Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation
CAHR Conference 2017
Thursday April 6th and Friday April 7th, 2017
Hotel Bonaventure, Montreal, Quebec
ACKNOWLEDGEMENTS

This meeting was supported by a Planning Grant from the Canadian Institutes of Health Research (CIHR), Institute of Aging. This meeting was a collaboration between the Canadian Association for HIV Research (CAHR), Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC), Realize (formerly the Canadian Working Group on HIV and Rehabilitation), and the Living with HIV (LHIV) Innovation Team who partnered for the Ancillary Meeting focused on self-management in the context of HIV and rehabilitation.

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Claire Kendall (University of Ottawa)* Ancillary Meeting
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Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation

Date last revised: June 29, 2017
Speakers (Ancillary Meeting)
Cliona Ni Cheallaigh (Trinity College Dublin)
Clare Liddy (Bruyère Research Institute)
Richard Harding (King’s College London)

Speakers (Special Plenary Session)
Mr. Larry Baxter (Community Member)
Mr. Matthew Halse (ACCM)
Dr. Colm Bergin (St. James’s Hospital)
Dr. Julian Falutz (McGill University Health Centre)
Ms. Esther McDonnell (Chelsea and Westminster Hospital)
Dr. Kelly O’Brien (University of Toronto)

Student Rapporteurs (Ancillary Meeting)
Lisa Boucher (Bruyère Research Institute)
Andrew Eaton (University of Toronto)
Alex Terpstra (The Ontario HIV Treatment Network)
Eugene Nam (The Ontario HIV Treatment Network)
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*Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation*

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MAIN MESSAGES

- CIHRRC collaborated on two HIV and rehabilitation endeavors at the 26th Annual Canadian Conference on HIV/AIDS Research in April 2017:
    This meeting brought together 32 stakeholders, including researchers (n=10), clinicians (n=6), representatives from community organizations (n=5), representatives from funding organizations (n=3) trainees (n=4), and people living with HIV (PLWH) (n=4) from Canada (n=27), the United Kingdom (UK) (n=2), the United States (US) (n=1), and Ireland (n=2) to exchange research evidence related to HIV, aging and rehabilitation.
  - **Advancing HIV, Aging and Rehabilitation: Where Does Rehabilitation Fit in the HIV Care Cascade?** (Special Plenary Session - Friday April 7th, 2017).
    This session featured the role and emerging evidence for rehabilitation in the context of HIV, aging, and multi-morbidity across both the life course and the HIV care cascade.

- Eleven core grant applicants, and representatives from a key collaborator organization, six invitees from the UK who were clinicians and/or people living with HIV, and 28 additional invitees were invited to attend the sessions to translate knowledge and develop a plan for a collaborative research proposal to address emerging priorities in HIV, aging, and rehabilitation.
  - The Ancillary Meeting (April 6) was focused on self-management intervention research in the context of HIV, aging and rehabilitation.
  - The Special Plenary Session (April 7) focused on translating research evidence and clinical practice related to HIV, aging and multi-morbidity across countries that share similar HIV disability issues and identifying the role of rehabilitation in the HIV care cascade.

- This meeting was supported by a Planning Grant from the Canadian Institutes of Health Research (CIHR), Institute of Aging. This meeting was a collaboration between the Canadian Association for HIV Research (CAHR), Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC), Realize (formerly the Canadian Working Group on HIV and Rehabilitation), and the Living with HIV (LHIV) Innovation Team who specifically partnered for the Ancillary Meeting focused on self-management in the context of HIV and rehabilitation. Twitter updates: #RehabHIV.

- Evaluations of the Ancillary Meeting indicated that the majority of participants agreed or strongly agreed (95%, 19/20) that the meeting achieved its goal of planning for future self-management initiatives in the context of HIV, aging, and rehabilitation.
  - Strengths of the meeting included: engaging and excellent presenters, well organized, diverse interdisciplinary nature of attendees and perspectives, and a great opportunity for discussions and collaborations.
  - The majority of participants (95%, 19/20) thought they would be able to apply the content covered in the meeting to their work.

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Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation

Date last revised: June 29, 2017
EXECUTIVE SUMMARY

The Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC), in partnership with Realize (formerly the Canadian Working Group on HIV and Rehabilitation), the Canadian Association for HIV Research (CAHR), and the Living with HIV (LHIV) Innovation Team, hosted the Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation Ancillary Meeting and Special Plenary Session on Thursday April 6 and Friday April 7, 2017 in Montreal, Quebec at the Hotel Bonaventure.

Our overall goal was to advance an international research agenda that will address research and educational priorities in HIV, aging and rehabilitation by developing partnerships among people living with HIV (PLWH), researchers, clinicians, and community organizations in Canada, the United Kingdom (UK) and Ireland. Specific objectives were to:

1) To facilitate knowledge transfer and exchange (KTE) on HIV, aging and rehabilitation research, clinical practice and service delivery among people aging with HIV, researchers, clinicians, representatives of community organizations, and policy stakeholders in Canada, the UK and Ireland;

2) To establish new research and clinical partnerships in the field of HIV and aging internationally;

3) To plan a collaborative international research proposal that will address priorities in HIV, aging and rehabilitation recently identified at an International Forum on HIV and Rehabilitation Research.

4) To foster mentorship and training in HIV, aging and rehabilitation research;

5) To develop a plan to expand and sustain an international collaborative research team called the Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC). This collaboration will build on existing expertise and formally enhance linkages between researchers, clinicians, trainees, and older adults living with HIV in Canada, UK, and Ireland, to address priorities in HIV, aging and rehabilitation.

