

FRANCISCO IBÁÑEZ CARRASCO

DALLA LANA SCHOOL OF PUBLIC
HEALTH, UNIVERSITY OF
TORONTO.

EXPERIENCE OF
PEOPLE LIVING
WITH HIV &
NEUROCOGNITIVE
DIFFICULTIES
WITH SERVICES
AND SUPPORTS



**Dalla
Lana**

**School of
Public Health**

LIFE/WORK ROADMAP



HEADS UP ROADMAP

HEADS UP 1

2015 - 2017

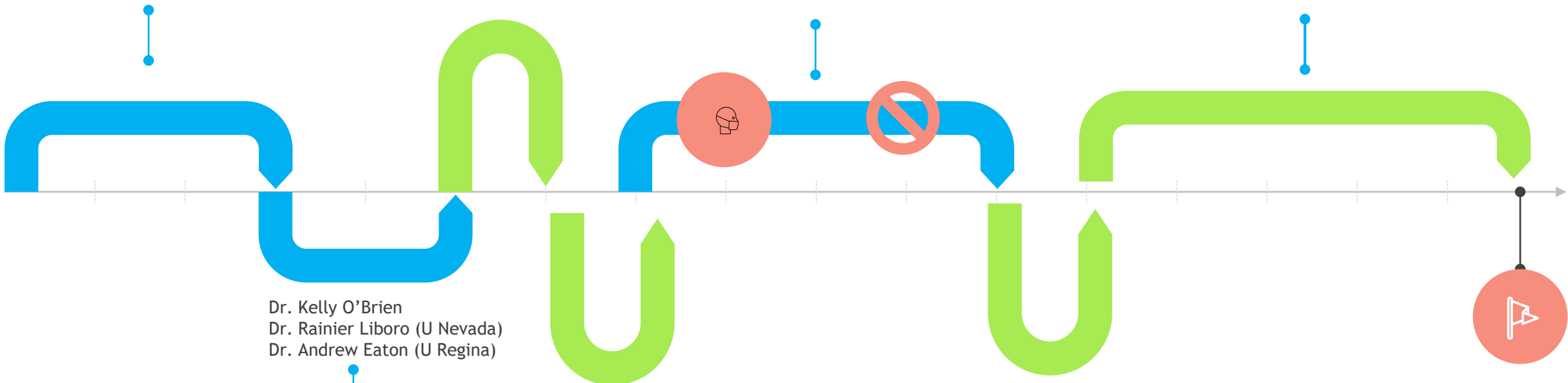
NPI: Dr. Ibanez-Carrasco

HEADS UP 2

2019 - 2023

NPI: Dr. Catherine Worthington UVIC

PROCESS & RESULTS



Dr. Kelly O'Brien
Dr. Rainier Liboro (U Nevada)
Dr. Andrew Eaton (U Regina)

COLLABORATIVE WORK

2017 - 2019

DATA GATHERING & ANALYSIS

Dr. Rachel Landy
10 PRAs WORK & QUAL ANALYSIS

KMB
CAHR 2023
5TH FORUM UK

FIRST, LET'S REVIEW ONE KEY
CONCEPT IN THE HEADS UP2
STUDY

THE CANDIDACY FRAMEWORK

THE CANDIDACY FRAMEWORK

- Accessing services is a process – a person’s candidacy (eligibility) is negotiated between people and services, and changes over time
- Involves a person’s preferences, knowledge, feelings, cultural understandings, the characteristics of a service and the provider's expectations of how people will use services



Candidacy dimension / stage	Description
Identification of candidacy	“I think these are symptoms that I should ask a health care provider about.”
Navigation	“I know who to talk to about this.”
Permeability	“Has the process been made simple for me, as a patient?”
Appearances at health services	“I will go to an appointment or service, and I will express my concerns and problems. I know how to do this.”
Adjudications	“The staff in a health care program or service will find me eligible.”
Offers & resistance	“The service offers linkages for me. I grapple with my own fears, anticipated stigma, etc.” “My health care provider recommended a service, but I don’t think it is right for me.”
Operating conditions	“The institutions have money and will to sustain a service I need (e.g. anal dysplasia clinic). The operating hours are convenient for me.”

