exclusion on one hand and of coercion, lack of comprehension, and involuntary participation on the other. As a result, researchers should try to avoid research recruitment shortly after arrival in the country of resettlement unless such timing is necessary, and if so, rigorous attention to the benefits and risks for participants is paramount.

Secondly, if refugees perceive that participation in research is mandatory, they are more likely to participate. The perception of mandatory participation seemed most likely to occur if research activities appeared to be related to government activities. Consequently, researchers need to pay particular attention to the power dynamics and the perceptions that may occur as a result of any stated or assumed research affiliations. The voluntary nature of participation must be clear stated and understood.

Thirdly, participants indicated that a refugee’s fear of consequences of not participating also may inappropriately increase a participant’s willingness to participate at
any time. Researchers should be aware of this possibility and make special efforts to inform participants that their health and opportunities will not be impacted by refusal to participate.

Based on the findings of this research, there are several recommendations that emerge for individuals conducting health research with refugees. To improve recruitment without ethical compromise, researchers should consider logistical factors such as selecting convenient times and locations, providing childcare, and consider providing reasonable financial reimbursement for participants' time. With respect to communication factors, we recommend ensuring all research materials and in-person communication are available in the participants' own language, providing clear information about the purpose of the research, and ensuring comprehension. With respect to the timing of recruitment, be cautious about recruitment of refugees in the first several months after arrival.

To aid in conducting the research, we also recommend engaging research assistants who speak participants' language and who are good communicators with strong interpersonal skills. For sensitive research topics consider using RAs who are the same gender as the target population. Engaging RAs who are personally acquainted with potential participants are who are affiliated with health or settlement services may also enhance recruitment, however, one must be cautious that this does not result in coercion or the perception of involuntary participation.

To maximize the benefit of research participation for refugees, if possible, researchers should consider providing opportunities for participants to learn about health or settlement issues during their participation in the research project.

Based on the findings of our research, researchers should also be aware of the characteristics of refugee subgroups that may correspond to recruitment challenges and corresponding strategies that may aid in engaging these groups. Refugees who have lower education or who are illiterate may have more trouble participating in research. This can be addressed by using appropriate terminology and providing assistance for reading written materials. Refugees who have been exposed to war may also be reluctant to engage in research. Researchers should consider the ethical
appropriateness of recruiting this population, and consider the benefits and harms of participation for these individuals. Refugees, who for various reasons may have negative attitudes towards research such as suspicion of research and fear of loss of confidentiality are less likely to engage in research. To address this, researchers can ensure transparency of research procedures, adequate disclosure, opportunities for questions, and diligent attention to maintaining confidentiality. With respect to gender, some female refugee subgroups may be shy or have fear of shame. This may be addressed by utilizing female RAs. As for males, they may have more concerns about financial and occupation commitments that could be affected by participating in research. This can be addressed by planning appropriate times for research activities and providing financial reimbursements.

There were several elements of this research design that pose threats to the validity of the results. There was of course a selection bias. Given that the purpose of this study was to understand refugees’ willingness to participate in research, and the fact that sampling was non-random and participation was voluntary, we must recognize that the study sample was in fact a subset of refugees who had already demonstrated their willingness to participate in research. However, we believe that our sample is reasonably representative of the respective refugee populations locally as overall two-thirds of all individuals contacted for this study agreed to participate. Further, comparing the demographics of our study sample to the respective GAR populations in BC shows that our sample is well suited to represent the population of GARs that settled in BC between 2005 and 2009 as it draws from appropriate source countries, settlement municipalities and age groups. Our sample, however, had a greater proportion of women than the source population.

There may have also been a social desirability bias. The setting for the focus groups was of a social nature, with food, child care and reimbursement provided for participants. The setting might have resulted in participants feeling obligated to speak positively about research as a means of reciprocity. To address this concern, we encouraged participants to be honest with their opinions and let them know that their honesty was of value to us. As a testament to this, there were comments and questions in the Farsi/Dari, Somali, and Arabic groups that were critical of health research generally and challenged elements of our own study such as whether or not our
research would have the ability to impact change in the health system. The Karen group, however, was universally positive and even with probing nobody offered dissenting viewpoints that were critical of research or our study.

The analysis of translated focus group content by a researcher outside the cultures of interest may also limit the validity of analysis. This was addressed by engagement with the RAs in analysis and review of key findings. Lastly, this study was limited in that it only focused on four government assisted refugee language groups. It is unclear if results can be extrapolated to other GAR populations, refugee claimants and other vulnerable immigrant groups. However, given the similarity of themes between these four diverse populations, we suspect that many of these themes are important to consider for most refugees regardless of source country.

8.5. Conclusion

In conclusion, this is the first study to address refugees’ perspectives on willingness to participate in research specifically targeting refugees participants. This study identified twenty-three variables that impact refugees’ willingness to participate in research. Results from this study allowed us to make recommendations about enhancing refugees’ engagement in research in an ethical manner for refugees generally and subgroups of refugees that may have more difficulties engaging in research. These results and recommendations should be considered in the engagement of refugees for future health research.
9. The informed consent process for research involving refugee participants

9.1. Introduction

Research involving refugees as study participants poses unique ethical challenges. While refugees often demonstrate remarkable resilience they can also be vulnerable, particularly when engaging as subjects in research. Ethical concerns can occur due to language and cultural barriers, low levels of education, financial burdens, perceived lack of rights, dependency on host country governments, endemic hostility and a history of physical or emotional distress. These factors can create power imbalances between researchers and participants. Consequently, some refugees may be at risk of engaging in research without understanding it’s voluntary nature, engaging in research despite known risks due to a lack of perceived alternatives, or at worst, being coerced to participate in research.

To address ethical challenges in health research broadly, researchers have several scholarly frameworks to guide engagement with participants. A practical article “What makes Clinical Research Ethical?” in the Journal of the American Medical Association outlines essential requirements to guide researchers in conducting ethical research and in 2007 Ellis et al. applied this framework to research with refugees and reviewed the literature to provide specific considerations for each requirement in the refugee context. From this work, we can see that one of the most significant challenges for conducting research with refugees is ensuring participant autonomy. Autonomy in research entails that individuals are capable of deliberation and can act under their own direction without obstruction. Maintaining autonomy in medical research is facilitated through the process of informed consent. For research involving refugees, there are numerous reasons to suspect that the standard Western informed consent processes might not be adequate for maintaining autonomy for non-western participants.
Despite these challenges associated with ensuring informed consent, the research to date on this process with refugees is limited to expert opinion, case studies and literature reviews. There is a paucity of empirical evidence\textsuperscript{24} from research that has directly studied the informed consent process with refugees and there is no research to date that we are aware of that seeks refugees’ perspectives directly on the informed consent process.

To address this knowledge gap, we designed a study to specifically observe the informed consent process with refugees and elicit refugees’ voices on the topic. We designed our inquiry around the five major principles of informed consent: disclosure, comprehension, capacity, voluntariness and documentation of consent\textsuperscript{25}. The literature on challenges with each principle when applied to refugees was reviewed (included in the results section). We attempted to address and evaluate the known challenges and integrated best practices into designing an optimal informed consent process for our study. We then conducted four focus groups with different refugee populations and used both quantitative methods to empirically observe how each refugee population interacted with the informed consent process in our study and qualitative methods to elicit refugees’ own words in focus groups about the consent process. Our study reveals new challenges and facilitators to conducting informed consent with refugees and raises important cross-cultural concerns about what makes research ethical.

9.2. Methods

The data for this paper was collected as part of a larger Canadian qualitative focus group study of four government assisted refugees (GARs) language groups including Arabic (Iraqi), Dari (Afghani), Karen (Burmese) and Somali (Somalian) refugees. We used five different recruitment methods (in person recruitment at a health care clinic, cold calls from a health care clinic, community centres, research assistant personal contacts and participant contacts) and three different informed consent options (a traditional language concordant consent form and two options for implied consent) to observe practical and ethical issues for research with refugees. It also involved language concordant focus groups that examined participant perspectives on practical and ethical issues of conducting research with refugees. Participants were asked to fill
out three questionnaires (on demographics, knowledge and attitudes) during the focus group session. Four language concordant research assistants (RAs) were hired to aid in recruitment and to conduct focus group sessions. Institutional recruitment was centred at two health clinics in Greater Vancouver called the New Canadian Clinics (NCCs) and focus groups were hosted at nearby community centres (MOSAIC and DIVERSEcity).

The informed consent process was designed to focus on clearly addressing the five principles of informed consent including disclosure, comprehension, capacity, voluntariness and documentation of consent. These principles were studied quantitatively and qualitatively. Observational data was collected at three points in time. First, health clinic staff used data collection sheets to document the first encounter with potential participants at the health clinics (appendix B and C). These included how many individuals were asked to participate, their response and any staff comments. Second, RAs used a different data collection sheet to document follow up phone calls (appendix E) including the individuals intent to participate and any questions or concerns they might have. Third, the lead researcher kept field notes regarding the focus groups sessions and during discussions with each RA after the focus group session. Quantitative data was collected by documenting each participant’s choice about how to document their consent.

Qualitative data was collected during the focus group sessions. Case studies were designed to elicit commentary from participants about the five elements of the informed consent process. Each session was recorded then transcribed and translated by the RAs.

For analysis, observational data was analyzed thematically, looking at successes and challenges with each of the five steps in the informed consent process. Participants’ choices for documentation of consent were analyzed to generate consent rates for the three options for informed consent studied. The focus group transcripts were analyzed by the lead researcher with input from the RAs using coding and thematic analysis to assess participants’ opinions on each element of the informed consent process.
9.3. Results

The results of our literature review, a description of how the research process unfolded, and our quantitative and qualitative data are presented together by each stage of the informed consent process.

9.3.1. Disclosure and comprehension

Disclosure, that is, insuring that participants are adequately informed, is often complicated by language barriers and by insufficiently trained research assistants. Inappropriate translation of research material and lack of professional interpretation of verbal interactions can result in the inaccurate exchange of information. Research personnel who lack appropriate cultural competency or familiarity with endemic concepts of health and research may be unable to convey information appropriately or accurately to participants, thus preventing them from being truly informed.

Comprehension refers to a participant’s ability to understand the purpose of the research and the implications of participating in the research. Comprehension can be compromised in migrant populations. Participants may struggle with understanding due to illiteracy, low levels of formal education and lack of familiarity with research. If there is a power differential, assessing comprehension can be difficult if participants are unwilling or unable to disclose a lack of understanding due to fear, embarrassment or a desire to please. As a result, for refugees there is a higher risk of individuals consenting without understanding their rights or refusing to participate due to a lack of understanding the rationale or objectives of the proposed research.

To address the anticipated difficulties with disclosure and comprehension, we hired four bilingual research assistant to aid in recruitment and for conducting the focus groups sessions. In addition to language, three of the four RAs also shared similar migration histories and culture as their target population. We hoped that the RA demographics would help to address language and cultural barriers and address power imbalances. Each RA participated in three training sessions on research, recruitment and focus group facilitation. A separate research meeting with the RAs and the health clinic staff took place to review effective disclosure techniques.
The first opportunity for disclosure for participants who were recruited at the health clinic (our primary recruitment method) occurred during their initial encounter with a health care worker. A simple description of the study was offered verbally through an interpreter accompanied by a language concordant handout (appendix A). Potential participants were invited to receive a follow-up phone call from the language concordant RA. Of the twenty-three patients approached at the NCC every single patient agreed to receive a phone call. No concerns were documented by NCC staff. For those contacted through a community center or by a potential participant (secondary recruitment methods), the initial disclosure process was not documented, however, these individuals were asked to inform the potential participant about the nature of the study and invite them to share their contact information with the RA or to contact the RA directly. In total, we documented at least 73 potential participants who were informed of the study through one of our five recruitment methods.