To achieve these objectives, we planned and implemented two sessions at the CAHR 2017 Conference: 1) Ancillary Meeting focused on self-management intervention research in the context of HIV, aging and rehabilitation; and 2) Special Plenary Session as part of the CAHR Conference that focused on how rehabilitation may contribute to better outcomes across the treatment cascade.

Who Attended? The Ancillary Meeting was invitation only and brought together 32 stakeholders, including researchers (n=10), clinicians (n=6), representatives from community organizations (n=5), representatives from funding organizations (n=3) trainees (n=4), and people living with HIV (PLWH) (n=4) from Canada (n=27), the United Kingdom (UK) (n=2), the United States (US) (n=1) and Ireland (n=2) to exchange research evidence related to HIV, aging and rehabilitation. The Special Plenary Session was open to all CAHR delegates who attended the conference.
This report provides an overview of the **Self-Management Interventions in HIV Rehabilitation Research Meeting** (Ancillary Meeting) and **Special Plenary – Where does Rehabilitation fit in the care cascade?**

- At the **Self-Management Ancillary Meeting**, speakers and discussion sessions addressed issues related to: 1) successful aging in the context of HIV and rehabilitation; 2) overview of chronic disease self-management (CDSM) theory in practice; 3) chronic disease self-management intervention research in HIV and rehabilitation in Canada and internationally; and 4) moving forward with a research agenda in CDSM in HIV and rehabilitation. The meeting provided an opportunity for a range of stakeholders to respond to current research evidence and present new and emerging research evidence and experiences related to self-management in HIV, aging and rehabilitation. Structured small and large group discussions and Q&A segments enabled participation throughout the day and a facilitator was in place to engage attendees while adhering to the agenda. See Program at a Glance (Appendix A).

- At the **Special Plenary Session – Advancing HIV, Aging and Rehabilitation: Where does rehabilitation fit in the care cascade?** speakers focused on the role and emerging evidence for rehabilitation in the context of HIV, aging and multimorbidity and reflected on where rehabilitation fits within the care cascade.

**How Can I Access the Meeting Materials?** A video recording of the Special Plenary Session is openly accessible on the CAHR YouTube site: [https://www.youtube.com/watch?v=9uFbH5j6tXQ](https://www.youtube.com/watch?v=9uFbH5j6tXQ). The Ancillary Meeting was not video recorded but speaker slides focused on self-management can be accessed by clicking here.

**What were the Strengths and Challenges of the Meeting?** We conducted an evaluation of the Ancillary Meeting with attendees. We received evaluations from 20 of the 32 meeting participants. Respondents indicated that the presentations were informative, engaging and covered a breadth of topics. Speakers and participants represented a range of interdisciplinary and international stakeholders which contributed to diverse perspectives and fruitful discussions. Participants indicated that diversity among attendees contributed to a variety of interesting perspectives; and that they enjoyed opportunities for informal discussion and collaborations.

Participants also found that an overwhelming amount of information was presented in a short amount of time and it was difficult to achieve consensus on specific research objectives in one day. In the future, they would appreciate the meeting being spread over a longer period of time (1.5 to 2 days). Additionally, participants found the room to be small and somewhat crowded. Finally, participants indicated they would have appreciated more breaks to process the information provided. Overall, participants found the meeting to be a well-organized, informative and productive event.

**Who Do I Contact for More Information?** For more information about the meeting, please contact Kelly O’Brien ([kelly.obrien@utoronto.ca](mailto:kelly.obrien@utoronto.ca)), Francisco Ibáñez-Carrasco ([francisco@universitieswithoutwalls.ca](mailto:francisco@universitieswithoutwalls.ca)) or Kate Murzin ([kmurzin@hivandrehab.ca](mailto:kmurzin@hivandrehab.ca)).
CONTEXT

HIV is now considered a chronic illness in countries such as Canada, UK, the United States, and Ireland. Approximately 30% of people living with HIV (PLWH) in Canada are over 50 years of age and this proportion is expected to increase over the next decade. A similar pattern may appear in other developed countries where people living with HIV have reliable access to treatment. People are aging with a range of physical, cognitive, mental and social health challenges associated with HIV and comorbidities, despite improvements in survival and increased access to treatment. The rising prevalence of cardiovascular disease, diabetes, bone and joint disorders, neurocognitive disorders, and cancers further add to the complexity of disability experienced by PLWH over the life course. Adults aging with HIV can face additional challenges of ageism, stigma, mental illness, income insecurity and lack of social support. Therefore, it is essential that health communities respond to the changing needs of adults aging with HIV, specifically by increasing the role of rehabilitation.

Rehabilitation in the context of HIV includes any prevention or treatment activities and services that address body impairments, activity limitations and social participations restrictions experienced by an individual. Rehabilitation services such as physical therapy can help address disability. It is hypothesized that the demand for rehabilitation will increase for those with HIV and other chronic and episodic illnesses as the population ages. However, the field of HIV and aging is still emerging, with Canada, Ireland, the United Kingdom (UK) and the United States (US) growing as leaders in the field. People aging with HIV in these countries experience similar challenges related to retirement and income support, accessing rehabilitation services, and increasing complex multi-morbidity. Canada is an international leader in mobilizing the dynamic field of HIV rehabilitation research, however, the provision of rehabilitation for older adults with HIV remains limited. In contrast, in some areas of the UK, HIV rehabilitation service delivery is more established and accessible across the continuum of care. Forming partnerships and exchanging knowledge with others in countries where individuals experience similar issues related to HIV and aging is essential to addressing research priorities in this emerging field.

Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC)

In October 2009, a group of UK and Canadian researchers and clinicians, in partnership with the Canadian Working Group on HIV and Rehabilitation (CWHGR), obtained funding from the CIHR Meetings Planning and Dissemination Grants competition to conduct a research meeting in London, UK. The goal of this meeting was to develop a collaborative research agenda to address the research priorities in HIV and rehabilitation. At this meeting, the Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) was formalized as the first international research collaborative on HIV and rehabilitation (http://cihrcc.hivandrehab.ca/). Recently, CUHRRC changed its name to the Canada-International HIV Rehabilitation Research Collaborative (CIHRRC). CIHRRC is now comprised of 77 PLWH, researchers, clinicians, representatives from community organizations and policy stakeholders in Canada, the UK, the United States, Ireland and the UK.

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Ireland, and the US with an interest in HIV and rehabilitation research. Members meet biannually by teleconference to share knowledge and collaborate on research initiatives. CIHRRC members have collectively pursued initiatives in each of the research priority areas in HIV and rehabilitation, such as: exploring the prevalence of comorbidities, disability and rehabilitation service use among PLWH in Canada; conducting a policy analysis comparing rehabilitation service access in Canada and the UK;\textsuperscript{33} evaluating the uptake of an electronic resource, the E-Module for Evidence-Informed HIV Rehabilitation (http://www.realizecanada.org/en/resources/e-module);\textsuperscript{34} developing evidence-informed practice recommendations on the rehabilitation of older adults with HIV;\textsuperscript{35} and developing and assessing the measurement properties of a new HIV disability questionnaire.\textsuperscript{36}

CUHRRC, in partnership with CWGHR, planned and hosted the International Forum on HIV and Rehabilitation Research, on June 13-14, 2013 in Toronto, Ontario, Canada. The Forum brought together 92 stakeholders to share current research evidence related to the six priority areas. The priority areas aligned with six key research priorities established by CWGHR in an earlier scoping study.\textsuperscript{37} The Forum also offered an opportunity to review and update the research priorities to respond to new and emerging issues related to HIV and rehabilitation.\textsuperscript{38}

CUHRRC, in partnership with the Rehabilitation in HIV association (RHIVA), planned and hosted the 2nd International Forum on HIV and Rehabilitation Research: Advancing International Partnerships to Address Key Research Priorities in HIV and Rehabilitation, on October 11, 2014 at the Chelsea and Westminster Hospital in London, England. The Forum brought together 51 stakeholders to facilitate knowledge transfer and exchange (KTE) on HIV and rehabilitation research, clinical practice and service delivery, among PLWH, researchers, clinicians on HIV, representatives of community organizations, and policy makers in Canada, UK and Ireland; and to foster new research and clinical partnerships in HIV and rehabilitation internationally. The Forum provided an opportunity for a broad range of stakeholders to respond to current research evidence and present new and emerging evidence and experiences related to HIV and rehabilitation.

On May 12, 2016, CUHRRC in partnership with the Canadian Working Group on HIV and Rehabilitation (CWGHR) and the Canadian Association for HIV Research (CAHR), planned and hosted the 3rd International Forum on HIV and Rehabilitation Research at the Delta Winnipeg, Winnipeg, Canada. The Forum brought together 69 stakeholders to facilitate knowledge transfer and exchange (KTE) on HIV and rehabilitation research, clinical practice and service delivery, among PLWH, researchers, clinicians, representatives of community organizations, and policy makers in Canada, UK and Ireland; and to foster new research and clinical partnerships in HIV and rehabilitation internationally. The Forum provided an opportunity to foster mentorship and training in HIV and aging research and to identify new and emerging research priorities in HIV, aging, and rehabilitation.
On April 6 and April 7, 2017, CIHRRC in partnership with Realize (formerly known as CWGHR), and CAHR, planned and hosted an Ancillary Meeting focused on Self-Management in HIV and Rehabilitation, in collaboration with the Living with HIV (LHIV) Team and a Special Plenary session and focused on how rehabilitation may contribute to better outcomes across the treatment cascade. This meeting built on previous CIHRRC initiatives, including the past three International Forums on HIV and Rehabilitation Research.

LIVING LONGER, LIVING WELL: ADVANCING RESEARCH PRIORITIES IN HIV, AGING, AND REHABILITATION

Part 1 – Ancillary Meeting

The goals of this meeting were to 1) define and discuss chronic disease self-management (CDSM) in the context of HIV; 2) share lessons learned about chronic disease self-management (CDSM) intervention-based research in the field of rehabilitation and in the context of HIV; 3) identify current gaps and recommendations that will inform future CDSM intervention-focused research on adults living with HIV; 4) explore partnerships and appetite for developing a network on CDSM research, focused in HIV and rehabilitation; and 5) develop a plan for, and discuss the feasibility of, a future catalyst grant proposal focused on the implementation and evaluation of a CDSM intervention for adults living with HIV.

Part 2 – Special Plenary Session
The Ancillary Meeting was followed by a special invited symposium on HIV, Aging and Rehabilitation at the 26th Annual Canadian Conference on HIV/AIDS Research (CAHR 2017) on Friday April 7 titled, “Advancing HIV, aging and rehabilitation: where does rehabilitation fit in the HIV care cascade”.

