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How can we Increase Physical Activity for People Living with HIV

2019 Think Tank Report

**4 March 2019
Toronto, Ontario**





Realize is a national charitable organization working to improve the quality of life of people living with HIV and related conditions through rehabilitation research, education, and cross-sector partnerships. **Realize** members are individuals and organizations that have an interest in HIV, disability and rehabilitation. These include: community-based HIV/AIDS, disability and rehabilitation organizations; national professional associations and individual clinicians; unions; private-sector companies; people living with HIV and other disabilities; health care, social care and human resources professionals; and other people who are interested in HIV, disability and rehabilitation.

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Realize would like to thank all those from across Canada who participated in this Think Tank, entitled “**How can we increase physical activity for people living with HIV?**” held at St. Paul’s on Bloor in Toronto, Ontario on Monday, March 4th 2019.

Think Tank 2019 Planning Committee:

Realize would like to recognize and thank Paul Curwin, Ron Rosenes, and Ken Zolotar (from ParticipACTION) who provided rich input into the form and content of the event.

Think Tank Facilitators:

We would like to particularly acknowledge, and thank Ron Rosenes for facilitating the Think Tank.



Table of Contents

Acknowledgements	3
Introduction.....	5
Think Tank Goals.....	5
The Day	6
Discussion.....	7
Participant Evaluation Results	9
Conclusion	10
Appendices	11
Appendix A - Agenda	11
Appendix B – Facilitator Guide	13
Appendix C – Pre-Event Survey	15
Appendix D – Post-Event Survey	18
References.....	21

Introduction

Recommendations for physical activity indicate that adults in Canada should participate in 150 minutes of moderate to vigorous intensity physical activity each week (CSEP, & ParticipACTION, n.d.). Physical activity has benefits for people of all ages which include improved learning and long-term memory, lower risk of chronic disease, and increased life expectancy, among other advantages. For people living with chronic health conditions, physical activity can help with managing symptoms, slow down the progression of illness, and prevent development of additional chronic conditions (CSEP, & ParticipACTION, n.d). Accordingly, physical activity is considered to be a low-cost way to promote chronic disease prevention and to encourage overall health (Tuso, 2015). Several Canadian organizations are dedicated to encouraging physical activity throughout the lives of people in Canada. (ParticipACTION, 2018; Sport for Life, 2018). Community- based HIV organizations and fitness centres also have an important role to play in promoting physical activity people living with HIV.

Despite the known benefits and national-level initiatives, less than 20% of adults in Canada participate in the recommended amount of physical activity (Colley et al., 2011; Sport for Life, 2016). People living with HIV have been found to participate in physical activity at even lower rates than the general population (Webel, 2015; Vancampfort, 2018). Reasons for decreased participation can be attributed, at least partially, to various individual and social barriers that people living with HIV may experience such as pain, limited social support, financial constraints, accessibility concerns, and fear of stigma. People living with HIV often live with more comorbid chronic health conditions than the non-HIV infected population (Schouten et al., 2014; Webel 2015). Along with this burden of chronic health conditions, people living with HIV are especially likely to face barriers as a result of their gender and their HIV status.

This leads to the question of “How can we increase physical activity for people living with HIV?”

On March 4th 2019, *Realize* asked that question.

Think Tank Goals

The goals for this year’s Think Tank were:

1. Develop partnerships with a focus on physical activity and health for people living with HIV
2. Develop strategies to increase access to physical activity for people living with HIV
3. Build capacity through partnerships and learn from each other

The Day

The Think Tank was held at the St. Paul's on Bloor in Toronto, Ontario and ran from 9:30am to 3:00pm. Seventeen people (21 including **Realize** staff) attended the Think Tank. Participants came from all across Canada, and various sectors of the HIV and fitness/physical activity communities, and included people with lived experience of HIV and/or other chronic health conditions, rehabilitation specialists, physical activity professionals and researchers. This diverse group also included women, people from various ethnic backgrounds, and people with disabilities.

Tammy Yates, **Realize**'s executive director, welcomed the participants, and acknowledged the Indigenous land upon which we were hosting the event. Tammy introduced the day's facilitator; Ron Rosenes. Ron welcomed participants and outlined the importance of this topic to people living with HIV and the greater fitness community, followed by covering the aims for the day, reviewing the agenda and outlining group norms. Finally, before the discussion of the day started, Puja Ahluwalia from **Realize** set the context of the day by providing definitions of physical activity, national recommendations and the research related to HIV and physical activity.

The Think Tank was divided into three breakout discussions in small and large groups. A designated person facilitated the small group discussions and took notes in the small group discussions.

Further details on the breakout discussions can be found in the Agenda and Facilitator Guides (Appendices A and B)

Ken Zolotar, ParticipACTION, presented on the current initiatives that ParticipACTION is currently running at a national level. These initiatives have the goal of increasing physical activity in Canada, with a focus on priority populations including people who identify as LGBTQI, women, and newcomers.