The second opportunity for disclosure occurred with the phone call from the RA during which potential participants were given a detailed description of the purpose of the research, the methods of the study, the availability of childcare and lunch, the reimbursement of $25, assurance that results would be kept confidential and that participation was voluntary. A second phone call was made to most participants to remind them about the study closer to the focus group date and also to allow time for any additional questions. In total, fifty-five of the 73 potential participants received a phone call from the RA. However, 18 of the 73 did not as participants who were invited by a spouse or a parent did not necessarily speak to the RA directly. We cannot be certain about the quality of disclosure provided to these individuals by their families.

During the RA phone call, potential participants were invited to ask questions to aid in assessing comprehension. Documentation by the RAs revealed that about a quarter of those contacted (18 out of 55 contacted) asked at least one question about the study. The most questions were documented in the Arabic group and the fewest in the Karen group. Questions were mostly about the time, location, whether or not they could invite other people and what sort of questions would be asked.

On the day of the focus group, the third opportunity for disclosure occurred with a didactic presentation by the RA. The RA used some printed pictures to aid in the
discussion. The RAs noted that some words did not translate well into their participants’ language making both oral and written disclosure challenging. For example, the Somali RA could not find an appropriate word for ‘research’ and instead had to use the phrase ‘generating new knowledge’. Individuals appeared to be comfortable asking questions during the focus group sessions where clarification was sought readily about the nature of the research study and for filling out the questionnaires.

From the focus groups, four key themes about disclosure and comprehension emerged. The first was the need for adequate disclosure. There were nine comments indicating the importance of clear disclosure.

Somali Female: You would think that, well I would think, that the person can accept or be ok with it, for example this session, we accepted, but if someone refuses they probably need someone to explain to them further what the research is about. That no harm will come from it, and a lot of things. Just like you explained to us everything. So if that happens, I think that 100% the person will accept

One comment suggested engaging a third party such as an interpreter or a community member to aid in disclosure. There were no comments suggesting that disclosure was unnecessary or undesirable.

Two themes emerged about asking questions. Fifteen comments indicated that participants thought refugees would be comfortable asking questions in our case study. On the other hand, five comments, all from the Arabic group, indicated concern about a participant feeling uncomfortable asking questions. Comfort with the language of engagement was a key determinant for a participants’ likelihood of feeling comfortable asking questions.

Farsi/Dari Female: I will first ask him why he wants the information. Why do you want access to my info? If he doesn’t answer it well, then no.

Arabic Male: Some might feel shy because he afraid of making mistakes in language or in behavior.

For comprehension, seventeen comments were given, particularly through the case study and the question “What if (fictional participant) doesn’t understand the research, will he still participate?” There were many strong statements by participants indicating the need for comprehension prior to participation. Participants indicated that if
they did not understand the purpose of the study, they would not participate, or, similarly, that if they did understand the study they would participate. It was clear that comprehension was valued. There were concerns that comprehension could not be achieved if there were language barriers.

*Arabic Male:* For me, I wouldn’t agree to participate in any research if I didn’t understand.

*Arabic Female:* I think if the person speaks English, he would understand the research more than one who doesn’t. The later might be lost between the researcher and the interpreter.

Of note, evidence of inadequate comprehension became apparent during the focus group for the Somali and Karen sessions. Several participants demonstrated through their comments that they believed the session was actually a health education session and were not distinguishing a difference between health research and health education.

### 9.3.2. Capacity

Capacity broadly implies an individual’s ability to reason and make his or her own decisions. Capacity in refugees, as with any population, can be affected by age and mental capacity. With certain vulnerable migrants capacity can also be impacted by real or perceived extraneous cultural or political circumstances that may limit an individual’s liberty. Practically, an individual’s ability to participate in research may be impacted by language barriers or by illiteracy.

Capacity was addressed initially by having an age cut off of 19 years old and health care workers and RAs were asked to consider at their own discretion the appropriateness of inviting anyone with known or obvious decreased mental capacity. Knowing that language and illiteracy could impair a participants’ capacity, we designed all parts of the study to be accessible to those without any English language skills or literacy.

Observationally, we did not observe any overt examples where a participant was incapable of deciding whether or not to participate independently. However, we did observe difficulties for some participants to engage in certain elements of the study. In
the Somali and Farsi/Dari groups some participants struggled more than expected with filling out the written questionnaires. We had designed each questionnaire to only involve circling answers or for one word responses. The RA would read out each line one at a time and a participant could request help from the RA, the lead researcher or a neighbor for documenting their response. As expected, several participants needed help from the RA or a neighbor to guide them line by line and indicate which symbol to circle for true or false, which end of the Likert scale to mark a response and which multiple choice option to select. Nevertheless, this process took much longer than expected and we were no longer able to ensure a participant’s autonomy nor confidentiality with respect to their answers on the questionnaire.

From our qualitative findings, although the focus group scripts did not specifically inquire about capacity four themes relating to the ability to participate in research emerged organically. Insufficient language skills were mentioned by all focus groups as a barrier that might result in somebody declining participation or participating despite insufficient understanding.

*Karen Female:* It is necessary to do a research more and our people were not being shy and have courage to participate more. I can say only yes and no. For example: If I can speak English like (name) I am not shy I am going to participate more and I am not shy.

Education or literacy was mentioned as a factor influencing a participants’ ability to participate. Five comments stated that illiteracy and lack of education would impair a potential participants’ ability to understand the research.

*Farsi/Dari Female:* I'm (the fictional participant) and I am illiterate. In Afghanistan the circumstances did not allow me to get an education. There was war and I moved around and was a stranger and I don't know what to decide and what to do. I will think to myself why should I go? I’m illiterate. I can’t answer questions. I don’t understand. I understand nothing. What am I gonna say when I go there?

On the other hand, three comments indicated a belief that illiteracy and lack of education did not mean that one couldn’t participate in research. This was captured most clearly by a Somali woman who said that someone with a low level of formal education could still contribute to research “*because you still have a brain, and if you put your mind to it you can change something.*”
Lastly, in the Farsi/Dari group, a fourth theme relating to capacity emerged. Three participants indicated that a history of exposure to war may negatively impact a refugees’ ability to participate in research.

_Farsi/Dari Female: Even if there is a translator, if I’m (the fictional participant), illiterate and just arrived from Afghanistan, have no language skills and have lived through war conditions where there were guns and rockets, and there were times we couldn’t get a dried piece of bread to eat, my head doesn’t work, I have no business there. I won’t participate._

9.3.3. **Voluntariness**

Voluntariness means that an individual agrees to participate in research under conditions that are free of undue influence and coercion. In research with refugees, voluntariness can be impacted by a power imbalance between researchers and participants\(^6\). Refugees may also be influenced by a desire to please or to act altruistically\(^{24}\). Reimbursements or promises of reward might be unreasonably persuasive in the context of refugees who often live in poverty and this may lead to coercion\(^{25}\). For refugees from sociopolitical environments that violate human rights, they may not trust that an invitation to participate in research is truly voluntary and fear negative consequences to declining participation such as deportation or loss of legal status\(^{24}\). In collectivist oriented cultures, individuals may be influenced by the desires of their family or community, or may even defer the decision to participate in research to another individual\(^{24}\). The western construct of voluntariness may not be valid in all ethno-cultural contexts.

In our study design, we tried to facilitate voluntary participation by informing participants at each stage of the process that participation was voluntary. For those being recruited at the health clinic we specifically indicated that their ability to receive ongoing health care would not be impacted by their decision to participate. While food and a financial reimbursement were offered, we felt that these were not out of proportion to the participant’s contribution of time, and participants were also informed that they were welcome to leave after lunch and that they would still receive their reimbursement.

Evidence of voluntary participation was apparent in all four groups. Most participants contributed eagerly during the focus groups sessions and for the most part
were in no rush to leave at the end of the sessions. Many participants lingered to chat, shook hands with the research team, expressed gratitude, and in the case of three Somali participants, gave the researchers a hug. One Karen male concluded the session by saying “On behalf of us we are very happy to participate in this research study and thank you for doing a research and we would like you to do more research study in the future” [sic]. Further evidence of voluntary participation was seen in the number of participants who opted to include their name on the demographics questionnaires. Participants were clearly told that this was not required nevertheless, 46 out of 48 participants wrote their name on the form or had a neighbour write their name for them.

Yet despite our efforts to inform participants of the voluntary nature of the study, there was a possibility that some of the participation was involuntary. For example all 23 participants approached at the NCC agreed to receive a follow-up phone call. While this high rate of agreement may have been truly voluntary, only 13 ultimately attended the focus group sessions. This suggests that NCC patients may have had difficulty saying no to a member of their health care team.

There may have been also been involuntary participation resulting from our snowball sampling approach. Parents and souses often volunteered to bring their family members and the RA did not necessarily speak to these family members independently. The level and type of persuasion utilized within families is unknown, but the potential for involuntary participation existed as we had five participants bring a spouse and six other participants bring adult children, of which at least two noticeably participated very little in the focus group session.

In the focus group case studies, participants’ impressions about voluntariness were elicited. The RA asked participants several questions including “If Mr. X doesn’t understand will he still participate?” and “What does Mr. X think will happen to him if he doesn’t participate?”

We found four participant comments that suggested refugees would make decisions about participation voluntarily.
Farsi/Dari Female: I have to know why is he asking me. I will not answer him.

Somali RA: So would you tell the researcher or interpreter that you are actually happy to take part? Would you share that with them? Somali Female: Yes, but only if I actually did like it

However, we found 15 comments that indicated a likelihood of involuntary participation due to compliance with authority (8), suggesting that recruitment invitations from individuals associated with government or authority may result in involuntary participation.

Arabic Female: I have the same experience. A person came to me at welcome house (with an interpreter). She said that she represents some governmental organization and she asked me to participate. It wasn’t a nice way …I was confused and exhausted after a long trip. The recruitment was like an order to obey. I couldn’t say no.

Farsi/Dari Female: And I would find if it is necessary by the government to participate, if it is necessary, then I would participate.

Somali Female: Whoever comes to me, I would take anything that is given to me.

There were three comments indicating that a fear of the consequences of not participating might lead to involuntary participation.

Somali Male: He might take part, because he fears that if he doesn’t, they will not help him. So he might even sign the papers without knowing what he is signing.

Two comments suggested that a desire to reciprocate a favor or a kindness would influence the likelihood of participation, which may or may not be considered voluntary.

Arabic Female: If the welcome house worker was very nice to me, and helped me to do important paper work, I would say yes.

Somali Female: When I was new and I came, someone comes to me, they already welcomed me, I really don't know them that well yet, so I will do whatever they tell me to do.

Similarly, participants revealed that family members may have decided whether or not another family member would participate.
Farsi/Dari Female: Ask the guy...pardon me for interrupting you. I signed him up and he said he won’t come. I told him that I signed him up and that he should go, now ask him the question, why? Farsi/Dari RA: Had your mother not signed up, would you have made you decide to come? Farsi/Dari Male: ((laughs)) Um, I don’t know, because they are not in my age group. I mean, what would I say? They are the crown of my head. But…

As mentioned previously, the nuances of how family members invited or persuaded their family to attend is unknown, thus, its impact on voluntariness is unclear.

Lastly, language barriers were also linked directly to the ability to participate voluntarily as demonstrated by this Somali participant:

Somali Male: Since Ali is new, and this man is an interpreter, he can’t really tell the interpreter hey I’m not satisfied with you. And he can’t express his concerns to the researcher either, since he doesn’t know the language. He doesn’t even know how to say “no”. And the interpreter is getting into other business that is not related to the research and Ali can tell based on the body language, so he is automatically suspicious of the interpreter.