The objectives of this 1.5 hour long session were: 1) to reflect on the role and emerging evidence for rehabilitation in the context of HIV across both the life course and the HIV care cascade; 2) to facilitate knowledge transfer and exchange on HIV, aging and rehabilitation research; and 3) to highlight examples of rehabilitation in practice for people aging with HIV.
APPROACH

The Special Plenary and Ancillary Meeting were supported by a Meeting, Planning and Dissemination Grant from the Canadian Institutes of Health Research (CIHR), Aging Institute. CIHRRC also acknowledges the financial support of Realize (formerly known as the Canadian Working Group on HIV and Rehabilitation). The meeting involved an intensive process of planning and development leading up to the event. Upon receiving notification of funding, members of the Core Planning Team had their first meeting via teleconference in November 2016 to begin planning for the meeting.

Core Planning Committee

In November 2016, a Core Planning Committee was formed which included co-principal applicants and principal knowledge users of the CIHR Planning Grant. The purpose of the Core Planning Committee was to oversee the planning and implementation of the meeting. Members of this committee met early on with the larger CIHR Planning Grant Team via teleconference to refine the agenda and speakers for the Ancillary Meeting and Special Plenary Session on HIV, Aging and Rehabilitation at CAHR 2017.

This Core Planning Committee met three additional times leading up to the meeting to discuss advancements made in the planning of the meeting. Specific activities included:

- Developing a timeline for the planning process,
- Advertising the meeting, preparing for the Special CAHR Plenary Session,
- Planning the meeting agenda and program,
- Connecting with potential speakers and panelists,
- Finalizing catering, travel and accommodation details,
- Developing a filming and media plan,
- Discussing the evaluation process,
- Designing the registration process,
- Finalizing and distributing participant and speaker invitations,
- Establishing opportunities for and preparing rapporteurs,
- Liaising with meeting speakers prior to the meeting, and
- Determining the specific outcomes of the meeting.

The core planning committee updated the broader CIHR Planning Grant team on relevant items via e-mail throughout this process.

Invitations

Participation in the Ancillary Meeting was by invitation only. The Core Planning Committee developed a list of invitees which included PLWH, clinicians, academics, representatives from AIDS Service Organizations (ASOs) and Community-Based Organizations (CBOs), community members, Realize and CIHRRC members, and representatives from funding organizations with expertise and interest in self-

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management interventions in HIV and rehabilitation. Personal invitations were sent via email in January 2017. There was no registration fee for the meeting. The special plenary session was open to all CAHR delegates and promoted widely through conference communication. We also used the CIHRRC Twitter Account (@CIHRRC) to promote the Special Session.

Invited Speakers and Volunteers
Twelve researchers, clinicians and community members engaged in the field of HIV, aging and rehabilitation were invited to present as part of Ancillary Meeting and/or Special Plenary Session. Three speakers presented during the introductory portion of the Ancillary Meeting and three speakers presented during the core portion of the Ancillary Meeting. Six speakers presented during the Plenary Session. Four graduate students were involved as rapporteurs for the Ancillary Meeting.

Pre-meeting Planning Teleconferences
In November 2016, the Core Planning Team began to hold pre-meeting teleconferences. The purpose of these teleconferences was to enable the Core Planning Committee to discuss the logistics and proceedings of the meeting. The last of these planning teleconferences included the panelists of the Special Plenary Session, enabling the speakers to get acquainted with each other and discuss their topics of presentation before the meeting.

Post-Meeting Activities
The Core Planning Committee met once via teleconference after the meeting to debrief on the overall meeting planning process and the meeting itself, discuss the next steps, and address post-meeting activities such as the evaluation process. We compiled the evaluations from the meeting into a report provided to Realize.

ANCILLARY MEETING AND SPECIAL PLENARY SESSION OVERVIEW
The event began with the Ancillary Meeting (Thursday April 6, 2017) and ended with the Special Plenary Session (Friday April 7, 2017). Please see Appendix A for the Ancillary Meeting Agenda and Appendix B for the Special Plenary Session Agenda.

Part 1 – Ancillary Meeting
The Ancillary Meeting titled “Self-Management Interventions in HIV Rehabilitation Research – Addressing Research Priorities in HIV, Aging, and Rehabilitation” consisted of three speakers from Canada, the UK, and Ireland including Cliona Ni Cheallaigh (Mercer’s Institute for Successful Aging, Trinity College Dublin), Claire Liddy (University of Ottawa), and Richard Harding (King’s College London), who presented on 1) the meaning of successful aging in the context of HIV and rehabilitation; 2) chronic
disease self-management; and 3) rehabilitation dimensions in patient reported outcome measures (PROMS) for HIV & self-management strategies. The meeting included a Moderator, Patty Solomon (McMaster University), who facilitated a 5-minute question and answer session after each presentation. Interaction was encouraged through Q&A as well as informal discussions during break and lunch. The meeting included a number of features to enhance knowledge transfer and exchange. Participants were provided a hard copy of the meeting program which included the agenda and key messages from each presentation, as well as biographies of the speakers.

