


Innovating to remain connected while staying apart: The Thrive PRAs maintain focus on Older Adults Living with HIV in Vancouver Coastal Health during pandemic restrictions.

Antonio Marante, Sharyle Lyndon, Claudette Cardinal, Patience Magagula, Anna Vorobyova, Surita Parashar*

We acknowledge with gratitude all the participants of the Thrive study – those who are living and those who have gone on to the spirit world – who have shared their stories with our team in hopes of supporting research projects that will make a difference in their communities ~Thrive team.



*We have no conflicts to disclose.

 amarante@bccfe.ca



Thrive

Is a Community Based Research study conducted on the traditional, ancestral, and unceded homelands of the territories of the x^wməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish) and Səl̓ílwətaʔ (Tsleil-Waututh) Nations.

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in HIV/AIDS



Background

- In 2017 a **planning study** was conducted to identify gaps in services for **older adults living with HIV/AIDS** (OALHIV) (over 50 years old) in each of the five health authorities in British Columbia.
- The planning study found that community-based organizations are providing services for PLHIV, but there are **important gaps in care** that remain.
- **Social-structural challenges** experienced by OALHIV continue to impede access to these service



*Notes: 1) this survey was conducted in 2018, and participating Community-Based Organization may have since altered their services; 2) We are collaborating with partners in the Fraser Health Authority to identify service gaps in that region.

- In response to the results of the planning study and **invaluable insights from a Peer Research Associate**, a follow up Community Based Participatory Research project was launched.
- The **Thrive study** aims to comprehensively assess how OALHIV manage their health and navigate the health systems in BC, and specifically **characterize their access to Home and Community Care (HCC)** services in the Vancouver Coastal Health Authority region.
- HCC services are publicly subsidized **care and rehabilitation provided to people with acute, chronic or rehabilitative needs.**
- The Thrive Research Coordinator and Peer Research Associates **co-conduct interviews** with OALHIV who have ever accessed or attempted to access home and community care. These qualitative interviews document the experiences of OALHIV accessing or attempting to access HCC.
- The Thrive team is also conducting interviews with service providers to gather the **provider perspective on the set-up of HCC services in BC** and whether these services are meeting the needs of people aging with HIV.



Evolution of the Peer Research Associate role

- Peer Research Associates (PRAs) are individuals with living experience of the study topic who are trained in Research Methods.
- Over the course of the project, four PRAs were hired for the Thrive project. All Thrive PRAs are OALHIV and have living experience with HIV/Mental Health/Stigma and Discrimination
- All PRAs are trained in Research Methods, Data Privacy and maintain strict confidentiality
- PRAs work collaboratively with academic researchers, clinicians, and other PRAs
- PRAs recruit, screen & interview participants, maintain records, and perform other research duties (e.g. literature reviews)
- PRAs spearhead all community engagement, and liaise with CBOs and community members

Prior to the public health restrictions to curb the spread of COVID, PRAs conducted all these tasks in person at the study office

The COVID-19 pandemic led to a temporary pause on all research activities. Since research has resumed, it has been entirely virtual, a change which has:

- Impacted PRA-participant interactions (can no longer read body language, offer in-person support)
- Shifted roles and responsibilities within the team (one of our PRAs manages all virtual meeting scheduling and leads many aspects of the analysis process)
- Required the adoption of new approaches to connecting with participants and community
- Demanded many changes to the operationalization of the study (resubmission/amendments for ethics, compensating study participants, managing confidentiality)
- Led to the development of entirely new process for team-based remote qualitative data analysis



Experiences of PRAs working remotely

Successes

- Increased involvement of a research team member whose participation was impacted due to health issues.
- IT and Privacy support enabled our team to securely record interviews, review audio files, send recordings for transcription, and analyze transcripts.
- Able to maintain confidentiality.
- Increased PRAs' technical skills.
- Secure remote Access of documents and training in qualitative research software (NVIVO).
- Online meetings and fluid collaborative analysis.
- Made considerations for hearing impaired participants to participate remotely through an ethics amendment.
- Reciprocal learning from each other

Challenges

- Level of difficulty depends on specific software of communication.
- Technical difficulties:
 - Low Internet bandwidth
 - Outdated hardware, or limited webcam.
 - Microphone functionality.
- Additional duties managing technical tasks (technical set-up)
- Lack of body language.
- Problems with interactive communication, cut conversations
- Notifying participants and providers we are recording the session
- Maintaining morale, motivation, and team and participant connection in the face of social isolation and uncertainty



PRA's Virtual Learning

- I gained positive experience in developing knowledge in working with peers and professors in areas of study. *Patience Magagula*
- Helping others through the maze(s) of getting the help they want/need has always been important to me, now during COVID 19 (and hopefully past it) my lived experiences have given me a new sense of purpose, especially in research. *Sharyle Lyndon*
- The difficulties in the beginning became less as the training continued in order to shift into collaborating virtually with meetings, and interviews over the phone while amidst the COVID-19 pandemic. The Thrive team has shown how effective and adaptable we have been through active participation and reciprocal learning. *Claudette Cardinal*
- Working at a distance is great. You also have to deal with loneliness and disconnection with external world including our participants and team members. *Antonio Marante*