From Conception to Community Engagement: Our Research Journey

The IRIS Project: Evaluating Inequities in Refugee & Immigrant Health Service Access
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Introduction

Our project

The Evaluating Inequities in Refugee and Immigrant Health Service Access (IRIS) project is a longitudinal, community-based, mixed-methods study of im/migrants’ access to health services in B.C., Canada. The IRIS project defines im/migrants as immigrants and migrants with permanent and precarious immigration status, including people with temporary immigration status or without immigration status. IRIS holds ethical approval from the Simon Fraser University (SFU) and Providence Health Care/University of British Columbia (UBC) harmonized ethics review boards.

IRIS aims to understand and generate recommendations for policies and programs that improve health, well-being, and access to health services for people who are im/migrants in B.C., including (i) sexual and reproductive health services for women and (ii) COVID-19 related testing and care. IRIS performs both quantitative and qualitative research.

The quantitative arm of the project involves analyses of confidential, linked health and immigration system data to understand health services use.

The qualitative arm involves interviews with im/migrants and service providers with lived experiences, follow-up interviews, and active referrals to health and social supports. Both arms are guided by a community engagement framework that involves priority-setting and guidance by community partners, collaborators, participants, and community advisory board members at all research stages.

Our origins

The IRIS project was started in 2018, and its beginnings were informed by a review of literature that demonstrated inequities in im/migrant women’s sexual and reproductive health (SRH) access in Canada (Machado et al., 2021). Following these findings, the IRIS team took time to build relationships and consult with im/migrants and service providers about the health service access of im/migrant women in Metro Vancouver.

September – November 2018

We conducted five group consultations using a short, semi-structured interview guide with high-level questions regarding priorities around im/migrant women’s healthcare access. These consultations took place in English, Farsi, Spanish, and Tigrinya. Three consultations were audio-recorded, while two involved note-taking by our research team. Building on what we learned from these focus groups, the findings of our literature review, and in collaboration with community members, we developed the initial focus of IRIS: the sexual and reproductive health (SRH) access and experiences of im/migrants who self-identified as women.

Late 2018

A 2018 review of trans health content in The IRIS project was established and built on partnerships with local im/migrant-serving community organizations, including MOSAIC, Pacific Immigrant Resources Society (PIRS), Sanctuary Health, and Watari Counselling and Support Services (Watari), as well as a research team with im/migration experience and expertise in qualitative, quantitative, and health services research.
**March 2020**
We expanded the focus of IRIS to quantitatively examine COVID-19 service use, testing and infection rates among people who tested positive. We also worked to develop a qualitative understanding of the impacts of COVID-19, including shifts in health service delivery, on im/migrants’ health and health service access.

**Our team**

The IRIS project currently operates with the support of eight distinct yet overlapping team roles:

- a. Administrative staff who schedule meetings and support budget management.
- b. Community researchers who help bridge research with community by conducting data collection, supporting data analysis and leading community advisory boards.
- c. Principal investigators who manage the project budget and support the project direction and operations.
- d. Project coordinators who support team functioning.
- e. Quantitative analysts who prepare quantitative data for team analysis.
- f. Research assistants and collaborators who support the team with research processes.
- g. Research associates who provide hands-on support for the qualitative and quantitative arms.
- h. Transcriptionists who translate and transcribe all written research documents (e.g., interview guides, summaries of findings) and interviews. The majority of IRIS team members have im/migration experience (through varied pathways) which informs data analysis and interpretation.

**Our community relationships**

The IRIS project has community relations at four levels with:

- Community advisory boards & participants
- Partners
- Collaborators
- Public

These relationships were built over time and continue to be strengthened through respectful communication and collaboration.

We currently have four community advisory boards that function in English, Farsi, Spanish, and Tigrinya. These support most of the languages spoken by participants. Several of the advisory boards are facilitated by IRIS team members from the same communities; this helps community members feel more comfortable participating in activities, and also ensures that communities are represented throughout the research project. We engage with all participants by requesting feedback throughout the stages of research. Participants can engage with the project as community partners, community collaborators or community members.