9.3.4. Documentation of consent

The final step in ensuring the principle of autonomy involves the act of giving consent. This is the step where an individual indicates that they are willing to participate. This typically takes place with the signing of a written consent form. Obtaining written consent can be negatively impacted by a participants’ literacy level or by their suspiciousness of signing ‘official’ documents. Orally based cultures may prefer oral or implied consent however these methods introduce potential challenges and may encounter resistance from ethics review boards.

In our study, we created three options for participants to indicate their consent to participate. These three options included signing a language concordant consent form, implied consent by handing in signed or unsigned questionnaires, and implied consent by participation in the focus group session. See table 9.1

Table 9.1. Options for conveying consent to participate

<table>
<thead>
<tr>
<th>Component of Study</th>
<th>Consent</th>
<th>No Consent</th>
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</thead>
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</table>

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With respect to reviewing the consent form, for the benefit of potential illiterate participants the RA read through or summarized each section of the consent form. Each participant had a language concordant consent form in front of them during the presentation. Some participants, particularly in the Arabic group, read the form while the RA presented.

At the end, participants were invited to sign the form. The signing involved printing their name and then signing their name. Some participants did not know how to sign their name and asked a neighbor to sign on their behalf.

Following this, participants were asked to place their consent form in a large envelope with their questionnaires for submission. Participants were invited to submit their envelopes, but were also informed that they could choose not to. Participants were then informed that a conversation would soon begin, and consent would be implied by participation, whether or not they had signed the consent form. Participants were also informed that they could leave. The overall informed consent process on the day of the focus groups was the fastest at about ten minutes for the Arabic group and the longest at about twenty-five minutes for the Somali group.

Of the 48 individuals who attended the focus group session 47 also chose to hand in their consent form. Of the 47 consent forms that were handed in, 44 were signed for a signed consent rate of 92%.

Analysis of the signed consent forms demonstrated that six participants did not print their name and only signed their name. Some of these signatures were small pen marks without the typical pattern of a traditional signature. Three participants only wrote their first name. Five participants printed their name twice instead of having a stylized signature, however this may have been in the cases where participants` asked a

<table>
<thead>
<tr>
<th>Whole study</th>
<th>Signed consent form</th>
<th>Did not sign consent form AND left/did not participate in focus group session AND did not hand in questionnaire.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus group discussions</td>
<td>Implied by participation in focus group conversation.</td>
<td>Left or chose not to speak during focus group session.</td>
</tr>
<tr>
<td>Questionnaire</td>
<td>Handed in signed or unsigned questionnaire.</td>
<td>Did not hand in questionnaire.</td>
</tr>
</tbody>
</table>
neighbor to sign on their behalf. In total, only thirty consent forms clearly documented a complete printed name and a signature while fourteen (32%) of the signed consent forms had some degree of ‘error’.

All four individuals who did not sign their consent forms were from the Farsi/Dari group. Beyond this, there was no obvious demographic pattern common to the four individuals. This group of four included males and females, ages in the second and third decades of life, and educational attainment ranging from none to university education.

For implied consent for the focus group component of the study, nobody left any of the sessions. From observations by the RAs and the lead researcher, all individuals participated to some degree, albeit a few participants contributed minimally to the discussions. Thus, given our statement of implied consent with the focus group component of the study by participation alone, all participants consented to this part of the study. This is a 100% implied consent rate for the focus group component of the study.

For implied consent to the questionnaire component of the study, forty-seven out of 48 participants handed in their questionnaires. Forty-six out of the 47 also voluntarily included their name on their questionnaire, including the three who did not sign their consent form. Thus, there was an implied consent rate of 98% for the questionnaire component of the study. Table 9.2 provides a summary of consent rates and figure 9.1 and 9.2 show schematics of participation rates from initial invitation to documentation of consent.

Table 9.2. Consent rates by component of study

<table>
<thead>
<tr>
<th>Component of Study</th>
<th>Consent</th>
<th>No Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole study</td>
<td>Signed consent form =44/48 = 92% or, participated in focus groups conversation AND handed in signed or unsigned questionnaire =48/18 = 98%</td>
<td>Did not sign consent form AND left/did not participate in focus group session AND did not hand in questionnaire. 0/48 = 0%</td>
</tr>
<tr>
<td>Focus group discussions</td>
<td>Implied by participation in focus group conversation.</td>
<td>Left or chose not to speak during focus group session.</td>
</tr>
</tbody>
</table>
Figure 9.1. Conceptual image for participation from invitation at the New Canadian Clinics through to documentation of consent.
From the focus groups, participants in the Somali, Arabic and Karen group were asked how they would like to document their consent to participate in research. There was not enough time to cover this topic in the Farsi/Dari group. Signing consent forms, giving verbal consent, or just participating without any formal documentation were offered by the RA as examples.

In the Arabic group it was clear that most participants were comfortable with documentation of consent with a signature and preferred this method. In the Somali group, there was no consensus. One Somali participant preferred no documentation while another strongly indicated a preference for documentation. One participant suggested that individuals should have a choice of options for documentation, while another stated that they would comply with whatever was offered. There was concern about arousing suspicion for both recording consent in writing and verbally. There was
limited discussion on the topic in the Karen group with one participant indicating comfort with signing a consent form so long as the content was understood. There were no dissenting voices following this comment.

In regards to written consent forms, participants were asked if they preferred a short (1-2 pages) or long (10 page) consent form. There was a strong trend towards preferring a shorter consent form with 20 comments supporting a short consent form or a summary. However, there were three comments about the acceptability of longer consent forms if needed to sufficiently convey necessary information. Two participants suspected that a longer consent form would arouse increased suspicion about the consent form process. Lastly, participants indicated a strong preference for consent forms to be written in their own language (eleven comments) with only two participants preferring English.

9.4. Discussion

These findings suggest considerable cross-cultural consensus about the importance of ensuring disclosure and comprehension. Special considerations are necessary for written and oral communication and additional time is required to address language and literacy barriers. In our study, even with these efforts, there was still evidence of inadequate comprehension amongst participants, particular for participants from populations with low literacy and education levels. To address this, we recommend pilot testing of all research materials with members of the target population. Participant commentary also highlighted the importance of feeling comfortable with asking questions as a means to ensuring comprehension and noted that language barriers and shyness may be barriers to asking questions.

Our study elicited new factors to consider with respect to impacting capacity to give consent including low education, illiteracy and previous exposure to war. Interestingly, participants’ expressed divergent views on the impact of low education and illiteracy. Some refugees felt participation in research could be unattainable due to low education and illiteracy. However, others felt this was irrelevant and that refugees with low education and illiteracy still had much to offer. Thus, researchers should empower
refugees with low education and literacy so that they may have the opportunity to participate if desired.

Ensuring voluntariness was the most challenging aspect of the informed consent process, particularly in understanding the impact of recruitment by familiar individuals. Participants indicated that recruitment by known or unknown authority figures, family members or by someone who had been of assistance may influence participation. A parallel analysis of recruitment patterns (chapter 7) for this study also revealed that recruitment by a familiar person (either a known individual or somebody with shared ethno-cultural characteristics) such as a familiar RA, a community worker, a friend or a family member, was associated with higher recruitment rates.

Utilizing a familiar person in recruitment addresses the traditional power imbalance between researchers and participants. In ideal circumstances, this may help interested but otherwise fearful or shy potential participants engage in an opportunity while at the same time foster autonomy by enhancing comprehension and empowering participants to comfortably decline participation. However, given the lower rates of refusal with increased familiarity that we witnessed, one has to question whether familiarity enhances participation voluntarily or rather due to feelings of obligation or a desire to please.

Alternatively, we may need to consider alternative paradigms for assessing voluntariness in social systems that ascribe to hierarchical decision making. It is possible that participants may be entrusting decision making to a familiar person assuming that the familiar person would only invite them to participate if the benefits outweighed the risks. This transfer of decision making may be more frequent in collectivist cultures that are comfortable allowing others to decide on their behalf, or when comprehension is difficult, such as in populations with limited knowledge or research experience, or when research protocols are complex. This is supported in our study where some members of the Somali and Karen groups participated despite inadequate comprehension. A Somali participant articulated this transfer of decision making clearly when asked about signing the consent form: “You are responsible adults, we trust you, there is no need for signatures.”
Western medical ethics emerges from a culture that highly values autonomy. Thus, this transfer of decision making may be viewed as unethical as the ability to weigh pros and cons for ourselves can be very important in preventing coercion. However, we must consider the limitations of prioritizing autonomy as a proxy to protect vulnerable populations in research. Decision making is complex, and despite researchers' best attempts, adequate comprehension may be limited and vulnerable populations may rely on or even privilege other decision making criteria. The real question here perhaps is not whether or not participation is “voluntary” by medical ethics, but what is ethical and voluntary in the context of the refugee populations’ ethical paradigm.

Lastly, with respect to documentation of consent, the use of the traditional consent form was supported by some but not all of our refugee populations even though 92% of participants chose to sign a consent form in our study. There was a preference for short language concordant consent forms. Preferences thus might be culture specific and other options such as implied and oral consent should be made available following community consultation. By having options for implied consent available in our study, the consent rate improved to 98%.

The strengths of this study were its explicit focus on the consent process, rather than a secondary analysis of research designed for other purposes. The consent process was designed considering the most up to date recommendations from the literature, yet still identified ongoing challenges. Triangulation of observational findings, descriptive statistics and qualitative data created reliability in our findings. Further, by adding the perspectives of refugee participants, our research adds validity to previous researchers’ conclusions and adds the richness of the voice of participants to the dialogue.

The limitations of our study include that the analysis of translated focus group content was done by a researcher who was not a member of the cultures in the study. This was addressed by engagement with the RAs in analysis and review of key findings. This study only focused on four government assisted refugee language groups. It is unclear if results can be extrapolated to other GAR populations, refugee claimants and other vulnerable immigrant groups. On certain themes, such as disclosure and comprehension, there was consensus across the four diverse populations, and we
suspect that many of these themes are important to consider for most refugees regardless of source country. However, for some domains, such as preferences for documentation of consent, there was divergence. This highlights the need to understand and consider the specific sociocultural context of each refugee population when designing research protocols.

9.5. Conclusion

Empirical research addressing ethical concerns for research with refugees is scarce. Our mixed-methods study has added to this nascent field by directly examining the informed consent process including disclosure, comprehension, capacity, voluntariness and documentation of consent, amongst four refugee populations in Canada. We identified cross-cultural consensus about the importance of ensuring disclosure and comprehension in the face of language barriers and illiteracy. We identified additional factors impacting capacity, including low level of formal education, illiteracy and exposure to war. Ensuring voluntariness was found to be the most challenging aspect of the informed consent process, particularly in understanding the impact of recruitment by familiar individuals. The use of the traditional consent form was supported by some refugee populations, with a preference for short language concordant forms, but this might be culture specific and other options should be made available following community consultation.
10. Conclusion

Nearly 12,000 refugees arrive in Canada annually\(^1\). These newcomers often have unique health challenges due to pre-migration misfortunes\(^{4,29-31}\). Once in Canada, refugees may continue to struggle with health concerns due to further settlement stressors and barriers to accessing health care\(^9,32,33\). Research, particularly in the domain of access to primary care, is needed to help understand and address barriers faced by refugees\(^{12}\). However, there are practical\(^14\) and ethical issues\(^{24}\) that must be considered when engaging potentially vulnerable participants such as refugees in research studies. These challenges, to date, insufficiently understood.

This study was designed to acquire new understanding of practical and ethical issues in conducting research with refugees. Specifically, we achieved this through two parallel research processes. The first was by designing a study specifically focused on observing the practical and ethical issues encountered when conducting a research study with refugees. The second was to explore refugees’ perspectives about ethical and practical aspects of participating in health research.