Nkosi, B., Seeley, J., Ngwenya, N. *et al.* Exploring adolescents and young people’s candidacy for utilising health services in a rural district, South Africa. *BMC Health Serv Res* **19**, 195 (2019). <https://doi.org/10.1186/s12913-019-3960-1>

USING THE CANDIDACY
FRAMEWORK TO
UNDERSTAND SERVICE
ACCESS AND USAGE FOR
PEOPLE AGING WITH HIV
AND NEUROCOGNITIVE
CONCERNS: FINDINGS
FROM A COMMUNITY-
BASED RESEARCH STUDY

- **Background:** In Canada, 50% of people living with HIV and 20% of new infections are in people over 50 years of age. As people age with this chronic disease, 25-50% will develop neurocognitive impairments.
- HEADSUP!2, a community-based research study, applies the **candidacy framework**, which describes how people determine their eligibility for health care services, to better understand the experiences of people living with HIV when navigating care services for neurocognitive challenges.
- **Methods:** Using a community-based research approach and engaging a peer researcher team throughout the research process, people aging with HIV and experiencing neurocognitive concerns in Montreal and Toronto were recruited through community networks to participate in a qualitative interview. Participants were offered an opportunity to be interviewed by an interviewer with lived experience of HIV. Interview transcripts were analyzed using a participatory team approach for themes related to their candidacy including access, and usage of services and supports from identification of a need to receipt of treatment.
- **Results:** 15 people living with HIV participated in qualitative interviews in French or English. Findings suggest participants experienced barriers to care at each level of candidacy. Common experiences included fear of cognitive diagnosis, dismissal of symptoms as “aging”, prioritizing co-existing health issues, and lack of knowledge of treatment options.
- **Conclusion:** This study highlights that there are barriers at every step of candidacy that limit care for people aging with HIV who experience cognitive concerns. These findings can inform resources and health care services for people aging with HIV and neurocognitive concerns.

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- Background: In Canada, 50% of people living with HIV and 20% of new infections are in people over 50 years of age. As people age with this chronic disease, 25-50% will develop neurocognitive impairments.
- Objectives: HEADSUP 2, a **community-based research** study, applies the **candidacy framework**, to understand the experiences of people living with HIV when navigating care services and supports for their neurocognitive difficulties.
- Methods: Using a community-based research approach and engaging a peer researcher team throughout the research process, people aging with HIV and experiencing neurocognitive concerns in Montreal and Toronto were recruited through community networks to participate in a qualitative interview. Participants were offered an opportunity to be interviewed by an interviewer with lived experience of HIV. Interview transcripts were analyzed using a participatory team approach for themes related to their candidacy including access, and usage of services and supports from identification of a need to receipt of treatment.
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USING THE CANDIDACY FRAMEWORK TO UNDERSTAND SERVICE ACCESS AND USAGE FOR PEOPLE AGING WITH HIV AND NEUROCOGNITIVE CONCERNS: FINDINGS FROM A COMMUNITY- BASED RESEARCH STUDY

- Objectives: In Canada, 50% of people living with HIV and 20% of new infections are in people over 50 years of age. As people age with this chronic disease, 25-50% will develop neurocognitive impairments. HEADSUP!2, a community-based research study, applies the candidacy framework, which describes how people determine their eligibility for health care services, to better understand the experiences of people living with HIV when navigating care services for neurocognitive challenges.
- **Methods:** Using a community-based research approach and engaging a peer researcher team throughout the research process, people aging with HIV and experiencing neurocognitive concerns in Montreal and Toronto were recruited through community networks to participate in a qualitative interview. Participants were offered an opportunity to be interviewed by an interviewer with lived experience of HIV and also to bring a trusted person for a **dyadic interview**.
- **Analysis:** Interview transcripts were analyzed using a participatory team approach for themes related to their candidacy including access, and usage of services and supports from identification of a need to receive of treatment.
- Results: 15 people living with HIV participated in qualitative interviews in French or English. Findings suggest participants experienced barriers to care at each level of candidacy. Common experiences included fear of cognitive diagnosis, dismissal of symptoms as “aging”, prioritizing co-existing health issues, and lack of knowledge of treatment options.
- Conclusion: This study highlights that there are barriers at every step of candidacy that limit care for people aging with HIV who experience cognitive concerns. These findings can inform resources and health care services for people aging with HIV and neurocognitive concerns.