Community partners include im/migrant-serving organizations that we regularly engage with: MOSAIC, Sanctuary Health, and Watari.

Community collaborators include im/migrant-serving organizations that we occasionally engage with: Migrant Rights Network, Healthiest Babies Possible, MOSAIC Youth Services, Multi-Agency Partnership, PIRS, SUCCESS, and Umbrella Multicultural Health Co-Operative.

Community members include im/migrants who are part of the general public that we engage with through knowledge translation via social media, community forums, churches, etc.
Community engagement backbone

Community engagement within the IRIS project involves engaging with community members across research stages with intentional consideration and communication around community capacity and needs.

The community engagement backbone (see Figure 1) is a diagram that community advisory board members and IRIS team members designed collaboratively as a visual representation of the project’s commitment to community engagement. The backbone also highlights the key values of the IRIS Project and concrete examples of how community members can participate in the project across the research activities.

The development of the backbone continues to be a collaborative effort between IRIS team members and community members, and is a living diagram that is subject to change based on evolving community and team needs.

The backbone diagram visually represents how community engagement processes are a central component of the qualitative and quantitative activities that take place within IRIS.

Figure 1. IRIS Community Engagement Backbone Diagram
As a first step to developing the diagram, the team discussed the values that they felt were important to their work.

These values included:

- Community & shared perspectives
- Collaboration
- Caring
- Empowerment
- Transparency
- Respect
- Inclusion
- Listening
- Expression & identity
- Learning
- Co-existing power differences

As a team, we spent time grouping related values, and narrowed down the list until three key values emerged: collaboration, respect, and relationship building.

**Collaboration**

The IRIS project is built on collaboration between IRIS team members, community members, and community partners. This means that we work to include community perspectives and advice at each stage of research. We also acknowledge that power differences between the IRIS team and community members may exist.

These power differences may be based on factors like:

- Race and ethnicity
- English fluency
- Im/migration status
- Education & research experience
- Payment from the research project to community members

We are committed to actively reflecting on these power differences and learning from community members to work towards more equal power-sharing.

**Respect**

We respect the diverse identities and experiences of the community members that we work with, as well as their lived experiences with im/migration. We prioritize creating opportunities for community members to share their knowledge throughout the research process. Through research built on community engagement, we aim to provide community members with formalized research findings that reflect their experiences and can inform community advocacy.

**Relationship building**

The IRIS team is focused on building meaningful relationships with community members and the community partners we work with throughout the research process. We invite community advisory board members and participants to take on different roles throughout the research process. This might include developing skills they already have (e.g. sharing findings through social media, creating posters, etc.). We also offer training to support new skills so that these community members can participate in research activities that are meaningful to them. Part of relationship-building is reciprocity, or giving back to the people and communities that we work with, both within and beyond the scope of the IRIS project. We prioritize this by offering people and communities support outside the research project when we can (e.g. immigration application support or referrals to legal, health and social services).

**Developing the backbone**

Following discussions regarding the values that underpin the community engagement backbone, we worked to define our commitments and responsibilities to community members at each stage of research (see Figure 1).
By engaging in reflective conversations about our responsibilities to community members, we considered how we could provide support beyond the research process and address power dynamics through care and capacity building. Examples of how community members could participate in the project resulted from these meetings, reflections about how community members have engaged with research activities previously, and discussions around other new activities.

A draft backbone diagram was first prepared by a small group of IRIS team members before being shared with the full IRIS team for feedback. Once this feedback was discussed and integrated, the diagram was shared with community members at the IRIS project’s first multilingual community advisory board meeting in April 2022. Community members shared feedback on the backbone during this meeting, through direct conversations with community researchers, and in writing via email and WhatsApp. This feedback is incorporated into subsequent versions of the community engagement backbone diagram.

