

# Older People Living with HIV as Peer Research Associates: Reflections on the Role and Experiences PANACHE Ontario

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## COI Declarations:

Dr. Sharon Walmsley has participated on advisory boards, speaking engagements, symposiums, and clinical studies for ViiV Health Care, GSK, Merck, Janssen, and Gilead Sciences. She receives support as the chair of HIV clinical management and aging from the Ontario HIV Treatment Network.

Kate Murzin has consulted for Capacity Builders (OCSA), has been a member of the Ontario HIV Treatment Network (OHTN) Scientific Advisory Board, has received research funding from OHTN and is an employee at *Realize*.

Elizabeth Racz has received honoraria from OHTN HIV Endgame funding and research funding from the Canadian Institutes of Health Research, and is employed at *Realize* and the University Health Network.



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# Background

- Peer capacity building and engagement in community-based research (CBR) embodies GIPA (Greater Involvement of People with HIV/AIDS) and MEPA (Meaningful Involvement of People Living with HIV/AIDS) principles.
- Involvement of community in all stages of research improves the research process and outcomes
- As part of the PANACHE Ontario study, Peer Research Associates (PRAs), reflecting diverse communities, co-facilitated nine community consultations in Ontario.

# Methods

- Eight Ontario community members, who were older adults and living with HIV were hired, engaged and trained in community-based focus group facilitation by the PANACHE team.
- The PRAs' experiences of the role and reflections on the importance of CBR were recorded to inform future training and capacity building.

# Results

## Strengths of the role

- Given their diversity and experiences the PRAs were often a resource for one another and a lay information source for the participants in focus groups- they particularly identified this strength in the areas of access to services or interpretation of current research findings such as Undetectable= Untransmittable (U=U).
- PRAs reported feeling “privileged to be a part of meaningful work that affects change” [PRA1] and being part of something “bigger than myself” [PRA2].

## Challenges of the role

- Finding balance in their focus groups between letting participants share their stories, without overtaking the conversation was a common theme reported by the PRAs. “The most challenging part for me was to find a way to allow voices in from those who seemed to defer to those who were the most vocal” [PRA3].
- PRAs across all sites echoed the need for more diversity of voices and the need to engage hard to reach communities.

# Discussion- Lessons learned

- The PRA's experience highlights the strengths and ongoing challenges of engaging diverse communities of people living with HIV.
- An integral component of the community based research process, engaging and training PRAs with diverse backgrounds takes time and requires commitment of many stakeholders
- The reflections of PRAs underline the importance of their ongoing CBR participation and can help to optimize the process for future studies
  - Peers as facilitators created a safe environment for participants to share concerns and questions
  - PRAs suggested that one on one interviews might allow improved access to hard to reach populations.