These two parallel research processes were studied in the context of four focus groups in 2011 in British Columbia Canada (BC) with four different government assisted refugee (GAR) language groups, Arabic (Iraqi), Farsi/Dari/Dari (Afghanistan), Karen (Burmese), and Somali (Somalia). Four language concordant research assistants (RAs) were hired to facilitate the research process. Recruitment took place using five different planned and naturally evolving recruitment strategies and the success rates of each recruitment strategy were evaluated. Informed consent took place using three different methods for documenting consent and participant choices were carefully observed. Three questionnaires were administered inquiring about participants’ demographics, knowledge and attitudes. Lastly, the content of the focus group sessions explored participants’ perspectives on practical and ethical issues in health research.
This research identified important practical and ethical considerations for engaging refugees in research from both the observational analysis and qualitative findings.

Firstly, our assessment of participants’ experience with research and their knowledge about research and research ethics demonstrated that refugees with low levels of formal educational opportunities had limited experience with research, limited knowledge about research and high levels of confusion about research. Refugees from regions with higher educational opportunities had more knowledge and experience with respect to research. With respect to knowledge of research ethics, most, but not all, refugees were knowledgeable about the need for disclosure and comprehension and the maintenance of confidentiality in research. However, knowledge about the voluntariness of research was alarmingly low. These finding suggest that some refugee populations may be at risk of coercion and involuntary participation.

Practically, our observational findings demonstrated that nearly two thirds (66%) of all participants who were invited to participate in our study choose to attend the focus group session. This high rate of participation demonstrates the feasibility of engaging refugees in research studies. Notably, the rates of participation ranged from 50-82% based on language group and from 52-89% based on method of recruitment. The observable trend in these rates suggested that participation rates were highest when there was increased familiarity, conceptualized broadly as having shared linguistic, cultural or demographic characteristics as the ‘recruiter’ or affiliations with the recruitment location.

Practically, through our qualitative findings, refugee participants described twenty-three variables that might impact a refugees’ willingness to be a participant in a research study. These variables related to both the research, such as recruitment methods, the purpose of the research and the research team members; and to the individual characteristics of the potential participants, such as participants’ demographics, attitudes towards research and knowledge or experience with research previously. Most importantly, the participants’ perspective highlighted three variables that would increase recruitment success but with some ethical concerns. These included recruitment into a research study shortly after arrival in the host country,
allowing refugees to perceive that participation in research may be mandatory, or not addressing a refugee participants’ fear of the potential consequences of not participating.

With respect to ethical concerns, observation of the informed consent process in our study identified barriers and facilitators to addressing disclosure, comprehension, capacity, voluntariness and documentation of consent. Disclosure and comprehension were facilitated by training RAs and recruitment team members, providing language concordant written and oral information and repeating information on numerous occasions. Insufficient disclosure and comprehension were identified when relying on word of mouth recruitment strategies and when informing participants with limited literacy and low formal education. Limited literacy and low formal education were also observed to impact individuals’ capacity to participate independently and additional help from the research team or fellow participants was frequently needed. Our observations suggested that most participation was voluntary, however, there were subtleties observed suggestive of inadvertent or intentional persuasion by familiar figures. Observation of consent rates revealed a high rate of signed consent (92%), however there was an even higher rate of implied consent (98%) for various components of the study.

Adding participant perspectives to the discussion of ethics helped to identify cross-cultural consensus about the importance of ensuring disclosure and comprehension. Our qualitative findings identified additional factors impacting capacity, including low formal education, illiteracy and exposure to war. Adding the participant perspective helped to understand the subtleties noted about voluntariness of participation when recruitment involved familiar individuals. Namely, it highlighted the need to consider alternative ethical paradigms for understanding what is ‘voluntary’ in hierarchical societies where relationship may be valued above autonomy when considering research participation. Finally, the use of the traditional consent form was supported by some refugee populations, with a preference for short language concordant forms, however this might be culture specific and other options such as implied or oral consent should be made available following community consultation.
These findings are consistent with previous research on the topic of practical and ethical considerations of research with refugees\textsuperscript{14,24,25}. However, previous research has drawn conclusions from observing studies designed for other purposes, extrapolating findings from other minority non-refugee populations, or based on researchers’ expert opinions. This study is unique in that it was designed to evaluate the consent process specifically and to explore refugees’ own opinions and experiences. Consequently, it has identified new factors to consider when designing research studies with refugees and has allowed for a more nuanced exploration of the complexities of cross-cultural research ethics.

In the broader context of traditional Western research bioethics that consider beneficence, non-malfeasance, justice and autonomy, this research adds depth of understanding to the principle of autonomy when applied to refugee participants. However, the observations and participant contributions made in this study may also be extrapolated to consider broader implications for understanding benefit and harm from research participation and how to make research more equitably accessible in a just manner to all interested participants. In the future, adding refugees perspectives in each of these domains specifically may be valuable.

There are several elements of this research design that pose threats to the validity of the results. We have attempted to address each of these by having a clear understanding of their potential impact and adjusting our methods, analysis and conclusions appropriately.

With respect to our study goals of understand factors influencing refugees’ willingness to participate in research our study has an inherent selection bias. We must recognize that the data we collected was from a subset of refugees who chose to participate in research and had already demonstrated their willingness to be research subjects. The bias could result in a study population quite different then the larger population which it aims to represent. This bias was addressed by documenting the total number of individuals invited to participate with an aim to understand why individuals were declining participation. Overall, our participation rate was 66% and the primary documented reasons for not participating were logistical due to timing and location.
Further, our study sample shared many characteristics to the overall GAR population in BC\textsuperscript{28}, thus we feel it is a reasonably representative sample of the population.

There was possibly a social desirability bias. The setting for the focus groups was of a social nature, with food, child care and reimbursement provided for participants. The research team was pleasant and friendly with participants. While all of these measures were in place to ensure the comfort and respect of participants, the setting may have resulted in participants feeling obligated to speak positively about research as a means of reciprocity. In order to address this, we encouraged participants to be honest with their opinions. We used sample quotes during the case study sharing negative views of research in order to demonstrate to participants that this type of feedback was okay. We were successful in eliciting critical feedback about research generally in most focus groups, with the exception of the Karen group where participant quotes were almost universally positive and non-critical.

The validity of research conclusions may be prone to error when interpreting participant views across culture. To address this concern, the four bilingual research assistants were consulted regularly throughout the study to aid in creating the right environment for the focus groups and for providing context to participant comments.

With respect to external validity and the ability to extrapolate our findings beyond our study participants caution is necessary with extending our quantitative findings due to our small study sample and its non-random sampling nature. While prudence is necessary with extrapolating qualitative findings, the depth of understanding afforded with this methodology can lead to insights that might translate more appropriately beyond our study population. However, this study only focused on four GAR groups that may or may not be representative of GARs as a population.

Future research on ethical and practical issues of conducting research with refugees should focus on acquiring cross-cultural understanding of ethical principles such as voluntariness and capacity. This research has demonstrating the limitations of a traditional Western bioethical framework in cross-cultural research contexts. Other ethical principles or frameworks should be explored. One ethical approach would be to focus on human dignity, that is, acknowledging innate human value, respecting
participant beliefs and respecting participants’ privacy and dignity. A clinical framework that could be explored in the context of research ethics is cultural safety. This term was coined by Maori nurses in New Zealand and it explores the idea that quality clinical care for ethnic minorities requires knowledge of cultural values in addition to self-reflection on behalf of the provider.

Future research conducted with refugees as participants should consider the findings of this research, particularly when designing research recruitment strategies, designing informed consent processes and when evaluating the overall ethicality of the research in question. With respect to the proposed longitudinal cohort study that precipitated this research, our findings support the feasibility of engaging GARs in BC as research participants and provides clear guidance for ensuring the ethical conduct of research with this population.

At every stage, as demonstrated in this study, understanding participant perspectives is invaluable to understanding the ethical implications of research. In line with this, our research supports engaging participants in research processes directly, such as through community consultation, including refugees on research teams, or through participatory research approaches. These are all appropriate strategies to improve the effectiveness of research recruitment, the validity of results and the ethical conduct of research with refugee populations.

In conclusion, this research was successful in achieving its objective of acquiring knowledge to aid in the creation of optimal and appropriate recruitment methods and ethical informed consent processes for research with refugees in Canada.
11. References


Appendices
Appendix A.

Language concordant oral description and written handout describing the research study

Arabic oral description and written handout

From a desire to improve the study participation of participants who are unfamiliar with the English language, the study included Arabic oral description and written handout describing the research study.

Arabic oral description and written handout:
دانش و نگرش پناهگاهان (موردن حمایت دولت) درباره فعالیت‌های تحقیقاتی چیست؟

کانادا سال‌های حدود 2000 پناهگاه را زیر حمایت خود در کانادا به شکل قانونی در زمان ورود به کانادا و تا مدتی بعد از آن در مراقبت دقیقی به دست آمده است. هم‌اکنون، همچنان برای نگهداری پناهگاهان، تحقیقات و توسعه، خود و خانواده‌ها در حال همکاری هستند. برای این که پناهگاهان، پناهگاه‌هایی با تحقیقات و کمک‌های مختلف و به خود شامل، تحقیقات و مشاوره‌های مربوط به پناهگاهان، این جلسه در دانشگاه کانادا به‌طور روزانه برگزار می‌شود.

این پروژه تحقیقی می‌تواند بخشی از پنجم خانواده داخلی داشته باشد. این شرایط در کانادا، 19 سال ساخته‌بازان و مورد خدمات دولت کانادا در این شرایط مشترک با آنها در یک گروه دائمی که پناهگاهان، یونیورسیتی و سازمان‌های جامعه‌می‌باشند و در پایتخت و سایر شهرهای کانادا، آنها در بیش از 20 دانشگاه بالادستیه و آموزش دهنده به برنامه‌های مختلفی در زمینه‌های مختلفی می‌باشد. همچنین، این جلسه همچنان به کانادا، ارزش‌داری و می‌باشد.

اگر آنها رضیپذیر می‌شوند که اطلاعات ویژه‌تری در مورد این پروژه داشته باشند و یا در شرکت کانادا به فرمسی زبان با آنها تماس گیرند، و سوالات را با سیاست‌های می‌باشد.

اگر فارسی و در صوتی می‌خندیم، بااین 19 سال ساخته‌بازان و پناهگاه‌ها (موردن حمایت دولت کانادا) هستند از دو دعوت می‌کنیم که در این پروژه تحقیقی که توسط دانشگاه بریتیش کلمبیا انجام می‌شود شرکت نمایید.

همانطور که می‌دانید عناصری از کانادا در زمان ورود به کانادا و تا مدتی بعد از آن در مراقبت دقیقی به دست آمده است. هم‌اکنون، همچنان برای نگهداری پناهگاهان، تحقیقات و توسعه، خود و خانواده‌ها در حال همکاری هستند. برای این که پناهگاهان، پناهگاه‌هایی با تحقیقات و کمک‌های مختلف و به خود شامل، تحقیقات و مشاوره‌های مربوط به پناهگاهان، این جلسه در دانشگاه کانادا به‌طور روزانه برگزار می‌شود.

این پروژه در مواضع موزاییک در برنامه بریتیش کلمبیا روز

اگر فارسی و در صوتی می‌خندیم، بااین 19 سال ساخته‌بازان و پناهگاه‌ها (موردن حمایت دولت کانادا) هستند از دو دعوت می‌کنیم که در این پروژه تحقیقی که توسط دانشگاه بریتیش کلمبیا انجام می‌شود شرکت نمایید.

