



Advancing Research and Practice in HIV and Rehabilitation: International Forum on HIV and Rehabilitation Research

Final Report

June 13-14th, 2013

Li Ka Shing Knowledge Institute, St. Michael's Hospital
Toronto, Ontario, Canada



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CIHR Dissemination Grant Team

Kelly O'Brien (Principal Applicant- University of Toronto)
Francisco Ibáñez-Carrasco (Principal Co-Applicant- Ontario HIV Treatment Network)
Elisse Zack (Principal Knowledge User- Canadian Working Group on HIV and Rehabilitation)
Catherine Worthington (Co-Applicant-University of Victoria)
Patty Solomon (Co-Applicant- McMaster University)
Richard Harding (Co-Applicant-King's College, London)
Jacqueline Gahagan (Co-Applicant-Dalhousie University)
Brenda Merritt (Co-Applicant-Dalhousie University)
Larry Baxter (Knowledge User- Canadian Working Group on HIV and Rehabilitation)
Rosalind Baltzer-Turje (Knowledge User-Dr. Peter AIDS Foundation)
Will Chegwiddden (Knowledge User- National Hospital for Neurology and Neurosurgery University College Hospitals London NHS)
Patriic Gayle (Knowledge User- Canada United Kingdom HIV and Rehabilitation Research Collaborative)
Tara Carnochan (Collaborator- Nine Circles Community Health Centre)
Soo Chan Carusone (Collaborator-Casey House)
Murray Jose (Collaborator- Toronto People with AIDS Foundation)

Student Rapporteurs

Allana Beavis (University of Toronto)
Duncan MacLachlan (University Without Walls)
Lydia Makoroka (University Without Walls)
Nathan Lachowsky (University Without Walls)
Charles Furlotte (University Without Walls)
Saipriya Vajravelu (McMaster University)

Core Planning Committee

Kelly O'Brien (University of Toronto)
Francisco Ibáñez -Carrasco (Ontario HIV Treatment Network)
Le-Ann Dolan (Canadian Working Group on HIV and Rehabilitation)
Janet London (Canadian Working Group on HIV and Rehabilitation)
Nkem Iku (University of Toronto)

Forum Filming and Media Team

Patriic Gayle (Canada-United Kingdom (UK) HIV and Rehabilitation Research Collaborative)
Ryan Kerr (Ontario HIV Treatment Network)
Mitch Harris (Ontario HIV Treatment Network)
Janet London (Canadian Working Group on HIV and Rehabilitation)

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EXECUTIVE SUMMARY

The Canadian-UK HIV and Rehabilitation Research Collaborative (CUHRRC), in partnership with the Canadian Working Group on HIV and Rehabilitation (CWGHR), hosted the *International Forum on HIV and Rehabilitation Research*, on June 13-14th, 2013 in Toronto, Ontario, Canada. The goal of the Forum was to translate research evidence on HIV and rehabilitation among people living with HIV, researchers, clinicians, representatives of community organizations, and policy makers in Canada and internationally. The Forum brought together a range of stakeholders to exchange research evidence related to six research priorities in HIV, disability and rehabilitation established by CWGHR in a national scoping study in 2008. This report provides an overview of the *International Forum on HIV and Rehabilitation Research* and our process of reviewing and updating new and emerging priorities in HIV, disability, and rehabilitation research.

The Forum was organized into six research evidence panel sessions with speakers from Canada, the United Kingdom (UK), United States (US), and Ireland addressing issues related to: 1) disability and episodic disability; 2) aging with HIV, concurrent health conditions; 3) HIV and the brain; 4) labour force and income support issues; 5) access to and effect of rehabilitation; and 6) measurement and tools. Structured discussions and Q&A segments enabled participation throughout the 2-day agenda and a facilitator was in place to engage attendees while adhering to the agenda. Please view the electronic Forum Workbook: <http://bit.ly/12fDEha>, for more details. To access the Forum films and slide presentations, please go to the Forum Knowledge Translation and Exchange (KTE) Library: <http://www.hivandrehab.ca/EN/AGM2013/>