**Respectful community engagement**

“Community” within the IRIS project includes im/migrant participants, im/migrant team members, and community partners. Im/migrant team members and community partners collaborate on the development of research materials, data collection, participatory analyses, and privacy and confidentiality agreements; the co-creation of clear, accurate dissemination products; and knowledge translation and exchange. IRIS uses a community-based research design to support cultural humility, transparent and respectful partnerships, and a collaborative process that involves im/migrants leading this research.

Community engagement within IRIS takes place at each research stage, and involves a structured process led by a community engagement group, which is made up of community researchers, a research associate, and a community engagement associate who are all members of the IRIS team. IRIS team members leading a research paper are required to share a community engagement plan with the IRIS team to assess and provide feedback. Once finalized, the community engagement group provides support with implementing the plan. Community engagement plans generally include a timeline, research focus, community engagement goals, and activities or steps to carry out the plan. Team members also consider how they plan to engage with community members throughout their research to plan for team and community capacity and support.

Within the IRIS project, there are three types of research in which community members may be engaged:

- New research
- Research in progress
- Finalized research

**New research**

At this stage, most of the analysis has not yet been completed; IRIS team members may host multilingual focus groups or community conversations to discuss the research area and understand community members’ thoughts on the relevance of the topic. Team members may also recruit community members to assist with upcoming research activities, such as developing research questions and leading interviews.

**Research in progress**

At this stage, some of the analysis has begun but has not yet been completed; IRIS team members may share preliminary findings with community members through multilingual presentations or community forums. Team members may also invite community members to complete the analysis and organize findings through focus groups, community discussions and advisory board meetings, or one-on-one sessions.
**Finalized research**

At this stage, most of the analysis has been completed; IRIS team members may consider ways to prioritize community members when disseminating research findings. For example, findings may be shared through multilingual short summaries, videos, presentations, or on social media. They may also organize focus groups or community discussions to understand how and with whom community members would like to see the research findings shared.

Regardless of the research phase, we always verify quotes and pseudonyms with community members whose experiences we discuss before we share final products. This means that participant quotes or pseudonyms used in any research product must be shared with those whose specific experiences are discussed. This supports a respectful process that prioritizes ongoing consent. We invite each participant to participate in a paid follow-up discussion should they wish to refine the information that they originally shared.
Qualitative research

Recruitment

Recruitment began in December 2018 and operates purposively and on an ongoing basis based on data and participant characteristics.

**December 2018 – February 2020**

Eligible participants of the IRIS project were im/migrants who self-identified as women; moved to Canada from another country; were aged 15-49 (reproductive age); and provided informed consent. Recruitment of purposive samples of im/migrant women, particularly those with precarious im/migration status, was supported by personal and professional networks of our community-based research team. This was done by creating and sharing study posters with community partners and collaborators, as well as word-of-mouth.

**March 2020**

We expanded the participant eligibility of the IRIS project to include im/migrants of all genders and communities, including farmworkers; moved to Canada from another country; and provided informed consent. This also involved creating new recruitment strategies in collaboration with community partners, collaborators, and community advisory boards to attend to the fast-changing environment, regulations, and impacts of the COVID-19 pandemic on different im/migrant communities.

Data collection

**December 2018 – April 2021**

We conducted semi-structured sexual and reproductive health (SRH) interviews with im/migrant women.

**January 2019 – 2021**

We conducted semi-structured SRH interviews with health and social providers. These interviews were one-on-one, in-depth and explored im/migration background, experiences with health services, and recommendations for service access. Multilingual and multicultural im/migrant interviewers and team members conducted interviews in private settings within our research offices, in a place of participants’ choosing, or virtually, to facilitate rapport. Interviewers explained the purpose of the study, the voluntary and confidential nature of participation, and obtained written informed consent. All sessions were conducted in participants’ preferred language (English, Dari, Farsi, Spanish, Tigrinya). Sessions were audiotaped and lasted 1.5-2 hours. After each interview, participants completed an interviewer-administered socio-demographic questionnaire to contextualize the sample. We gave all participants honoraria of $40 CAD in recognition of their time, expertise, and travel; referrals to health, social, and legal support; and childminding support as needed. To date, we have conducted 87 SRH interviews with im/migrant women and 11 SRH interviews with service providers in Dari, English, Farsi, Spanish and Tigrinya.