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- Methods: Using a community-based research approach and engaging a peer researcher team throughout the research process, people aging with HIV and experiencing neurocognitive concerns in Montreal and Toronto were recruited through community networks to participate in a qualitative interview. Participants were offered an opportunity to be interviewed by an interviewer with lived experience of HIV. Interview transcripts were analyzed using a participatory team approach for themes related to their candidacy including access, and usage of services and supports from identification of a need to receipt of treatment.
- Results: 20 people living with HIV participated in qualitative interviews in French or English. Findings suggest participants experienced barriers to care at each level of candidacy. Common experiences included fear of cognitive diagnosis, dismissal of symptoms as “aging”, prioritizing co-existing health issues, and providers’ lack of knowledge of treatment options.
- Conclusion: This study highlights that there are barriers at every step of candidacy that limit care for people aging with HIV who experience cognitive concerns. These findings can inform resources and health care services for people aging with HIV and neurocognitive concerns.

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- Conclusion: This **study highlights the current barriers** at every step of candidacy that limit care for people aging with HIV who experience cognitive concerns. These findings can inform resources and health care services for people aging with HIV and neurocognitive concerns.

I STOPPED WORKING LAST YEAR IN OCTOBER. I HAVEN'T LOOKED FOR A JOB.... IT WAS MOSTLY THAT BECAUSE I WOULDN'T REMEMBER STUFF AND THEN I WOULD ASK FOR HELP AND MY MANAGER WOULD SEEM TO BE UNDERSTANDING AS I HAD EXPLAINED WHAT WAS GOING ON. BUT WHEN IT CAME TO ASSESSMENT AT THE END OF THE YEAR, HE'D WRITE COMMENTS LIKE, "SHE HARDLY REMEMBERS ANYTHING," YOU KNOW, AND THEN GIVE ME A TWO OUT OF FIVE. SO, IN THE END I JUST FELT LIKE WHERE- THERE WAS LACK OF COMPASSION, YOU WOULD PRETEND TO UNDERSTAND WHAT I'M GOING THROUGH. AND THEN AT THE END OF IT ALL MAKE ME FEEL LIKE I WAS WORTHLESS (OCCUPATIONAL IMPACT)



Betrayal of trust, degrees of disclosure, and the three kinds of stigmas continue to be significant qualitative themes in HEADS UP 2 and much social-behavioural research on the quality of life of persons living with HIV.




I FEEL LIKE I'M RELYING MORE ON UH JUST HAVING TO WRITE THINGS DOWN OR MAKING SURE THAT IT'S IN MY CALENDAR. UH, SO I, I FEEL LIKE YOU KNOW I'M RELYING MORE ON THOSE TECHNOLOGIES AND TOOLS TO BE ABLE TO KIND OF REMEMBER WHAT TO DO AND KEEP A TASK LIST. UH, YOU KNOW IT'S, I KNOW EVERYONE DOES THAT AND TASK LISTS ARE IMPORTANT FOR WORK. BUT I FEEL LIKE I, I REALLY AM DEPENDENT ON IT NOW THAN I USED TO BE, JUST BECAUSE I DON'T FEEL LIKE I CAN TRUST MY MEMORY IN TERMS OF UH REMEMBERING YOU KNOW WHAT TO DO AND THE PRIORITIES
(COGNITIVE STRATEGIES)



The lessons learned in rehab research apply to the use of wearables to aid forgetfulness, word smithing, improving attention and motivation, even improving motors skills/coordination, etc. (**Tizneem Jiancaro. PhD. Postdoctoral Researcher. Episodic Disability & Rehabilitation Lab Dept. of Physical Therapy. University of Toronto May 2022**)

- “Wearable devices are connecting health care to daily life”. The Economist. 11 May 2022
- “On the one hand, they [wearables] are making life more medicalised,On the other hand, they are ushering in a shift in the balance of responsibility between medical treatment provided by clinicians and what patients do to improve their health.”
- Measurement is a first step, but increasing activity requires additional components, like “goal setting, self-monitoring, positive feedback and social support”. The Conversation. 4 May 2022. Scott Conger. David Basset. Lindsay Troth.
- Challenges include increasing surveillance, digital inequities, overtraining, increasing quantity over quality (exercise form), and overriding the sense of felt experience.
- In Canada, “only one-fourth of Indigenous communities have access to broadband internet, compared with 97% of urban households,” “access to the internet from home reduces sharply for Canadians aged>65 years,” “access to the internet does not translate into adoption”



An illustration of a doctor and a patient. The doctor, on the left, is wearing a white lab coat, a blue shirt, a blue tie, and a white surgical mask. He has a stethoscope around his neck and is holding the patient's hand. The patient, on the right, is wearing a blue hijab, a blue top, and a white surgical mask. The background is red with a halftone dot pattern and radiating lines. A speech bubble is positioned between them, containing text.