همانطور که می‌دانید عناصری از کانادا در زمان ورود به کانادا و تا مدتی بعد از آن در مراقبت دقیقی به دست آمده است. هم‌اکنون، همچنان برای نگهداری پناهگاهان، تحقیقات و توسعه، خود و خانواده‌ها در حال همکاری هستند. برای این که پناهگاهان، پناهگاه‌هایی با تحقیقات و کمک‌های مختلف و به خود شامل، تحقیقات و مشاوره‌های مربوط به پناهگاهان، این جلسه در دانشگاه کانادا به‌طور روزانه برگزار می‌شود.

اگر فارسی و در صوتی می‌خندیم، بااین 19 سال ساخته‌بازان و پناهگاه‌ها (موردن حمایت دولت کانادا) هستند از دو دعوت می‌کنیم که در این پروژه تحقیقی که توسط دانشگاه بریتیش کلمبیا انجام می‌شود شرکت نمایید.

همانطور که می‌دانید عناصری از کانادا در زمان ورود به کانادا و تا مدتی بعد از آن در مراقبت دقیقی به دست آمده است. هم‌اکنون، همچنان برای نگهداری پناهگاهان، تحقیقات و توسعه، خود و خانواده‌ها در حال همکاری هستند. برای این که پناهگاهان، پناهگاه‌هایی با تحقیقات و کمک‌های مختلف و به خود شامل، تحقیقات و مشاوره‌های مربوط به پناهگاهان، این جلسه در دانشگاه کانادا به‌طور روزانه برگزار می‌شود.
Karen oral description and written handout
Somali oral description and written handout

**UJEEDO:**

Si loo wanaajiyi daryeelka cafimaad ee qaxootiga dowlada caawiso, cilmii baarid dheerii ah ayaa loo baahanyahay. Madaama ay yihii bulsho iska tabar yar, waxaana u baahanahay sida ugu wanaaga badan oo loogu qaban karo cilmii baarid bulshada tan si loo dheeli tiro kayeelida tajribadaan mid wax ku ool u ah kaqaybgalayaasha iyadoona laga heli karo macluumaad muhiim ah oo horseeda isbadal. Mashruucan waxa loo hagaajije si loo ogaado mowqifka qaxootiga ay dowlada caawiso ee kuadaan cilmii baarida, aqoonta ay u leeyihiin cilmii baarida iyo ogalaashadooda ka qaybgalka cilmii baarid.

*Mowqifka Aqoonta Qaxootiga Dowlada Caawiso eekuadan Cilmii Baarida*

Hadii a d khudashidaha Soomaliga, aadnakaweyntahay 19 san oo kana mid tahay qaxootigadowladacaawiso, waxaankugucasuumeenna aadka kaqaybgashid mashruuc ilmibarid ah oo qab erka ee ooqojojaxacada UBC.

Waynuka war qaba na dhibkafi farahabadandadkada laakiin Canada kucusub soowajahamarka ee samtay laakiin cafimada ka dib u dha cad qaybqashid iyo toos. Si loo fahmo baahidi qaxootigawaxaa loo baahanyahay in la sameeyocilmibarid. Waxaan jecel na hayi neynu gaanomowqifka in ku aadanarimahaan.

Natiijada mashruucan waxa uu noogolaandaan oo ayaa neliidu wanaagsan u fahanodanii hiroyinka xiriirka aad u baahanyahay in la sameeyocilmibarid. Waxa aan jecel na hayi neynu gaanomowqifka in ku aadanarimahaan.

Mashruucan waxa uu akhiciid oo noocarta DIVERSEcity, magaalada Surrey, maalinta _____ sacada _______. Kaqaybgalkaagamashruucan waxa aha mid ah shir 2 saac ah oookubaxaay ooluqadaa xaqiijiiisSoomaaliga uu horseeda kanoonidoon ocilmibare.

Waxa qab la hay garoostaasuu aalooguudoogaagaaban, waxaan ka qaybgalidoonta aqoon is weedaarsi.

Waxaadahaanid ooanta amartishar afkeena. Waxeeynubixindoona 20 doolaroomarisoor ah, qadooyi 5 doolaroottikii kaba saka ah. Hadii a d caruur leedahay, waynukuu xeyneenaaintaad shirkakujirtid. Waadkumahadsantahayka qaybgalkaaga.
Appendix B.

New Canadian Clinic recruitment data collection form

Recruitment Data Form

Agrees: Agrees to follow up phone call
Declines: Declines follow up phone call, does not want information about date and time
Maybe: Declines follow up phone call but takes information about date and time
Comments: Any comments by the person who approached the patient about the interaction.
Comment on your perception of their comprehension, their comfort, questions they had, their body language etc. Initialize your comment.

<table>
<thead>
<tr>
<th>Date</th>
<th>Agrees</th>
<th>Declines</th>
<th>Maybe</th>
<th>Comments (Name of data collector)</th>
</tr>
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<tbody>
<tr>
<td>June 21st, 2011</td>
<td>X</td>
<td></td>
<td></td>
<td>Seemed a bit confused, but happy to learn more with a phone call. Cindy</td>
</tr>
<tr>
<td>June 21st, 2011</td>
<td></td>
<td>x</td>
<td></td>
<td>Understood request, but too busy for anything else right now. Lynn</td>
</tr>
<tr>
<td>June 23rd, 2011</td>
<td></td>
<td></td>
<td>x</td>
<td>Asked if their husband could come too. Will take information and discuss at home. Ranjit</td>
</tr>
</tbody>
</table>
Appendix C.

New Canadian Clinic: Agree to follow up phone call

<table>
<thead>
<tr>
<th>Date</th>
<th>Name</th>
<th>Gender</th>
<th>Phone Number</th>
<th>Comments (ie. Best time to call)</th>
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<tr>
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Appendix D.

Research assistants follow up phone call guide
Phone call check list

- Have excel spreadsheet open so you can make note of information right away
- If nobody answers, leave a message saying you will try to call them back. Try calling back at different times/different days at least five times. Only leave one message.

Introduction and background information

- Your name, associated with University of British Columbia, calling in regards to research they were told about at New Canadian Clinics
- Purpose of the study (learn more about GARs and health, in particular about doing research with GARs)
- Method of study (2 hour focus group session, questionnaires and group discussion, tape/video recorded, with research assistant and lead researcher Patricia Gabriel)
- Benefits (Dinner, childcare, transportation reimbursement of $5 and honorarium of $20)
- Confidential (personal information will not be shared, will not be asking medical information)
- Voluntary (whether or not you participate is optional)

Information about focus group

- Date
- Time
- Location
- Check that they have written down this information

Confirm they fit eligibility criteria

- Over age 19
- Have been in Canada for less than 5 years

Questions to ask participant

- Are they planning on coming?
- Will they be bringing any other adults over the age of 19 who will also be participating?
- Will they need to bring their children?
- Is it okay to give them a reminder phone call?

After Phone call

- Check that all columns of excel spreadsheet are filled
- Email copy of excel spreadsheet to Patricia once a week during recruitment phase and again when complete
  - Make sure to remove name and phone number column prior to sending over email
Appendix E.

Research assistants follow up phone call data collection

<table>
<thead>
<tr>
<th>Follow Up Phone Calls</th>
<th>Language Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location of Recruitment</td>
<td>Contacted? (yes or no)</td>
</tr>
<tr>
<td></td>
<td>Planning to come? (yes, no or maybe)</td>
</tr>
<tr>
<td></td>
<td>Attended focus group? (yes or no)</td>
</tr>
<tr>
<td>Comments or question during phone call</td>
<td></td>
</tr>
</tbody>
</table>

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Appendix F.

Language concordant consent forms

English, Arabic, Farsi/Dari, Karen and Somali language consent forms.

SUBJECT INFORMATION AND CONSENT FORM
Government Assisted Refugees Attitudes and Knowledge about Research

Principal Investigator:
Janusz Kaczorowski
Department of Family Medicine
University of British Columbia
604 827 4396

Co-Investigator(s):
Dr Patricia Gabriel
Department of Family Medicine
University of British Columbia
778-323-3360

Sponsor: Canadian Institutes for Health Research

Purpose

You are being invited to take part in this research study because you are a government assisted refugee living in British Columbia, Canada. You can participate if you are over the age of 19 and you speak either English or one of the selected language groups.

Each year, Canada accepts about 3000 government assisted refugees. We understand that refugees have health care concerns when they arrive and during their resettlement. In order to better understand their health care needs, research is needed. We would like to learn how government assisted refugees feel about being participants in research so that we can learn the best way to do this research.

Study Procedure

This study will take place in British Columbia at one of the New Canadian Clinics in Burnaby or Surrey. The study involves a two hour meeting where you will be asked to fill out a questionnaire and participate in a group discussion.

Potential Risks

It is possible that you might feel uncomfortable sharing your ideas within a group setting, but we will do our best to make you feel at ease. You do not have to answer any questions that you are not comfortable with.

Potential Benefits

Version #3. June 17, 2011
You may benefit from the opportunity to share your ideas within the group and with the researchers.

We hope that the information learned from this study can be used to understand the best way to do research with government assisted refugees in order to lead to better research strategies in the future. If you would like to receive a copy of the results of this study, please inform the researchers and we will provide you with a copy of the final report.

Confidentiality:

All documents will be identified by a code number and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study. Any computerized data will only include anonymous data and be password protected.

We encourage all participants to refrain from disclosing the contents of the discussion outside of the focus group; however, we cannot control what other participants do with the information discussed.

Remuneration/Compensation:

In order to defray the costs of inconvenience and transportation each participant will be receive and honorarium in the amount of 20.00$.

Contact for information about the study:

If you have any questions or desire further information with respect to this study, you may contact Patricia Gabriel at 778 323 3360.

Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604 822 8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your access to further services from the New Canadian Clinic.

Your signature below indicates that you have received a copy of this consent form for your own records.
الجهة المنظمة للبحث:
جامع كولومبيا البريطانية والمؤسسة الكندية للأبحاث الصحية.

الفرض من البحث:

معرفة مدى نظرة اللاجئين المدعومين حكوميا ومعرفتهم بمواضيع الأبحاث والمشاركة في الأبحاث المستقبلية.

في كل عام تستقبل كندا ما يقارب 3000 لاجئ عن طريق السعادة الحكمية. يقيمون أن كثيرًا من اللاجئين لديهم بعض المشاكل الصحية خلال فترة الوصول والتوطين. وغرض معرفة هذه المشاكل واجراء الاستبان الميداني وتطوير الخدمات الصحية لابد من أجراء هذه الدراسات والإناث.

إذا كنت من ضمن هذه الفئة وعمرك أكثر من 19 سنة ولديك أقل من 5 سنوات إقامة في كندا فانت مدعو للمشاركة في هذه الدراسة لغرض التعرف على شعور اللاجئين تجاه المشاركة في الأبحاث المستقبلية.

طريقة البحث:

هذا البحث سيتم في احدى المواقع الخاصة بالقافذين الجدد إلى كندا: الأولى في براني وثانية في سوري. الدراسة ستكون على شكل اجتماع لمدة ساعتين حيث يمكنك الإجابة على استطلاع الاستبان والمشارك في المناقشة الخاصة بالبحث.

المخاطر المحتملة

من الممكن أن تكون مدعوم قد يشعر بعدم الراحة لتقاسم أفكارك ضمن إطار مجموعة، لذا سنعمل قصيرة جدًا لتعمل تشعر بالراحة.

الفوائد المتوقعة:

ستنافذ لك الفرصة للمشاركة برأيك وأفكارك ضمن أهداف الدراسة. إضافته إلى حصولك على 20 دولاراً وكميات و5 دولاراً لكلك تعاد مع وجهة طعام وخدمات رعاية الأطفال.