**February 2020**

We found that few SRH interviews were conducted with im/migrant women below the age of 30. We met with community partners and collaborators that serve young im/migrants to inquire about their thoughts and suggestions for ways to respectfully engage and converse with younger im/migrant women. These conversations suggested that a combination of group and individual sessions may allow for greater comfort and safety among young im/migrant women.
migrants’ participation, as well as elicit more in-depth responses. We created and shared a new recruitment poster with community partners and collaborators calling for participants aged 15-30, and recruited 11 participants.

**August – November 2020**
We conducted five one-on-one consultations and one focus group consultations with six participants, exploring young im/migrant women’s SRH priorities and needs.

**March 2020**
In light of the COVID-19 pandemic and the expanded participant eligibility to include im/migrants of all genders and communities (e.g., men farmworkers), we identified a need for a new interview guide that considered the impacts of the pandemic on access to healthcare, including vaccinations for COVID-19. We co-created an interview guide with members of the Spanish-speaking community advisory board (CAB) who were very engaged with the project at the time. This was an extensive process as we were also simultaneously learning about the COVID-19 pandemic.

**July – August 2020**
As changes in people’s healthcare access became apparent early during the COVID-19 pandemic, we also conducted follow-up interviews with 18 participants. These interviews were conducted in English, Farsi, and Spanish with participants who has previously participated in an SRH interview in 2019. These interviews asked participants how their access to healthcare, im/migration status, and other determinants of health changed since their previous interview.

**December 2020 onward**
We have conducted 24 COVID-19 specific interviews in English, Farsi, Spanish and Tigrinya, in-person or virtually via phone call, Zoom, WhatsApp, or FaceTime, following the same processes as SRH interviews.

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**Data analysis**

**April 2021**
The IRIS team developed a plan for team-based analyses.

**May – August 2021**
We developed a work plan for analyses and built team capacity conducting training in qualitative coding and assessing writing interests and needs. We also identified three research areas of interest: primary and virtual care, mental health, and sexual health.

**September 2021 onward**
The IRIS team has been engaged in team-based analysis around Primary and Virtual Care and Mental Health. So far, this has involved transcribing interviews, coding qualitative data, analyzing quantitative outputs, developing focused research questions, and identifying themes.

Analyzing data within IRIS involves a team-based, step-by-step process. When interviews and consultations are complete, we transcribe them verbatim; multilingual transcriptionists simultaneously translate interviews and consultations conducted in respective languages and transcribe them. A team member who speaks the same language then accuracy-checks each interview transcript. We assign unique codes to participants and remove all personal identifiers from transcripts to ensure anonymity. We then load transcripts into NVivo V12 for analysis (QSR, AUS). Our NVivo project for IRIS includes a codebook that continues to be adapted based on interview themes and participant characteristics. Our first step in data analysis usually occurs as part of the coding process within the IRIS project. We code each interview and consultation (one-on-one and focus group) using an iterative, team-based process and a combination of inductive and deductive approaches.
Once initial coding is complete, we draw on our community engagement backbone and Braun & Clarke’s (2022) six-phase process for a reflexive approach to thematic analysis. Within the qualitative arm, this looks like:

a. Familiarizing ourselves with the dataset: We read through the data several times to get familiar with it, and also start to make notes on our thoughts about the dataset. At this stage, we check in with community advisory board members to ensure that research question(s) reflect the needs and priorities of the community.

b. Systematically re-code and re-organize data: We reflect on coded data and how it relates to our research question. At this stage we also start to look for emerging themes.

c. Generate initial themes: We summarize key points in the dataset and start looking for patterns. We share these points with community advisory board members and frequently check in to discuss how the themes we are identifying resonate with their priorities, concerns, and experiences.

d. Develop and review themes: We take time to review our analysis and the themes we’ve identified, and also ensure that these things make sense in the context of the data set. We also consult community members at this stage to verify themes and explore new ideas and approaches to the data.