I WAS RECENTLY, WELL I STILL AM, DEALING WITH BLOOD PRESSURE ISSUES SO THAT SORT OF TAKES PRIORITY OVER, YOU KNOW MY LONG, ONGOING COGNITIVE ISSUES (TRIAGING OF HEALTH ISSUES)

RESULTS IN PLAIN LANGUAGE

DO NOT GET DOWN ON YOURSELF

Memory difficulties happen to all of us as we age, and it is likely to affect those of us living with HIV. That may be of little consolation but...



An illustration of two women in profile, facing each other as if in conversation. The woman on the left has short, dark hair and is wearing a green top. The woman on the right has long, dark hair and is wearing a teal top. Both women have their hands raised in a gesturing motion. The background is a light blue gradient.

DECIDE WHEN AND HOW TO TELL OTHERS

It is hard to trust, but sometimes it helps to tell a caregiver, a lover, a faith guide, or the human resources person where you work. However, when possible, you remain in control of your process of disclosure and it is often a strategic process. Disclosure is not always possible, complete or honored by others.



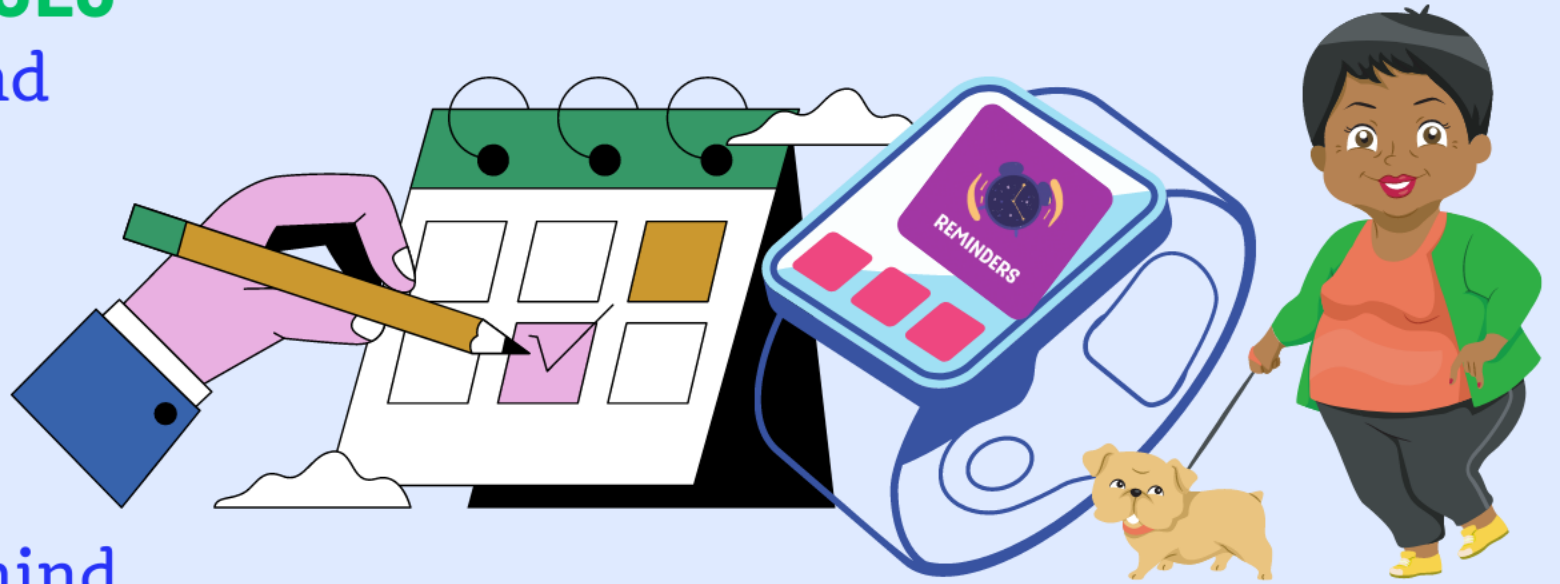
FIND HELP

Finding specialized help can be a challenge, but social workers, OTs, PTs can offer assistance.