Adria Quigley, Dalhousie, led the group in a chair yoga session between Breakout session #1 and #2. This short yoga class was used to encourage movement and demonstrate the simple ways that physical activity can be included within current programming.

All participants were encouraged to complete pre-event and post event surveys (See Appendices C and D). Both surveys attained a 100% response rate (17 pre-event, 23/29 post-event).

Discussion

HIV organizations currently offer various programs such as yoga, dance classes or walking groups. One representative discussed how they were offering a yoga program but were not getting the attendance that was hoped for. An organization that had medical and rehabilitation staff on site discussed a new exercise group that was being developed to encourage physical activity and provide participants with the skills to participate in the community. Representatives from physical activity organizations strived for inclusive programming but did not go out of their way to include people living with HIV over any other marginalized population.

Barriers were discussed throughout the day as there are many reasons that people living with HIV do not participate in physical activity and why some programs may not work for the population. Systemic and structural barriers were discussed in length as very relevant to this population. Poverty and homelessness were brought up in the context of Maslow's Hierarchy of Needs. For some people living with HIV they are already dealing with needs related to substance use, insecure housing, substance use, etc. that they already lead chaotic lives. The scheduling and coordination involved in including physical activity may not be feasible. One person commented that the positive benefits of physical activity can take time to accumulate which may also be a perceived barrier to continued participation in physical activity.

Other barriers include the presence of continued stigma and/or stigma-related trauma. For people who identify as transgender, going to a fitness facility can be difficult if washrooms and/or change rooms are designated by gender. From the community-based HIV organizations, barriers that they encountered were lack of finances to plan, or host physical activity programming and space restrictions. Women living with HIV were discussed as being a unique group that faces different barriers. Women often experience multiple demands including child care, and providing for the family within the home. One analysis completed by an attendee organization found that women living with HIV needed and wanted holistic programs that met their and their family's needs; which may include programs that are inclusive of the entire family.

Facilitators for physical activity were described as the use of technology (although this was described as a barrier as well), timing with other programs (such as right before a lunch program), the ability to develop a social network, education on the benefits, subsidized/free programming and a focus on the idea that physical activity does not have to be exercise. To facilitate the increase of physical activity for people living with HIV, community organizations indicated that they would appreciate some guidance related to funding options and specific guidance on the types of programs that are appropriate. Additionally, a list of programs where HIV organizational staff could get certified and/or find people who are already certified in providing physical activity would be helpful.



The concept of 'safer' spaces was brought up as a thing to consider for both the fitness and HIV communities. A safe space for one person may not be a safe space for another and therefore the goal should be to have safer spaces where the aim is to encourage the feeling of safety and comfort for all. An example from one HIV organization described that many organizations focus on including people living with HIV who identify as LGBTQ, however at times the needs of people who identify as heterosexual are overlooked. When it comes to fitness/physical activity facilities, the needs of people who identify as trans or non-binary are often overlooked especially when it comes to washroom and shower facilities.

Overall, participants recognized that there still remain many barriers, some which are difficult to overcome, related to participation in physical activity for people living with HIV. However, even with the multiple barriers and differing facilitators for different populations of people, all participants were motivated to try and overcome these difficulties to improve rates of physical activity for people living with HIV.

Participant Evaluation Results

Participants were invited to complete an online pre-event survey to determine expectations, knowledge of Think Tank concepts, and intention to take action on HIV and rehabilitation (Appendix C). Each participant was also provided with a survey to complete at the end of the event (Appendix D). There was a 100% completion rate for both pre- and post-surveys.

More than half of the respondents (76%) indicated that this was their first Think Tank event. Participants identified a number of expectations for the Think Tank: to learn more about how to incorporate physical activities for people living with HIV, and to improve accessibility for people with all levels of mobility; to increase partnerships and knowledge about programming in physical activity for people living with HIV; a comfortable, non-judgemental space for discussion and exploration.

Overall, the feedback received from participants in the post-event survey indicated that they were very satisfied with the Think Tank.

The most relevant take-away messages for the participants included: that there needs to be a cultural shift; we need to combine physical activity interventions with other programs, program implementation will be complex, mental health plays a huge role; and local community/recreation centres need to be educated on the needs of people living with HIV.

Participants also discussed recommendations for future Think Tanks. Recommendations included: more time for networking; providing/developing more concrete next steps; increasing the engagement of women; inviting people representing other chronic health conditions to learn from them

All participants indicated that they would apply the content from the Think Tank in their work. They indicated they would use this information by: discussing information learned with a colleague; teaching others about what they learnt; identifying a barrier and working to address it; and broaden the kinds of referrals that they make.