We used the official hashtag, #RehabHIV throughout the meeting. All attendees were encouraged to use Twitter throughout to further translate highlights from the meeting. During the Living Longer, Living Well event, 72 Twitter users tweeted, retweeted, or ‘liked’ a tweet with the hashtag #RehabHIV. To access the Twitter feed from the Forum go to: https://twitter.com/search?f=tweets&vertical=default&q=%23RehabHIV&src=typd

Part 2 – Special Plenary Session
The Plenary Session titled “Advancing HIV, aging and rehabilitation: where does rehabilitation fit in the HIV care cascade?” involved six panelists and one moderator including PLWH, researchers clinicians, and representatives from community-based HIV organizations who had the opportunity to comment and reflect on the research evidence presented at the Ancillary Meeting. The aim of the Plenary Session was to examine the role of rehabilitation in the context of HIV, aging, and multi-morbidity across countries that share similar HIV disability issues and to strengthen partnerships in HIV and rehabilitation research. This session was moderated by Kate Murzin (Realize) and speakers Larry Baxter (community member living with HIV since 1992), Mathew Halse (AIDS Community Care Montreal), Colm Bergin (St. James’s Hospital), Julian Falutz (McGill University Health Centre), Esther McDonnell (Chelsea and Westminster Hospital), and Kelly O’Brien (University of Toronto) presented on HIV, Aging and Rehabilitation in Canada, Ireland and the United Kingdom. The Panel Session was followed by a Q&A period and group discussion which was moderated by the Facilitator. Click here to view the video of the Special Plenary Session.

ANCILLARY MEETING
Speakers and Participants
Thirty-two participants convened in Montreal to discuss self-management interventions in HIV, aging and rehabilitation. Participants represented a broad range of stakeholders. The majority of participants indicated that they worked at a university (or other academic institution) (38%, n=12), and identified as researchers (31%, n=10) or clinicians (19%, n=6). See Table 1 for an overview of characteristics of meeting participants based on information gathered at meeting registration.

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### Table 1 - Characteristics of Meeting Participants (N=32)

<table>
<thead>
<tr>
<th>Participant Affiliation</th>
<th>Meeting Participants</th>
<th>Participant Role</th>
<th>Meeting Participants</th>
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<tbody>
<tr>
<td>Research/Knowledge Production Organization</td>
<td>3 (9%)</td>
<td>Researcher</td>
<td>10 (31%)</td>
</tr>
<tr>
<td>Hospital or Community-Health Centre</td>
<td>5 (16%)</td>
<td>Clinician</td>
<td>6 (19%)</td>
</tr>
<tr>
<td>University (or other Academic Institution)</td>
<td>12 (38%)</td>
<td>Representatives from community organizations</td>
<td>5 (16%)</td>
</tr>
<tr>
<td>Governmental Organization</td>
<td>1 (3%)</td>
<td>Representatives from funding organizations</td>
<td>3 (9%)</td>
</tr>
<tr>
<td>Funding Organization</td>
<td>3 (9%)</td>
<td>Students/Trainees</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Community-Based Organization</td>
<td>5 (16%)</td>
<td>People living with HIV</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>Community Member</td>
<td>3 (9%)</td>
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**Evaluation**

Twenty of the 32 participants (31%) completed the evaluation form. The evaluation highlighted strengths and successes for this event and provided valuable feedback to CIHRRC, Realize and the planning team.

The top five topics that participants articulated as “take home messages” from the meeting were:

- ✓ Health care professionals and caregivers play integral roles in self-management of chronic conditions,
- ✓ It is critical to address structural and systemic issues in the integration of self-management interventions,
- ✓ Self-management must be flexible and informed by individual patient goals,
- ✓ Asking people living with HIV, “How are you feeling?” is just as important as assessing health using clinical measures, and
- ✓ It is possible to establish and measure Patient Reported Outcome Measures and Patient Reported Experience Measures
Of the 20 respondents who submitted an evaluation:

- 19 (95%) agreed or strongly agreed that the meeting achieved its goal of planning for future self-management initiatives in the context of HIV, aging, and rehabilitation;
- 17 (85%) agreed or strongly agreed that they made new contacts which will be helpful to their work;
- 20 (100%) agreed or strongly agreed that the presenters were knowledgeable and communicated their ideas clearly;
- 19 (85%) agreed or strongly agreed that it was useful to learn about the self-management research and programming carried out in other countries;
- 20 (100%) agreed or strongly agreed that there was adequate time allocated for informal discussion among meeting participants; and
- 13 (65%) agreed or strongly agreed that their needs were accommodated for.

Of the 20 meeting evaluation respondents, 19 (95%) indicated that they would be able to apply the content covered in the meeting to their work.

<table>
<thead>
<tr>
<th>Table 2 - To what degree did participants gain new and relevant knowledge/insight in each of the content areas listed below? (n=20)</th>
</tr>
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<tbody>
<tr>
<td><strong>Topic</strong></td>
</tr>
<tr>
<td>Chronic disease self-management interventions</td>
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<tr>
<td>Living with the complexity of HIV and multi-morbidity</td>
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<tr>
<td>Strategies for aging successfully with HIV</td>
</tr>
<tr>
<td>Access to rehabilitation for people living with HIV</td>
</tr>
<tr>
<td>The role of rehabilitation for people living with HIV</td>
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Respondents provided informative and encouraging comments with regard to strengths and drawbacks of the meeting. Overall, meeting participants appreciated the organization of the meeting and found the presentations to be engaging, informative, and of high quality. Participants indicated that the diversity of attendees contributed to a variety of interesting perspectives; they enjoyed opportunities for informal discussion and collaborations.