نأمل أن المعلومات والنتائج المستخلصة من هذه الدراسة سوف تتيح لنا معرفة أكثر بالطرق التي يمكن منها أجراء دراسات وبحوث مستقبلي للأجئين لغرض تطوير الخدمات الصحية المتقدمة لهم.

إذا ردت بالتحية على نسخة من النتائج البحث، إخبار المشرفين على البحث مباشرة. لغرض توزيع نسخة من النتائج النهائية.

السرية:

Version #3. June 17, 2011
كل المعلومات والصور ستكون خاضعة لنظام سري دقيق ولا يتم كتابة أي اسماء للأشخاص المشاركين في البحث.

سيتم تحديد جميع الوثائق برموزًا ويحتفظ بها في خزانة ملفات مغلقة. لن يتم تحديد المشاركين بالأسم في أي نتائج من الدراسة المذكورة. وسوف تكون بيانات موسعة فقط مجهولة المصدر وتكون مجمعة بكلمة مرور.

نحن نشجع جميع المشاركين على الامتناع عن الكشف عن محتويات المناقشة خارج مجموعة الدراسة، ولكن لا نستطيع السيطرة على ما قد يفعله المشاركين الآخرين في المعلومات التي تم فتحها.

الأجر / التعويضات:

من أجل تقديم تكافؤ التغذية أو أي إعانة سوف يتلقى كل مشارك مكافأة بسعة 20.00 $. للاتصال للحصول على معلومات عن الدراسة:

إذا كان لديك أي أسئلة أو رغبة مزدهرة في المعلومات فيما يتعلق بهذه الدراسة، يمكنك الاتصال بالدكتورة باتريشيا غابيري 778 323 3360.

الاتصال المنهجي بشأن حقوق موضوعات البحث:

إذا كان لديك أي مخاوف حول طريقة ممارستك أو حول حقوق موضوع بحث، يمكنك الاتصال بمكتب خدمات البحث في جامعة كولومبيا البريطانية 8598-822-604-64 أو إذا كان لمساواتك طويلة عن طريق البريد الإلكتروني RSIL@ors.ubc.ca.

الطوعية:

المشاركة في البحث طويلة ولا تؤثر على حفظك على الخدمات الصحية في العيادة بما يكفي من الأشكال سواء كنت المشارك أو لم تتم. 

توقعنا أنك ستستفيد من نموذج التوازن للسجلات الخاصة بك. يتوقعون بناء على موافقات المشاركين في هذه الدراسة.

<table>
<thead>
<tr>
<th>Subject Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

Printed Name of the Subject
در مورد این پروژه تحقیقی و فرم اعلام رضایت

دانش و تکریم پناهگاهان (موردو مزاید دوپگ) انجام فعالیت‌های تحقیقاتی چیست؟

ممبر پروژه پژوهشی:

جنس پناه‌گری

پژوهشگر:

باقاب پهپادی خانواده، دانشگاه بریتیش کلمبیا

۷۷۸-۶۳۲-۲۶۸۴

پایان پروژه: موسمه کانادا تحقیقات سلامتی

اهداف این پروژه:

بنابراین وسیله از شما دعوت می‌شود که در این مطالعه تحقیقی شرکت کنید. زیرا شما پناه‌گر در (موردو مزاید دوپگ) هستید و در بریتیش کلمبیا کنار دومنیک ممکن افرادی که در صحت می‌کنید و با این ۱۹ سال من دارید از شما نتایج ممکن می‌کنید در این پروژه تحقیقی شرکت کنید.

هر سال کانادا ۲۰۰۰ پناه‌گر در مورد مزاید خود در میان دارند. این سه‌میلیون که ممکن پناه‌گر در زمان ورود به کانادا و تا پیشینه بعد از انگلستان مانند در مورد مختلف سلامتی خود و غذاهای دارد. برای شناخت بریتیش پناه‌گران انجام

به تحقیق و پژوهش دریم. ما این پروئیز به سه تا چه انسانی نسبت به شرکتکنین مسترکت در فعالیتها پژوهشی دارید. نتیج

این هماکاری این امکان را به ما می‌دهد تا تجربه از بهتر شناخته و ممکن شونده را برای پروئیز پژوهشی

این پروژه با کمیتی

روش پژوهش:

این پروژه در موسمه کانادا در بریتیش کلمبیا انگل می‌گردد. شما از این کار تحقیقی شاید بیش از

۲ ساخته با ممکنیتی و پژوهشکار غذاهای بوده. همچنین در این جمله از شما این ممکن می‌گردد که پروئیز به کتاب‌ها و

زبان‌ها اعتمال

مکان است از این شانزده در حضور جمعی برای کسانی دوپگ می‌باشد. ما تمام تلاش خود را خواهیم کرد که تا شما اساس

راه‌کاری کند. گرچه به سوال برای مشکل است می‌توانی به آن پاسخ دهد.
فوتیج احتکامی

همچنان است به طور مستقیم از سهیم دهنده اطلاعات به گزارشات و محققین استفاده کنید. اطلاعات که در صورتی که عهده‌دار باشید یک روشنایی از نتایج این تحصیل‌ریزیها در گزارش‌های بین‌المللی منتشر گردد.

اطلاعات شما محرمانه است:

تمام مدارک به وسیله پیکد شناسایی می‌شوند و بر مبنای قانون نگهداری داده‌های دادری می‌گردد. در هیچ‌کدام از گزارش‌ها گرفته شده و به وسیله اطلاعات شناسایی می‌شوند. اطلاعات داخلی کامپیوتری مانند ایمیل و دیگر رسانه‌های انتقالی، از شرکتهای کنترل می‌باشند. این اطلاعات ممکن است بتوانند هم به داخل یا خارج گذرگاه پژوهشی در خانم‌های دیگر از جمله تحت کنترل قرار دهند.

پذیرش:

از زمانی که در این کار پژوهشی دقت می‌شود، مسئولیت پذیرفته شده است. شما همچنین برای صرف همکاری در این گزارش وارد شده‌اید. در صورتی که فردی به شما آزادی و استقلال خواهد داشت، شما می‌توانید شرکت کنندگان را خارج از جمله تحت کنترل قرار دهید.

اعتماد:

از زمانی که در این کار پژوهشی دقت می‌شود، مسئولیت پذیرفته شده است. شما همچنین برای صرف همکاری در این گزارش وارد شده‌اید. در صورتی که فردی به شما آزادی و استقلال خواهد داشت، شما می‌توانید شرکت کنندگان را خارج از جمله تحت کنترل قرار دهید.

اطلاعات شما محرمانه است:

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اطلاعات شما محرمانه است:

تمام مدارک به وسیله پیکد شناسایی می‌شوند و بر مبنای قانون نگهداری داده‌های دادری می‌گردد. در هیچ‌کدام از گزارش‌ها گرفته شده و به وسیله اطلاعات شناسایی می‌شوند. اطلاعات داخلی کامپیوتری مانند ایمیل و دیگر رسانه‌های انتقالی، از شرکتهای کنترل می‌باشند. این اطلاعات ممکن است بتوانند هم به داخل یا خارج گذرگاه پژوهشی در خانم‌های دیگر از جمله تحت کنترل قرار دهند.

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اطلاعات شما محرمانه است:

تمام مدارک به وسیله پیکد شناسایی می‌شوند و بر مبنای Qa9

References:

[1] Reference 1

[2] Reference 2

[3] Reference 3

[4] Reference 4


Version #3. June 17, 2011

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SUBJECT INFORMATION AND CONSENT FORM

Government Assisted Refugees Attitudes and Knowledge about Research

Principal Investigator: Janusz Kaczorowski
Department of Family Medicine
University of British Columbia
604- 827- 4396

Co-Investigator: Dr. Patricia Gabriel
Department of Family Medicine
University of British Columbia
778- 323 -3360
ငှက်ပြင်ခမ်းရန်

ငှက်ပြင်ခမ်းရန်အတွက်သားဖြစ်သောအရေးကြီးများကို ပြောင်းလဲရန်အတွက် အသုံးပြုသူများကို အတောအတွက်ဖြင့် အထောက်အမှန်ဖြင့် ပြင်းထန်းရန် အဖြစ်သားဖြစ်သည်။

စိတ်ဝင်စားပြု

စိတ်ဝင်စားပြုပြီးစားပြုမှုများသည် အချက်အလက်များကို အလိုအလျောက် ထောက်ပံ့ထားပါသည်။ စိတ်ဝင်စားသောက်ကားများနှင့် စိတ်ဝင်စားသောက်ကားများကို အလိုအလျောက် ထောက်ပံ့ထားပါသည်။

စိတ်ဝင်စားပြုမှုကို ပြောင်းလဲရန်

စိတ်ဝင်စားပြုမှုကို ပြောင်းလဲရန် အလိုအလျောက်ပြောင်းလဲရန် အတွက် အလိုအလျောက် ပြောင်းလဲရန် အဖြစ်သားဖြစ်သည်။

စိတ်ဝင်စားပြုမှုကို ပြောင်းလဲရန်ရှိလိုအပ်သည်။

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Email: rsil@ors.ubc.ca. 联系 Marc Foulkes and/or Dr. Allan Belzberg, Fraser Health Research Ethics Board co-Chairs by calling 604-587-4681.
★အချက်အလက်သိစေ★

မြန်မာအချက်အလက်နှင့်ပတ်သက်သော ကြော်င့် လူနီးစားသော အချက်အလက်များအား လိုအပ်သော အချက်အလက်များကို ပြောင်းလဲစေရန် လူနီးစားသော အချက်အလက်များကို အသေးစိတ်ဖော်ပြပေးသည်။

ပြုလုပ်သူအကြောင်းအဖြစ် ကြေညာချက်သည် စာရင်းသားထိုင်ကြောင်း အခြေခံချက်အား သိရှိနေသည်။

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ဗိုလ်ချုပ်မှူးကြီးဌာနစီစ춰
SUBJECT INFORMATION AND CONSENT FORM
Government Assisted Refugees Attitudes and Knowledge about Research

Principal Investigator:
Janusz Kaczorowski
Department of Family Medicine
University of British Columbia
604 827 4396

Co-Investigator:
Dr. Patricia Gabriel
Department of Family Medicine
University of British Columbia
778-323-3360

Sponsor: Canadian Institutes for Health Research

Ujeedo
Waxaa lagu casumaayaa in aad ka qayb gasho cilmi baaris sababtoo ah waxaad tahay qaxooti ee dowlada caawiso ku nool gobolka British Columbia, Canada. Waad ka qayb gali kartaa hadii aad ka weyn tahay 19 sano aadna ku hadii kartid luqada ingiriiska ama luqad ka mid ah luqadaha la xushe.

Sanad walba, Canada waxa ay aqbashaa ku dhowaad 3000 qaxooti ee dowlada caawiso. Waan fahansan tineey qaxootiga leeyihii dhibaatay in caafimaadka ku saabsan marka eey soo galaan ilaa iyo marka aay degaan. Sida aan dhibaataynkaas caafimaadka ku saabsan aan o fahan, cilmi baris ayaa loo bahanyahay. Waxaan rabnaa inaan ogaano qaxootiga eey dowlada caaawiso waxa eey ka qabaan cilmi baaris ka qeybgaalkii.

Qaab Cilmo Baarida

Mashruucan waxa uu dhici doonaa mid ka mid ah xarunta xanaanada kanadiyaanka cusub ee kuyaala Burnaby ama Surrey. Mashruuca waxa ka mid ah labo saac oo shir ah, waxaana lagu waydiin inaad ka jawaabit su’uqol guud oo gaagaaban

Katarka macquul galka ah

Waxaa laga yaabaa inaad dareentid xogga ciriiri inaad ku hadashid dad badan dheexdooda, balse waynu isku dayeena in aadan dareemin wax ciriiri ah.