Even though you may have many other medical conditions going on, don't be afraid to bring up this topic with your healthcare provider. It may not be easy, but it's worth a try.

USE TRICKS AND TOOLS

- Your pet can remind you of meals & medication times!
- Use alarms and reminders in your gadgets
- Ask a friend to remind you of tasks
- Post a big calendar behind the door.
- Request that health providers sent you reminders.



MOVE, EXERCISE & DIET YOUR FAVES

They say that a healthy heart also supports a healthy brain. Take the time to move and exercise, ideally with others. When possible, get out and walk!

Many of us smoke, drink, take pills and like all kinds of fun food. If abstinence is not your thing, reduce the harm by dosing out these things - have a cheat day?.



From one POZ person to another

UNSOLICITED ADVICE REGARDING FORGETTING NAMES/WORDS, FOGGY BRAIN, AND LACK OF FOCUS

This advice does not all come from my imagination; it is based on tons of real neurocognitive and social behavioral research such as HEADS UP 1 and 2. [Read more by clicking here.](#)



DO NOT GET DOWN ON YOURSELF

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TELL THOSE WHO CAN REALLY HELP YOU

It is hard to trust, but sometimes a caregiver, a lover or the human resources person where you work can help. Disclosure is not always possible or complete.



FIND HELP

Finding specialized help can be a challenge, but social workers and occupational therapists can offer assistance. Even though you may have many other medical things going on, don't be afraid to bring up this topic with your healthcare provider. It may not be easy, but it's worth a try.

USE TRICKS AND TOOLS

Your pet can remind you of the times for food and meds, use alarms and reminders in your gadgets, ask a friend to remind you of tasks, post a big calendar behind the door, request that health providers send you reminders.



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PROCESS: WHAT WORKED

- Through COVID, we didn't drop the 10 PRAs team. We enhanced the participatory aspect with over 200 hours of paid work over two years including workshops and journaling.
- Capacity building workshops included self-care, how to journal, thematic analysis, interpretation and collaborative KMb.
- PRAs journalled using prompts from the Engagement Coordinators.
- PRAs co-developed data collection tools.
- We had one in-person meeting at end of year 3.
- What the PRAs did and discussed and the KMB they "made" (KMB) strongly support the results of the data analysis.

DO I KNOW YOU FROM SOMEWHERE?
We all forget names, dates, words or feel foggy and unfocused, right?

VOUS AI-JE DÉJÀ VU QUELQUE PART?
Nous oublions tous des noms, des dates, ou nous nous sentons flous et flous, n'est-ce pas ?

Journaling is one effective strategy of peer engagement with content and process in community based research. In the HEADS UP 2 Study about cognitive difficulties for people living with HIV, the peer researchers journalled their way through.

La tenue d'un journal est une stratégie efficace ou un engagement des pairs avec le contenu et le processus dans la recherche communautaire. Dans l'étude HEADS UP 2 sur les difficultés cognitives des personnes vivant avec le VIH, les pairs chercheurs ont consigné leur cheminement dans un journal.

Use your phone to read the QRs & see what they learned
Utilisez votre téléphone pour lire les QR

The HEADS UP 2 Study
Contexte de l'étude - Background

Mobilisation des connaissances - KMBsur quoi les pairs chercheurs ont écrit dans leur journal
What peer researchers journalled about

Logos at the bottom: CIHR IRSC, HEADS UP!, Dalla Lana School of Public Health, University of Victoria, ST. MICHAEL'S

PROCESS: WHAT DIDN'T WORK

- The neurocognitive side of the research was not completed. It would have given us a mix of lived experience and measurements.
- Bilingualism is expensive and logistically complex (AI helps).
- As per original protocol, the burden of engagement was carried by the Coordinator and two (EN – FRE) engagement coordinators and made heavier by C19.
- We ha to break a *wise practice* in working with PRAs: start the research work as soon as the PRA training is completed. This causes additional “drama.”



DEDICATED
TO SERGIO
GONZALEZ
PAVÉS