However, participants found that an overwhelming amount of information was presented in a short amount of time and it was difficult to achieve consensus on specific research objectives in one day. In the future, they would appreciate the meeting being spread over a longer period of time (1.5 to 2 days). Additionally, participants found the room to be small and somewhat crowded. Finally, participants
indicated they would have appreciated more breaks to facilitate processing of the information covered. Overall, participants found the meeting to be well organized, informative and productive event. Please view the meeting Evaluation Questionnaire (Appendix C).

CONCLUSION
This report summarizes the process, content, and outcomes of the Self-Management Ancillary Meeting and Special Plenary Session. The need for research in HIV, aging and rehabilitation continues to increase as people live longer and age with HIV. The field of HIV, aging and rehabilitation research is evolving to meet the current needs of PLWH, with Canada, the UK, Ireland, and the US as leaders. Rehabilitation in the context of HIV and chronic disease self-management are integral areas of inquiry and practice that effectively bridge academic disciplines, clinical practices and community efforts. Overall, the meeting was successful in defining and discussing chronic disease self-management in the context of HIV and rehabilitation and fostering new research partnerships among stakeholders in HIV, aging and rehabilitation across Canada and internationally.
REFERENCES


Appendix A: Ancillary Meeting Agenda

Self-Management Interventions in HIV Rehabilitation - Addressing Research Priorities in HIV, Aging and Rehabilitation

Thursday April 6, 2017, 830am-4pm, Montreal, Quebec
HÔTEL BONAVENTURE MONTRÉAL, Fundy room (Convention level)

Meeting Goal
To build partnerships, advance knowledge, and identify lessons learned for advancing an intervention-based research agenda focused on self-management (SM) in the context of HIV, aging and rehabilitation.

Meeting Objectives

1) To define and discuss chronic disease self-management (CDSM) in the context of HIV with HIV.
2) To share lessons learned about what is going on in chronic disease self-management (CDSM) intervention-based research in rehabilitation in the context of HIV.
   - Each invitee will be asked to provide a brief overview about their perspectives and experiences in CDSM focused research.
3) To identify the current gaps and recommendations that will inform future CDSM intervention focused research on HIV and rehabilitation with adults living with HIV.
4) To explore partnerships and appetite for developing a network on CDSM research focused in HIV and rehabilitation.
5) To develop a plan for, and discuss the feasibility of, a future catalyst grant proposal focused on the implementation and evaluation of a CDSM intervention for adults living with HIV.

Morning Objective / Focus
To discuss and share knowledge about the current state of expertise in CDSM research in the context of HIV and rehabilitation and identify recommendations for next steps.

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>830-900am</td>
<td>Breakfast</td>
<td></td>
</tr>
<tr>
<td>900-920am</td>
<td>Welcome &amp; Overview of Meeting Objectives</td>
<td>Patty Solomon; Kelly O’Brien; Claire Kendall</td>
</tr>
<tr>
<td></td>
<td>Introductions</td>
<td></td>
</tr>
<tr>
<td>920-945am</td>
<td>What does Successful Aging Mean in the context of HIV and Rehabilitation?</td>
<td>Cliona Ni Cheallaigh, Mercer’s Institute for Successful Aging, Trinity</td>
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<tr>
<td>Time</td>
<td>Session</td>
<td>Speaker/Location</td>
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<tr>
<td>9:45-10:15</td>
<td>What is Chronic Disease Self-Management?</td>
<td>College Dublin</td>
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<td></td>
<td></td>
<td>Clare Liddy, Bruyère Research Institute, Ottawa</td>
</tr>
<tr>
<td>10:15-10:30</td>
<td>Break</td>
<td></td>
</tr>
<tr>
<td>10:30-11:30</td>
<td>What's Going On in Chronic Disease Self-Management Intervention Research in HIV and Rehabilitation in Canada and Internationally?</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td>Group Discussion</td>
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<tr>
<td></td>
<td>What are the top 3: i) lessons learned; ii) key components for CDSM intervention; and iii) important steps for moving forward.</td>
<td></td>
</tr>
<tr>
<td>11:30-12:30</td>
<td>Moving Forward with a Research Agenda in CDSM in HIV and Rehabilitation - Breakout Session &amp; Rapporteur Reporting Back</td>
<td>All</td>
</tr>
<tr>
<td>12:30-1:15</td>
<td>LUNCH</td>
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</table>

**Afternoon Objective / Focus**

To develop a plan for, and discuss the feasibility of, a future catalyst grant proposal focused on the implementation and evaluation of a CDSM intervention for adults living with HIV.

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker/Location</th>
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</thead>
<tbody>
<tr>
<td>11:15-13:00</td>
<td>Welcome Back</td>
<td>Richard Harding</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation Dimensions in PROMS for HIV &amp; Self-management Strategies – a systematic review</td>
<td>King’s College London, United Kingdom</td>
</tr>
<tr>
<td>13:00-2:00</td>
<td>Break Out Session - Where are we at and where do we want to go?</td>
<td>All</td>
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<tr>
<td></td>
<td>Moving Forward Establishing a Catalyst Grant Proposal – Getting down to the details - Feasibility, Scope, Sites and Next Steps (Rapporteur Reporting Back)</td>
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<tr>
<td>2:00-3:15</td>
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<tr>
<td>3:15-4:00</td>
<td>Break</td>
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<tr>
<td>4:00-5:00</td>
<td>Report Back on Moving Forward and Next Steps</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td>Wrap-Up &amp; Evaluation</td>
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</tbody>
</table>
Appendix B: Special Plenary Session Agenda
Advancing HIV, Aging and Rehabilitation: Where Does Rehabilitation Fit in the HIV Care Cascade?