Conclusion

During the Think Tank participants discussed the barriers and facilitators for physical activity for people living with HIV, current programs that are being offered, and potential for new and creative programming. Participants recognized that some barriers were difficult to mitigate as they resulted from structural or systemic causes and/or are unique to different groups of people making it difficult to develop a one size fits all solution. However, physical activity was recognized as an important aspect of programming for people living with HIV especially when looking at the current recommendations and rates of participation.

Community-based HIV organizations face barriers related to space, skills and resources when considering developing/offering programming for people living with HIV. Conversely, physical activity and fitness organizations need to be educated on the needs of people living with HIV in order to ensure their programming is inclusive and accessible for people living with HIV.

Participants in the post-event evaluation responded that they enjoyed the day, and would use the information they learned and discussed. For future Think Tanks it would be good to consider allowing for more time to network, developing next steps as a group and adding a workshop that provides tangible takeaways. Invitations to organizations outside the HIV sector were made through ParticipACTION, however acceptance of these invitations was minimal. It may be appropriate to consider reaching out in a different way to try and encourage more participation.

Appendices

Appendix A - Agenda

2019 Think Tank:

How can we Increase Physical Activity for People Living with HIV

March 4th, 2019

9:30AM – 3:00PM

St. Paul's Church, 227 Bloor Street East, Toronto, Ontario, M4W 1C8

Facilitator: Ron Rosenes

Goals for the Think Tank:

1. Develop partnerships with a focus on physical activity and health for people living with HIV
2. Develop strategies to increase access to physical activity for people living with HIV
3. Build capacity through partnerships and learn from each other

Agenda:

Time	Item
9:30-10:00	Registration and light breakfast
10:00 -10:10	Welcome from <i>Realize</i>
10:10 -10:30	Framing the Day and Introductions What is a "Think Tank"? <i>"A think tank is defined as a process for in-depth consideration of issues and challenges whose relevance reaches beyond the individual person or program and the immediate time frame."</i> <i>(Caliva & Scheier, 1992)</i>
10:30 - 10:45	Ice Breaker
10:45 -11:00	Setting the Stage:
11:00 -11:30	Breakout #1 - Physical activity, HIV and chronic health conditions
11:30 – 12:00	Movement Break
12:00 – 12:30	Breakout #2 - Thoughts on developing a Wellness Guide
12:30 – 1:15	Lunch
1:15 – 2:00	ParticipACTION workshop



2:00 – 2:45 pm	Breakout #3 - Developing safe spaces for people living with HIV to participate in physical activity
2:45 – 3:00 pm	Wrap up and evaluation

Appendix B – Facilitator Guide

Facilitator Guide

Context

- This event brings together people from the HIV community, research and physical activity
- Goal to develop partnerships and strategies that cross sectors to increase physical activity participation for people living with HIV
- Recommended physical activity
 - 150 minutes per week
 - Minimum 10 minutes at a time
 - 2 days a week of muscle/bone strengthening
 - For adults 65+, with poor mobility
 - Add balance activities
- Less than 20% of adults in Canada meet these recommendations
 - Less than that in the population of people living with HIV
- A survey of community-based HIV organizations done by *Realize* in 2017 looked at rehabilitation, wellness and mental health services that support people living with HIV
 - 10/47 responded they offered yoga
 - 8/47 offered group exercise classes
 - 2/47 offered personal training
 - 3/47 offered tai chi
 - 3/47 offered walking clubs

Breakout #1 – Physical activity, HIV, and chronic health conditions

- **HIV community** – what physical activity do you currently do/offer? What physical activity would you like to do/offer?
- **Physical activity/fitness community** – what do you currently offer/promote for people living with chronic health conditions?
- What do you feel are barriers to physical activity for people living with HIV and/or other chronic health conditions?
 - Structural, systemic, behaviour change
- What do you feel are facilitators to physical activity for people living with HIV and/or other chronic health conditions?
 - Structural, systemic, behaviour change
- What is preventing you/your organization from offering physical activity programming for people living with HIV?
- Some community-based organizations indicate that they previously offered physical activity programming and their client base did not attend
 - Why do you think this happened?
 - What could be a good way overcome this?

Breakout #2 – Thoughts on developing a Wellness Guide

- What are your thoughts on the Wellness Guide?
- What would be helpful to add?
- Would you be able to use this to increase physical activity for people living with HIV?
 - Why or why not?
- What other information would you add?
- What information would you remove?

Breakout #3 – Developing safe spaces for people living with HIV to participate in physical activity

- Brainstorm ways that we can work together to increase inclusivity and accessibility for people living with HIV
 - In current programming
 - Future programming
- What can physical activity organizations do?
 - At a programming level
 - At an advertising level
 - At a staff level
 - Potential partnerships/future discussions to consider
- What can HIV organizations do?
 - At a programming level
 - At an advertising level
 - At a staff level
 - Potential partnerships/future discussions to consider
- What needs to be taken into account related to
 - Structural issues
 - Systemic issues
 - Behaviour change
- What suggestions do you have about forming partnerships between HIV organizations and physical activity organizations?