The Forum provided an opportunity for a broad range of stakeholders to respond to current research evidence and engage in a process of reviewing and updating the research priorities to better reflect new and emerging issues related to HIV and rehabilitation. The goal of updating the priorities was announced throughout promotion and initiation of the Forum; participants were aware that their discussion and feedback over the two days would inform a renewed or revised set of research priorities. Comments, ideas and recommendations related to the priority areas were documented through five mechanisms including: speakers' notes, Forum workbook, rapporteur notes, post-it notes, and evaluation forms. Documentation was analyzed to identify a series of new research priorities in HIV, disability and rehabilitation.

Development of a *Framework of New Research Priorities in HIV, Disability and Rehabilitation* is currently underway. Our aim is that this Framework may be used to outline a future plan for HIV, disability and rehabilitation research, at all stages of the research process, that will help increase our knowledge to enhance practice, programming and policy for people living with HIV.

Evaluation of the Forum indicated that both the content and structure of the Forum offered opportunities to reflect, connect and collaborate on issues related to HIV and rehabilitation. Speakers and participants represented a broad range of interdisciplinary and international stakeholders. Participants were able to make useful connections with other relevant stakeholders, and that learning

about rehabilitation programs and models in different countries was valuable. Nevertheless, the Forum required a great deal of organization and planning, as well as some logistical challenges related to scheduling large international teleconferences. The Forum agenda was ambitious with 24 presentations covering an immense amount of information. Important methodological lessons were learned in the process of planning, promoting and implementing an International Forum with such a diversity of researchers, intersectoral and interdisciplinary perspectives that may be of help to future organizers of similar events.

BACKGROUND

HIV is increasingly experienced as a complex and lifelong chronic illness. In Canada, the number of people living with HIV continues to rise, from an estimated 64,000 in 2008 to 71,300 in 2011 (an 11.4% increase) (Public Health Agency of Canada, 2012). Improvements in treatment have meant people are living longer with the disease. With optimum treatment, the life expectancy of people living with HIV may approach that of uninfected populations (Deeks et al. 2013). However, despite these improvements, HIV-positive individuals may experience a range of physical, cognitive, mental and social health-related challenges associated with HIV, which together may be termed, **disability** (Rusch, 2004, O'Brien 2010). The adverse effects of antiretroviral therapy, comorbidities, and aging, as well as challenges related to the social determinants of health, may further add complexity to the disability experienced by people living with HIV.

Canadian Working Group on HIV and Rehabilitation

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is a national charitable organization that works to improve rehabilitation services for people living with HIV and related conditions through integrated research, education, policy, and practice. CWGHR defines **rehabilitation** broadly, as any service or activity that addresses or prevents impairments, activity limitations and participation restrictions experienced by an individual (Worthington et al. 2005).

Key Research Priorities in HIV and Rehabilitation

In 2006, CWGHR began a scoping study to identify key research priorities related to HIV and rehabilitation to inform and enhance practice, programming and policy for people living with HIV. This work was carried out in two steps: the first was a comprehensive literature review of HIV and rehabilitation evidence in published and grey literature, and the second included a series of consultations where stakeholders reviewed preliminary findings from the literature review and provided insight on the emerging priorities in HIV and rehabilitation. Stakeholders included people living with HIV, researchers, clinicians, and policy makers with expertise in HIV and rehabilitation in Canada and the UK. Since 2008, the following six identified research priorities have guided CWGHR's work, forming an international research agenda for HIV and rehabilitation research:

- Disability and episodic disability
- Concurrent health conditions, aging with HIV
- HIV and the brain
- Labour force participation and income support
- Access to and effectiveness of rehabilitation
- Development and evaluation of outcome measurement tools

Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC)