Faa’iidoyinka macquul galka ah

Waxaa si toos ah oga faa’id doonta fursada aad la qayb battid filkraadaaga dadka kale iyo cilmi baareyaasha. Waxaan rajeeyneynna in macluumaadka laga bartan mashruucan loo isticmaal fahanka-sideda ugu wanaaga badan ee loola sameeyo cilmi baarid qaxootiga eey dowlada caawiso si mustaqbaalka cilmi baarid wax ku ool ah loo sameeyo. Hadii aad dooneysid inaad heshid nuskhad natiijada mashruucan, fadlan war gali cilmi baaraha weeynu kuu soo direeynaa mid.

Version #3, June 17, 2011
Siraha:
Dhamaan dukumentiyada waxaa laga oogaan doonaa magacyo gaar ah waxaana lagu hayni doonaa sanduug qofulan. Ka qayb galayasha looguma yeerayo wax magac ah marka uu mashruuca dhameestirmo. Dhaaman war bixiwaada la galiyso kombuyutarada waxaa eey ahaani doonan magic laabe yaal waxaana lagu difaaci doona eray sir ah. Waxaan ku boorineenaa dhamaan ka qayb galayasha in aysan ka hadlin wax alla wixii laga wada hadlo shirarka, laakinse ma difaaci karno waxa eey ka qayb galayasha ku sameeyaan warka aynu kwada hadalno.

Abaal marin:
Si loo xishmeeyo wakhtigaaga, ka qayb galayasha waxa eey heli doonaan 20 doolar. Si loo bixiyo qarashka safarkaaga waxaad heli doontaa 5 doolar. Qado iyo caruur ilaalin waynu ku silineenaa.

Yaad la xiriirii hadii aad qabtid su'aal
Hadii aad qabtid wax su'aal oo ah ama aad heeysid macluumaad dheeri ah ku aadan mashruucan, la xiriir Patricia Gabriel lamabarka 778 323 3360.

Yaad kala xiriiri arimaha ku aadan xuqquudaada
Hadii aad qabtid wax su'aal sida lagula xiriire ama xuqquudaada, waxaad la xiriirii kartaa xafiiska cimli baarista lamarka 604-822-8598 ama u qor E-mail RSIL@ors.ubc.ca. Waxaad kaloo la xiriiri kartaa Dr. Marc Foulkes iyo/ama Dr.Alann Belzberg, Fraser health Research Ethics board adoo ka wici kartid lamarka 604-587-4681.

Muwaafaqada
Ka qaybgalkaaga mashruucan waa ikhtiyaari waanad diidi kartaa inaad ka qaybgaashid ama waad ka bixi kartaa mashruucan waqtiigaad doontid iyadoo wax dhib ah kaa soo garreeynin sida aad oga heeshid cawimaad xarunta xanooniyiin kanadiyaanka cusub
Saxiixaga hoos waxa uu cadaynayaa inaad heshay nusichad foormka muwaafaqada. Saxiixaga waxa uu cadeeynaayaa inaad raali ka tahay inaad ka qayb gashid mashruucan

Subject Signature                        Date

Printed Name of the Subject

Principal Investigator/Designate signature

Version #3, June 17, 2011
Appendix G.

Knowledge questionnaire

1. People can be forced to participate in research
   True  False  Don't know

2. Personal information about people who participate in research is kept a secret
   True  False  Don't know

3. People who participate in research always get paid
   True  False  Don't know

4. People who participate in research should understand the purpose of the research
   True  False  Don't know

5. People who participate in research have to sign a form saying that they agree to participate
   True  False  Don't know

6. Once someone starts participating in a research study, they are not allowed to quit
   True  False  Don't know

7. Researchers need to get permission to do research
   True  False  Don't know
Appendix H.

**Attitudes, knowledge, experience and willingness Likert questionnaire**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>In between</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lot of experience with research in the past</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a lot of knowledge about research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doing research is very important</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am happy to participate in research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

![Smiley face](image1)

![Sad face](image2)
Appendix I.

**Demographic questionnaire**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Years in Canada</th>
<th>Education</th>
<th>Country of birth</th>
<th>First Language</th>
<th>Others Languages</th>
</tr>
</thead>
<tbody>
<tr>
<td>_______</td>
<td>______</td>
<td></td>
<td>Less than 1</td>
<td>None</td>
<td>Afghanistan</td>
<td>English</td>
<td>English</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 to 3 years</td>
<td>Primary school</td>
<td>Burma</td>
<td>French</td>
<td>French</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 to 5 years</td>
<td>Secondary school</td>
<td>Iran</td>
<td>Farsi/Dari</td>
<td>Farsi/Dari</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>More than 5</td>
<td>Post-secondary</td>
<td>Iraq</td>
<td>Arabic</td>
<td>Arabic</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Somali</td>
<td>Karen</td>
<td>Somali</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Other</td>
<td>Somali</td>
<td>Other</td>
</tr>
</tbody>
</table>

Other

English

French

Farsi/Dari

Arabic

Other

Other

Other
Appendix J.

Semi-structured focus group interview script

Government Assisted Refugees Attitudes and Knowledge about Research

Preparation Check List

2-4 Days before

☐ Confirm participant numbers
☐ Confirm number of children
☐ Confirm with caterer how many people we need food for
☐ Confirm with childcare volunteer

Day before

☐ Practice by reading through focus group interview guide again

Day of Items to Bring

☐ Consent Forms, 2 copies in each package, one for participants to take home (PG will bring)
☐ Questionnaire packages and envelopes (PG will bring)
☐ Name Tags (PG will bring)
☐ Note book/pen/extra pens
☐ Interview guide
☐ Markers for white board (PG will bring)
☐ Pictures (PG will bring)
☐ Tape recorder (PG will bring)
☐ Computer (PG will bring)
☐ Bring food
☐ Bring plates, napkins, drinks, cutlery (PG will bring)
☐ Envelopes with $20 + $5 bill (PG will bring)

Pre – Introduction (First hour)

☐ Welcome participants in a way that makes them comfortable
☐ Invite participants to help themselves to food
☐ Remind participants about childcare
☐ Distribute numbered questionnaires paper clipped to manila envelope
☐ Prepare name tags with first name and number
☐ Write ground-rules on board and two example questions (true/false about Vancouver and agreement statement about bananas)
☐ Sign cards with Thank You and your name (PG or RA)
Introduction

- Introductions of research team and participants
- Outline (Picture #1)
  - Will start with questionnaires
  - Then there will be a presentation
  - Then questionnaire part 2
  - Then there will be a discussion
- Ask if anyone has questions
- We will be tape recording the conversation
  - We want to capture everything you have to say.
  - We don’t identify anyone by name in our report. You will remain anonymous

Questionnaire Part 1

- Give the following key facts to participants before answering the questionnaire (Picture #2)
  - Research is a way of investigating to find out new things about the world
  - The primary purpose of health research is to understand why people get sick and how we can help people to get better
  - Often for health research, real people are needed to volunteer to be part of research. (Picture #3)
  - Researchers may ask these volunteers to do many things, such as answer questions, have their health checked, try new medications or let researchers read their medical records.
  - Whenever volunteers are used we call this “health research with humans.”
  - The following questions are about health research with volunteers

Example: “Now would like to ask you questions about your own experience and understanding of medical research that needs people to volunteer. The questions are all on your paper. I will read each question out loud. First, I will give you an example question and so that you understand how and where to mark you paper. Then I will show you the questions about medical research that involves volunteers and ask you to mark you paper alone. Please don’t talk or discuss the slides, but merely mark you own paper. There are no right or wrong opinions. Any questions? If you have any questions or problems while we are answering the questions about medical research with volunteers, please stop me and ask. If you have a questions, someone else almost certainly has the same question. It is important to me that you understand and can participate in this activity.”

- Knowledge questionnaire questionnaire (picture #4)
  - Do not let participants talk to each other or help each other on this part
  - Do example question on the board/using picture #4
  - Read through one line at a time
  - Ask participants to put answer forms in envelope. “I will be collecting the envelopes later.”
- Attitudes questionnaire (picture #5)
  - Do not let participants talk to each other or help each other on this part
  - Do example question on the board/using picture #5
  - Read through one line at a time
  - Ask participants to put answer forms in envelope. “I will be collecting the envelopes later.”
Informed Consent Part One (Disclosure and Comprehension)

“In every research study there is a time when we make sure that all the volunteers understand what the research is about and let us know that they are comfortable participating. We call this process “giving consent”. Most research usually involves having a consent form. In front of you is the consent form for this research. I am going to explain to you what is written in this consent form. You can follow along by reading or just listen to your explanation.”

Purpose: What is this research about? (Picture #6)
- Government Assisted Refugees in Canada
- Like all Canadians, GARs have health problems but they may be different types of problems (For example, GARs have different types of illnesses, language barriers and cultural differences.)
- We want to learn how to make health care better for GARs.
- We need to better understand the problems that GARs face in regards to getting health care in Canada. To do this we need to do research with GARs.
- We don’t know the best way to involve GARs as volunteers in research.

Study Procedure: What is this research? (Picture #7)
- Answering questions about some basic information about you, your experience with research
- Discussions about your opinions on different examples of research

Goals of this research?
- What is your experience with research in the past?
- What do you think is good and bad about doing research?
- What would make you more or less willing to participate in research?

What does participating in this research mean for you? (Risks and Benefits)
- Risks: Feeling uncomfortable, takes up some of your time
- Benefits: Sharing your ideas, helping refugees in the future

Confidentiality
- No one will know that you participated in this study, identified by a code number
- Please don’t talk about what we discuss here outside of this room

Remuneration
- 20$ at end of session and 5$ for transportation

Other
- Contact information on consent form
- You can stop participating at any time

Questions
- Are there any questions?

“Okay, before we go on, I want to make sure everybody understands what we have just been talking about. Can someone please summarize for me what we mean by “research”…….”
- Ask participants questions to assess clarification
  - Why are we doing this research?
  - What is involved in this research?
Giving Consent

“If you would like to help us with this study, there are different ways you can let us know that you agree to participate. One way is to sign the consent form. The other is to share your opinions in the next part of the session when we talk about examples. The third way is to give us the questionnaires at the end of the study.”

“If you do not want to participate in any part of this, you do not have to sign the consent form, you do not have to share your opinions in the next part of the session and you do not have to give us your questionnaires. You may still stay for the session and you may still have the honorarium.”

- Ask participants to put signed or unsigned consent form into the envelope.

Questionnaire Part Two

“We have one more questionnaire before we get to discussion. We want to know a little bit about you. I will read each line out loud. You do not have to write down your name, but if you do, we will not share it with anybody else.”

- Demographics form (Picture #8)
  - Read through one line at a time
  - Including name is optional
  - Ask them to put answer forms in envelope
- Hand in envelopes
  - Invite participants to hand in envelopes
  - Can wait till later if they want
  - Handing in envelopes means they understand and don’t mind us using their information
Focus Group Guidelines

“We are now going to talk about some different examples of research. This is going to be a group discussion. Before we get started, there are some basic ‘rules’ for how we would like to have this conversation.”

☐ We want you to do the talking
  ○ We would like everyone to participate.
  ○ I may call on you if I haven’t heard from you in a while.
  ○ Only one person should talk at a time
☐ There are no right or wrong answers
  ○ Every person’s experiences and opinions are important.
  ○ Speak up whether you agree or disagree; we want both positive and negative opinions
  ○ We want to hear a wide range of opinions.
☐ Respectful communications
  ○ If you have questions raise your hand
  ○ Don’t interrupt others
  ○ Don’t raise your voice
  ○ If you are off topic we may interrupt you to refocus the conversation
☐ What is said in this room stays here
  ○ We want everyone to feel comfortable sharing when sensitive issues come up.