e. Refine, define and name themes: We take time to refine themes by considering what each theme means, what each theme should be called, and the relationships between themes. We do this with regular input from community advisory board members.

f. Write up: At this stage, we start doing detailed writing on the research themes, and pulling in relevant background information. The write up is a collaboration between IRIS team members and community advisory board members.
Quantitative research

Data connection

The quantitative arm of this project uses linked administrative health and immigration data to examine patterns of health services use. Administrative data are collected by governments for the purposes of administering services and programs (for example, paying doctors or processing the arrival of immigrants in Canada). Administrative datasets were not designed for research, but we can use them to answer research questions. By connecting health and immigration data we can do research about how access to care differs among groups with different immigration experiences.

The databases that we look at include data for everyone in B.C. that is registered for MSP, meaning that our analysis is based on a whole population, not a sample that might be different from the rest of the population in important ways; this can be important in providing a complete picture of this population. The main limitation of the quantitative data we use is that people excluded from access to immigration status and health insurance are not reflected in the data. We look to qualitative data to help us to understand their experiences.

Data access

We access data through Population Data BC, which helps coordinate the application to access data from different sources, and then links data from different sources together (Population Data BC, 2022). They remove any identifying information (e.g. health number, name, and/or date of birth), and replace it with a unique number that is meaningless outside of the study. This lets our research team connect individuals across datasets without being able to identify specific people. We also work within a secure research environment and we only report statistics about groups, so there is no risk of connecting research information to individual people. An application to use the data goes through both ethics review and robust data access approval processes.

Data analysis

To answer each research question, we need a specific set of statistical analyses. Through an iterative process of preliminary analyses and discussions with team and community members, we shape the final analysis and design the best way to present it in order to answer each one of our research questions. We present our data in many ways, including graphs, tables, or written descriptions.

When we are analyzing data, we think about intersectionality — the idea that many factors like immigration status, socio-economic status, race or ethnicity, or sex and gender influence a person’s experience and how they interact with various systems (Crenshaw, 2017). We are careful to check for situations where patterns may differ at intersections of categories (e.g. immigration groups, age, and sex/gender).

Some of the analyses are descriptive and present results numerically. We use tools like percentages, frequencies, and proportions to understand patterns in im/migrant health. For example, in one of our analyses, we looked at the percentage of people who received one or more COVID test and found there were differences tied to immigration status (Wiedmeyer et al., 2021). We also look at factors like class and English proficiency that shape the use of health care. When we do this analysis, we think carefully about the structures and pathways that connect these factors to health care use, and try to reflect these in our analysis choices.
We plan and conduct analysis as a team. This includes people who work with qualitative data and who manage community engagement alongside people with experience analyzing quantitative data. This group also includes team members with different experiences of immigration and health care use. This helps connect the choices we make in analysis with information about experiences reflected in the data. When we have initial results, we bring them to IRIS’ four community advisory boards and relevant community partners (e.g. Watari, MOSAIC, Sanctuary Health, Migrant Rights Network) to ask for their help interpreting the results and identifying any missing pieces for analysis. We think carefully about ways to present data that are as simple and clear as possible.
Conclusions & acknowledgements

Conclusions

The makeup of our team, our focus on values and community engagement, and our mixed-methods approach are factors that we feel make the IRIS Project unique. We are sharing this to document our research and community engagement processes for community members and others who are interested in our project or interested in conducting similar research with immigrant communities. We are grateful for the trust of the community members that we work with—none of our work would be possible without them.

Acknowledgements

We are extremely grateful to the IRIS study participants and community partners for their time, trust, courage, and valuable contributions to this research, as well as our study staff for their expertise. Some of our former team members are not listed above, but their efforts, knowledge, and contributions have fundamentally shaped our work and findings, and we thank them for the time they spent with us.

We would also like to thank the members of our community advisory boards for their contributions to the IRIS project. As a community based research project, working with community members is crucial, and our work wouldn’t be what it is without them.

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