Session Title: Advancing HIV, Aging and Rehabilitation: Where Does Rehabilitation Fit in the HIV Care Cascade?

Session Moderator: Ms. Kate Murzin, Health Programs Specialist, Realize

Panel Presenters:
Mr. Larry Baxter, Community Member Living with HIV since 1992, Halifax NS
Mr. Matthew Halse, Executive Director, ACCM, Montreal, QC
Dr. Colm Bergin, Consultant Physician in Infectious Diseases, St. James’s Hospital, Dublin, Ireland
Dr. Julian Falutz, Comprehensive HIV & Aging Initiative (CHAI), McGill University Health Centre, Montreal, QC
Ms. Esther McDonnell, Occupational Therapist, Chelsea and Westminster Hospital, London, UK
Dr. Kelly O’Brien, Assistant Professor, Department of Physical Therapy, University of Toronto, Toronto, ON

Session Description:
Panelists will examine the role of rehabilitation in the context of HIV, aging and multi-morbidity. Discussion will focus on how rehabilitation may contribute to better outcomes across the treatment cascade.

Learning Objectives:
1. To reflect on the role and emerging evidence for rehabilitation in the context of HIV across both the life course and the HIV care cascade.
2. To facilitate knowledge transfer and exchange on HIV, aging and rehabilitation research.
3. To highlight examples of rehabilitation in practice for people aging with HIV.

Attendance: This session is open to all CAHR 2017 participants.

Session Hosts: This session is hosted by Canadian Association for HIV Research (CAHR), Canada-International HIV and Rehabilitation Research Collaborative (CIHRRRC) and Realize (formerly the Canadian Working Group on HIV and Rehabilitation)

Funding: This session is funded by the Canadian Institutes of Health Research

Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation 21

Date last revised: June 29, 2017
## SPECIAL SESSION AGENDA

**Advancing HIV, Aging and Rehabilitation: Where Does Rehabilitation Fit in the HIV Care Cascade?**

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speakers</th>
</tr>
</thead>
<tbody>
<tr>
<td>5:00-5:15</td>
<td>Welcome and Introductions</td>
<td>Kate Murzin (Moderator), Realize</td>
</tr>
<tr>
<td></td>
<td>- Overview of Agenda</td>
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<td></td>
<td>- Overview of Realize (formerly CWGHR) &amp; the HIV and Aging Initiative</td>
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<td></td>
<td>- Introduction to Canada-International HIV and Rehabilitation</td>
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<td>- Quick review of the HIV treatment cascade</td>
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<td></td>
<td>- Overview of the policy context in Canada, UK and Ireland</td>
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<tr>
<td>5:15-6:20</td>
<td>Panel Session: Where does rehabilitation fit in the HIV treatment cascade and what does this mean for people aging with HIV?</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<tr>
<td></td>
<td>What are the rehabilitation needs of people aging with HIV and how are these needs being met?</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>- High level findings of the HIV, Health and Rehabilitation Survey (HHRS)</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>- Health issues commonly experienced by people aging with HIV and what rehab services can do to address these</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>- Proportion of people accessing rehabilitation services and community-based HIV organizations</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>- Access to rehabilitation issues and the resulting need for novel community-based rehabilitation programming</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td>- Example: Community-based exercise project, in partnership with YMCA</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>What does it mean to be ‘engaged’ in care and treatment’?</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td>- People living with HIV long-term may not demonstrate an interest in collaboration with providers to manage their health</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>- Lack of awareness of available rehabilitation services and supports</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
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<td></td>
<td>- Conflicts between policy and goals of rehabilitation, for example, people wanting to return to the work force and/or volunteer, but being unable to do so because they will become ineligible for income supports they rely on</td>
<td>Matthew Halse, AIDS Community Care Montreal</td>
</tr>
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<td></td>
<td>What is ‘HIV care’? Rehabilitation services as the bridge between medical care and social supports</td>
<td>Larry Baxter, Community Member, Halifax</td>
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<td></td>
<td>- Not everyone living with HIV is capable/willing to be an enthusiastic self manager – what is the role of people aging with HIV?</td>
<td>Larry Baxter, Community Member, Halifax</td>
</tr>
<tr>
<td></td>
<td>- People may be willing to engage with rehabilitation providers, even if they are not interested in engaging with community-based HIV orgs</td>
<td>Larry Baxter, Community Member, Halifax</td>
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<tr>
<td></td>
<td>- Rehabilitation professionals can support people in working through homelessness, poverty, stigma – things that are not normally dealt with in the medical system, but have implications for retention in care</td>
<td>Larry Baxter, Community Member, Halifax</td>
</tr>
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<td></td>
<td>- Example: Halifax street health and methadone programs (involving OT)</td>
<td>Larry Baxter, Community Member, Halifax</td>
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</tbody>
</table>
## HIV Treatment and Care Goes Beyond Viral Suppression
- What are the geriatric syndromes that older people are facing today which are particularly amenable to rehabilitation
- Using geriatric medicine and rehabilitation approaches in HIV and aging care to address multi-system issues like frailty