Appendix C – Pre-Event Survey

Think Tank Pre-Survey: How can we Increase Physical Activity for People Living with HIV?

Welcome! Thank you for agreeing to participate in our Think Tank this year. We look forward to seeing you.

The goals of the Think Tank are to:

1. Develop partnerships with a focus on physical activity and health for people living with HIV
2. Develop strategies to increase access to physical activity for people living with HIV
3. Build capacity through partnerships and learn from each other

Taken together, the results of the pre and post-event surveys will give us a sense of what may have changed for Think Tank attendees as a result of participating.

Please note that completion of this survey is voluntary and all responses will be anonymous.

It will take approximately 10 minutes to complete.

We thank you for your support and look forward to rich discussions on March 4th.

Think Tank Pre-Survey:
How can we Increase Physical Activity for People Living with HIV?

1. Please rate how much you agree with the following statements from 1 (Strongly disagree) to 5 (Strongly agree):

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I have thought about physical activity for people living with HIV	<input type="radio"/>				
I understand the facilitators that would improve access to physical activity for people living with HIV	<input type="radio"/>				
I understand the barriers that hinder participation in physical activity for people living with HIV	<input type="radio"/>				

2. How would you rate your current knowledge about physical activity programming for people living with HIV?

- Very Low
- Low
- Moderate
- High
- Very High

3. What are your expectations for the Think Tank?

4. In what capacity are you attending the Think Tank today? Please choose only one.

- Not-for-profit organization representative
- Public health/healthcare professional
- Policy & decision-makers/leaders
- Educators
- Researchers/academics
- Global partners
- Individual

5. What is your area of expertise? Please check all that apply.

- Lived experience with HIV
- Lived experience with a chronic health condition
- Physical activity/fitness
- HIV (not lived experience)
- Rehabilitation services
- Other (please specify)

6. Have you attended a **Realize** Think Tank previously?

- Yes
- No
- Don't know/Can't remember

Thank you for taking the time to complete this pre-survey. See you on March 4th!

Appendix D – Post-Event Survey

Think Tank Post-Survey:

How can we increase physical activity for people living with HIV?

Monday, March 4th 2019

We encourage you to complete this tool with honesty and with confidence that the results are private and confidential. Results will only be shared as summarized data. It should take you no longer than 10 minutes to complete. Your completion of this questionnaire will inform our ongoing work.

1. Please rate how much you agree with the following statements from 1 (Strongly disagree) to 5 (Strongly agree):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have thought about physical activity for people living with HIV	1	2	3	4	5
I understand the facilitators that would improve access to physical activity for people living with HIV	1	2	3	4	5
I understand the barriers that hinder participation in physical activity for people living with HIV	1	2	3	4	5

2. How would you rate your current knowledge about physical activity programming for people living with HIV?

- Very low
- Low
- Moderate
- High
- Very High

3. In terms of today's discussion, what was the most relevant take-away for you?

4. Do you have plans to use the information from the Think Tank in your work?

- Yes No

If yes, how so?

- I plan to talk to discuss the material covered in the workshop with a colleague
- I plan to try out one or more of the skills I've learned in this workshop in my interactions with clients
- I plan to broaden my current referral list or to make a referral to a new service provider and/or organization
- I plan to talk to my supervisor about the workshop material and its implications for our organizational policies, practices and/or services
- I plan to ask my supervisor or a colleague to check in with me and hold me accountable as I work to apply my learning from this workshop
- I plan to seek out more training and/or professional development on the topics covered in this workshop
- I plan to teach others what I've learned in this workshop (e.g. by delivering a workshop for my colleagues, clients etc.)
- I plan to seek out a mentor who demonstrates the skills I learned in this workshop in their day-to-day practice
- I plan to identify and try to address a barrier or obstacle to implementing the skills learned in this workshop in my practice
- I would like to use the material covered in this workshop, but I'm not sure how.
- I have no plans to use the material covered in this workshop.
- Other (please specify)

5. Overall, how would you rate the following aspects of the Think Tank?

	Not Satisfied	Somewhat Satisfied	Neutral	Satisfied	Very Satisfied
The relevance of the topic	1	2	3	4	5
The objectives of the day were met	1	2	3	4	5
Participant diversity in terms of expertise, experience and ideas	1	2	3	4	5
Quality of the facilitation	1	2	3	4	5
Opportunities to network and connect with others	1	2	3	4	5

6. Any recommendations to improve the Think Tank model of knowledge exchange?

7. Any additional comments?

Thank you for taking the time to complete this post-event survey.

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