Discussion Part 1 – Opinions on Research (15min)

We asked you some questions earlier on the questionnaire. Now we are going to discuss some of those questions as a group.

☐ Do you have any experience with research in the past?
☐ Do you think research is important?
☐ What made you decide to participate in this research?
☐ Why do you think some people did not participate in this research?
Discussion Part 2 - Case Study

- Mr ( ) is a 30 year old man from ( ) (Picture #9)
- He has been in Canada for 1 week
- He is at Welcome House
- A 30 year old white English speaking man asks him to be a research participant (using an interpreter)
- The research involves asking him personal information about his life and his health

- Do you think he will participate? Why?
- What would he do to decide if he should participate?

- Make each of the changes below and ask the question again
  - Change participant to a woman alone
  - Change research assistant to a female
  - Change research assistant to someone who speaks the same language
  - Are there any other characteristics of the research assistant that would change how Mr ( ) feels about participating? (example: from the same country of origin, same culture)

- Change time to one day in Canada
- Change time to one year in Canada

- Change research to doing a health exam (Picture #10)
- Change research to doing health tests like x-rays, blood tests and stool tests
- Change research to taking experimental medication
- Change research to monitoring information about how they use the health care system over the next five years
  (Some research involves looking at computer data that can tell when somebody has been to the doctor, hospital or pharmacy. Researchers can look at this information without have to talk to people directly.
  - As above: including social and economic information like their occupation, income and education
  - How about if researchers were able to contact Mr ( ) again in the future to ask more questions?

- Change location to a health care setting like a hospital or Bridge Clinic or the New Canadian Clinic (Picture #11)
- Change location to a community setting like DiverseCity, MOSAIC or Options
- Change location to a Mosque or a Church

Other questions about Mr ( ) and the research study

- Let's pretend that Mr ( ) doesn't understand what the research is about. Do you think that he will tell the researcher some questions to help him understand better? Or will he probably say nothing? Why?

- Let's pretend that Mr ( ) still doesn't understand what the research is about. Will he still participate?

- Do you think that offering Mr ( ) $20 to participate will influence whether or not he participates?
Do you think Mr ( ) will worry that somebody at Welcome House will get mad at him if he doesn't participate? Do you think there is anything else he is worried might happen if he doesn't participate?

Let's pretend that Mr ( ) has decided to participate. What do you think is the best way for the researcher to document Mr Ali's decision? (Picture #12)

- Can prompt with the following ideas:
  - Reading a long form verses somebody explaining it to them
  - Sign a form
    - ten page form in English
    - ten page form in his own language
    - a one page form
  - Tell the researcher he is happy to participate
  - Tell the researcher while being tape recorded
  - Just participate without documenting anything

**Participatory Action Research Questions**

"Having members of the group being researched involved in planning and conducting research can be very helpful. For example, GARs being involved in research about GARs by deciding what the most important issues are and helping to decide how to do the research".

- Do you think GARs like yourself would be interested in working with researchers to design and do research studies?
- What do you think the most important issues are for GARs like yourself in regards to the health care system?
- Would you like to work with us in the future on research with GARs? If so, please write down your name and phone number on this piece of paper.

"We are now at the end of our time. We thank you very much for your participation. Please see Patricia on your way out to receive your thank you gift of $20 and $5 for your transportation costs."

If you have not yet handed in your questionnaires at this point, please do so now if you would like. If not, please take them home with you or dispose of them.

If you have any further questions or comments, please feel free to stay behind to talk to me further. Otherwise, you are free to go.

If you would like us to send you a copy of the results of this research in the future, please leave us your name and address. (Have a blank piece of paper for this purpose)".
Appendix K. Reflective essay on the researcher as a research tool: “To Wear a Hijab”

It was a hot summer’s day in July. My thesis proposal and ethical applications were done. I was finally ready to collect data. That month I would be hosting four focus groups with refugee participants from Somalia, Afghanistan, Iraq and Burma. As I left my house en route to my Somali focus group it suddenly occurred to me that I didn’t know what to wear. I anticipated that many of the participants would be dressed conservatively and that the women would be wearing full length skirts and hijabs. I was wearing a knee length skirt and tank top. Should I change? The question baffled me. “Up to that point, I hadn’t considered myself within my thesis. The concept that I was a variable within my research was a foreign idea. I hastily put on pants and a cardigan and left the house with the disquieting notion that further reflection was required.

My academic journey has exposed me to research for the past eight years, ranging from observational studies in behavioural ecology and epidemiological studies in HIV to clinical cohort studies. Paired with an undergraduate degree in science and a western medical education, my epistemological exposure had been almost exclusively to empiricism. With a desire to use research as an advocacy tool alongside my role as a family physician I was seeking further research training through a Masters of Health Science at Simon Fraser University. My research question had guided me unexpectedly towards qualitative methods. I leapt in, and while already knee deep in my study I started a qualitative methods course in September with a goal to better comprehend this new territory. Through this course, I became aware of myself as a research tool, and as articulated by Piantanida “developing oneself as instrument entails an honest understanding of what one brings to an interpretive inquiry” (Piantanida 1999). Consequently, this has led to reflections on the impact of my position, perspective and presence on my research, in particular on my research questions, methodology and relationship to my participants.

Research Questions

In my area of primary care research, the impetus behind most applied research questions is to find practical solutions to specific problems facing clinicians, communities or patients. In the real world, the competitive research landscape often witnesses
ulterior motivations, where questions are driven by career objectives, funding availability, publication opportunities and convenience. Due to this, I perceived objectives other than intellectual goals as distasteful distractions. As a result, I never considered how my own personal interest might have influenced the questions I was asking. Reflexivity was needed to 'out the researcher' (Finlay, 2002).

Reading Maxwell’s chapter on goals helped me to directly examine the many motives, desires and purposes that lead me to my thesis question. I realized it was not shameful to have other goals, but rather that it was important to recognize that “goals inevitably shape the descriptions, interpretations, and theories you create in your research” (Maxwell, 2005). In my journal I was able to write about my personal and practical goals. Considering personal goals helped me understand how major events in my life, in particularly in my family life led to my interest in refugee health. "My mother’s hospitality led to our nuclear family of four expanding on holidays. One thanksgiving memory includes distant cousins from Peru, a visiting teacher from Iceland, international students from Indonesia and a single work colleague from Namibia" (Journal entry October 2011). I also saw that my personal identity (see appendix part 1), in particular my theological worldview with a vision of equality independent of nation, gender or race, and the creation of a unified global society, was a driving force in my motivation to work with refugee populations in Canada.

In regards to practical goals, I had always known that my primary aim in doing research was to advocate. However, in the past, I perceived that research was value-free and researchers were required to be objective disinterested creators of knowledge where change should not be the specified objective. I felt that I had to keep my advocacy goals hidden. Directly identifying my advocacy objectives was liberating (see appendix part 2). Through this surfacing of personal and practical goals, I found myself in the creation of my research question.

*Research Methodology*

Discovering the researcher within the research question then made me question what role I played in selecting my methodology. The subtle yet significant difference between methods and methodology was unclear to me when I began my thesis even
though I had long before acquired the ability to translate my interests into research questions and identify methods to pursue these questions. It was not until reading Neuman’s chapter “The Meaning of Methodology” that I saw the selection of methods as more than a practical decision. The research paradigm, including ontology and epistemology, revealed that method selection was not a dispassionate process but again revolved around the researcher’s worldview.

Previously, I had not articulated my philosophical inclinations within research. I had moved unconsciously, yet ironically quite comfortably, from a quantitative to qualitative paradigm. In tutorial number two, I wrote “I feel really balanced between the positivist and interpretivist approaches. It really depends on the research questions and goals. The most important part is recognizing the limitations.”

Seeking methodological coherence in my research, it became important to describe the methodological underpinnings in my methods.

Ontologically, I found myself aligning with critical realism, which bridged my positivist inclinations in the study of natural science with my postpositivist sensibilities in the philosophical understanding of the social sciences. Additionally, embedded in critical realism is an awareness of power imbalance and inequity which fosters the use of research as an advocacy tool. Epistemologically, I maintained the positivist approach that research can seek to find one physical truth in physical domains, but equally recognized the need for careful, reflexive qualitative approaches for understanding the social construction of individual reality. Given that my thesis question sought to understand my participants’ subjective attitudes and objective knowledge about research, it was appropriate to utilize mixed methods. My understanding of the theory behind each method enabled me to capitalize on the strengths and enhance my awareness of the limitations of each method.

In regards to the skills required in qualitative methods, including observation, listening, questioning skills and reflective and analytic abilities, I was fortunate to discover that the communication skills I had acquired in my medical training were readily transferable to research purposes. Interestingly, the long recognized “art and science of
medicine” was also present in the domain of qualitative research, and I was pleased to be able to utilize interpersonal skills alongside intellectual skills.

**Relationship to Participants**

Considering the interpersonal aspect of qualitative research alerted me to a third way in which my presence might influence my research; my relationship to my participants. Given that my population of interest is refugees, as a Canadian born, Caucasian, English speaking, educated woman, there is an obviousness to my ‘otherness’. However, reflecting specifically on the many facets of a researcher’s identity helped me to see that it is not only the superficial physical traits that make me an outsider in my research. My worldview and values, while not seen directly by my participants, equally impact how my participants and I view each other (see appendix part 3). This awareness shed light on my summer wardrobe conundrum. Considering what to wear was an acknowledgment of my outsider status, but even had I engaged the preposterous notion of wearing a hijab, clothing alone would not have altered my otherness. My anxiety was not that I was so different from my participants, rather it was that I did not yet understand how these differences might influence the validity of my results.

Understanding my relationship with my participants has also been influenced by broader methodological considerations. The research project that started this journey was a refugee cohort study with methods that largely relied on collecting data virtually through provincial health databases. In this study, my participants would be passive, complicit subjects. Proposing the feasibility of this study triggered the need for a better understanding of refugee’s attitudes and knowledge towards research. This necessitated a study using qualitative focus group methods. In this study, my participants were seen as informants who possessed the expert knowledge needed to answer my research questions. However, there was a clear separation between the researchers and the participants. Throughout the study I started to worry about my risk of “colonising discourses of the ‘other’” (Fine, 1998) and I recognized the importance of hearing the community’s voice. In response to this, I added two final questions to my focus groups about participants’ desire to participate in conducting research and their research priorities.
These questions invariably led me to consider the possibilities of a community based participatory approach for future research projects with this community. The benefits of this approach would be the transfer of leadership into the hands of a vulnerable community and the opportunities for empowerment and skill development that could aid refugees in settlement and integration in Canada. The challenges in this approach would be the identification of a ‘community’ given the geographic, ethnic, cultural and linguistic diversity amongst individual refugees. Additional challenges would be the practical implications of working with a multilingual group with varying degrees of literacy, education and occupational experiences. I noted November 30th “Perhaps starting with a northern participatory praxis, focusing more on a utilitarian problem solving approach and connection to organizational change could balance the roles of the researcher and community, and in the future, shift to a Southern approach to better address issues of power.”

This last year, I have had numerous insights through experiential learning in the practical assignments in this course and my thesis based research activities and through conceptual discoveries such as reflexivity, ‘methodology’ not merely methods, and the role of community based participatory methods. In particular, I have uncovered the impact of my identity as a researcher and how it has shaped my research questions, methodology and relationship to my participants. These revelations have helped me to understand how I, as a research tool, might impact the validity of my research. Furthermore, they have also shown how I, as a researcher, might shape and be shaped by future research endeavours.

References


Maxwell (2005). Qualitative Research Design: An Interactive Approach, Chapter 2