## Beyond the Cascade: What happens after the final “90”?  
- The role of rehabilitation in maximizing function, promoting engagement in chosen activities, ensuring one can live safely in community setting but access limitations due to age-related eligibility criteria
- Palliative rehabilitation in the context of virologic failure and/or end-of-life with HIV and other comorbidities
- Quality of life low on the priority list in terms of UK health policy; cuts to rehabilitation funding/underfunding of the NHS

## How do HIV care and the cascade need to change?  
- Social Integration Health: Examining a model of care for people living with HIV in Dublin that goes beyond medical management and viral load monitoring
- Better ways of engaging people living with HIV in self management, for example, the “concierge of health” portal
- Lack of national data available to track progress toward 90-90-90 goals
- The need to integrate research across silos (comorbidities, quality of life, treatment outcomes)

## Panelist Discussion:  
- What role, if any, does rehabilitation play across the life course in terms of:  
  - HIV prevention?  
  - HIV testing?  
  - Linkage to care?  
  - Treatment adherence?  
  - Sustained viral load suppression?  
- Do we have research evidence to show that rehabilitation increases engagement in clinical HIV care? If not, why not? Are we working to fill this knowledge gap?  
- What is the role of rehabilitation once viral suppression is not possible? How can rehabilitation contribute to end-of-life care for people with HIV?  
- If policy makers measure programmatic success based on the HIV treatment cascade, how does this influence access to rehabilitation services for people living with HIV?  
- What is a realistic goal to aim for in the Canadian context, UK context, and Irish context for access to rehabilitation for people aging with HIV?  
- Do we need a rehabilitation cascade, or a quality of life cascade, or a disability cascade to measure our progress against?
Could existing clinical models for rehabilitation for people with HIV be applied in new contexts?
What might be some innovative models that could be used to enhance rehabilitation assessment, treatment and care for people with HIV?
How do we reconcile individual goals of care for people aging with HIV with the population health approach of the treatment cascade? Does rehabilitation have a role on both sides?

*Opportunity for interaction among panelists with the broader audience*

<table>
<thead>
<tr>
<th>6:20 – 6:30</th>
<th>Wrap-Up, Conclusions, Take Home Messages</th>
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<tbody>
<tr>
<td></td>
<td>• Highlight evidence-based resources for HIV, aging and rehabilitation</td>
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<tr>
<td></td>
<td>• Evidence-Informed Recommendations for Older Adults with HIV</td>
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<td></td>
<td>• Realize E-module</td>
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</tbody>
</table>

Kate Murzin (Moderator), Realize

Acknowledgements
Appendix C: Meeting Evaluation Questionnaire

Self-Management Interventions in HIV Rehabilitation - Addressing Research Priorities in HIV, Aging and Rehabilitation

Thursday April 6th, 2017, 830am-4pm, Montreal, Quebec

HÔTEL BONAVENTURE MONTRÉAL

Thank you for taking the time to complete our Meeting Evaluation. We encourage you to complete this form with honesty and with confidence that the results are anonymous and confidential. We use evaluations to inform the ongoing development of CIHRRC and Realize, and LHIV team activities and initiatives.

1. Which stakeholder groups do you represent/identify with? (please select the one you MOST identify with as your stakeholder group)

- Person Living with HIV (Please specify):
- Clinician (Please specify your discipline):
- Educator
- Academic (i.e. Located in an Academic Institution)
- Service Provider
- Researcher
- Policy Maker
- Volunteer
- Funder
- Student / Trainee (Please specify your discipline):
- Other (Please specify):

2. Where do you live? (city, country) __________________________

3. What type of setting do you work in? (check the one that best applies)

- Hospital
- University / Academic Institution
- Knowledge Broker/ Translation Organization
- Research Organization
- Community-Based Organization
- Community Health Centre
- Government Organization
- Other (please specify) _______________

4. What are the three most important “take-home messages” that you heard at the Meeting?

a) _____________________________________________________________________________

b) _____________________________________________________________________________

c) _____________________________________________________________________________

Living Longer, Living Well: Advancing Research Priorities in HIV, Aging and Rehabilitation

Date last revised: June 29, 2017
5. Please rate on a scale of 1 to 5, how much you agree with the following statements.

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) The meeting achieved its goal of planning for future self-management initiatives in the context of HIV, aging, and rehabilitation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b) I made new contacts which will be helpful in my everyday work.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c) The presenters were knowledgeable and communicated their ideas clearly.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d) It was useful to learn about the rehabilitation research and programming carried out in other countries.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e) There was adequate time allocated for informal discussion amongst meeting participants.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>f) My needs were accommodated (if applicable).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</table>

Comments?

6. To what degree have you gained new and relevant knowledge/insight in each of the content areas listed below?

<table>
<thead>
<tr>
<th>Little to None</th>
<th>Limited</th>
<th>Somewhat</th>
<th>Considerable</th>
<th>Extensive</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Chronic disease self-management interventions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>b) Living with the complexity of HIV and multi-morbidity</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>c) Strategies for aging successfully with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>d) Access to rehabilitation for people living with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>e) The role of rehabilitation for people with HIV</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
7. Will you be able to apply the content covered in the meeting to your work? (circle one)  
Yes  
No  
7a) If yes, how so? If not, please explain.

8. What were some strengths of the meeting (if any)?

9. What were some limitations of the meeting (if any)?

10. Do you have any recommendations for improving the meeting content or structure?

11. Are there topics or issues that were raised today that you would like to see covered in future CIHRRC or Realize meetings, Forums, workshops, or webinars?

12. Do you have any other comments, recommendations or reflections?

   Thank You for your Feedback!