In October 2009, a group of UK and Canadian researchers and clinicians, in partnership with CWGHR, obtained funding from the CIHR Meetings Planning and Dissemination Grants competition to conduct a research meeting in London, UK (Chegwidden 2009). 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. Membership includes people living with HIV, researchers, clinicians, representatives from community organizations and policy stakeholders in Canada and the UK with an interest in HIV and rehabilitation research (<http://cuhrrc.hivandrehab.ca/>; O'Brien et al. 2011). CUHRRC is now comprised of over 40 members who meet quarterly by teleconference to share knowledge and collaborate on research initiatives. CUHRRC members have collectively pursued initiatives in each of the research priority areas, such as: exploring the prevalence of comorbidities, disability and rehabilitation service use among people living with HIV in Canada; conducting a policy analysis of rehabilitation services access between Canada and the UK; evaluating the uptake of an electronic e-module for rehabilitation professionals on HIV; developing evidence-informed practice recommendations on the rehabilitation of older adults with HIV; and developing and assessing the measurement properties of a new HIV disability questionnaire. While CUHRRC and CWGHR have made significant headway in addressing the key research priorities in HIV and rehabilitation, this work had yet to be translated beyond the scientific research community.

CUHRRC, in partnership with CWGHR, planned and hosted the *International Forum on HIV and Rehabilitation Research*, on June 13-14th, 2013 in Toronto, Ontario, Canada. The Forum brought together a range of stakeholders to share current research evidence related to the six priority areas. The Forum also offered an opportunity to review and update the research priorities to respond to new and emerging issue related to HIV and rehabilitation. This report provides an overview of the International Forum on HIV and Rehabilitation Research, our process of reviewing and updating the research priorities, and our lessons learned throughout the planning and implementation of the international research event.

INTERNATIONAL FORUM ON HIV AND REHABILITATION RESEARCH

The goal of the Forum was to translate research evidence knowledge on HIV and rehabilitation generated through the CUHRRRC, CWGHR, and other partners among people living with HIV, researchers, clinicians, representatives of community organizations, and policy makers in Canada, United Kingdom, United States, and Ireland.

Specific Forum objectives were:

- 1) To disseminate current research evidence on HIV and rehabilitation in each of six key research priorities in HIV and rehabilitation identified by CWGHR in the national scoping study;
- 2) To promote knowledge translation and exchange of HIV and rehabilitation research among people living with HIV, researchers, clinicians, community organizations and policy makers that will inform future programs, clinical practice, policy, and rehabilitation service delivery;
- 3) To foster new research and clinical partnerships in HIV and rehabilitation between Canada, UK, United States, and Ireland;
- 4) To develop knowledge translation and exchange (KTE) materials including a detailed report and fact sheet summarizing the research evidence translated at the Forum, and a video library of Forum speaker sessions.
- 5) To update key priorities in HIV and rehabilitation research and develop a research bank of potential future research ideas.

PLANNING AND DEVELOPMENT

The International Forum on HIV and Rehabilitation Research was supported by a Dissemination Grant from the Canadian Institutes of Health Research (CIHR), HIV/AIDS Research Initiative, the Public Health Agency of Canada, The Ontario HIV Treatment Network and the University of Toronto. The Forum involved an intensive year-long process of planning and development leading up to the event. Upon receiving notification of funding, members of the CUHRRRC Steering Committee met via teleconference in August 2012. The purpose of this meeting was to strategize an approach for the Forum, specifically on how to coordinate the Forum with the CWGHR Annual General Meeting (AGM), CWGHR Annual Award of Excellence and 15th Anniversary Celebration.

Forum Core Planning Committee

In October 2012, a Core Planning Committee was formed which included co-principal investigators of the CIHR Dissemination Grant, CWGHR and CUHRRRC members, and CWHGR staff. The purpose of the Core Planning Committee was to oversee the planning and implementation of the Forum. This Committee met seven times leading up to the Forum to discuss advancements made in the planning of the Forum. Specific activities included: developing a timeline for the Forum, confirming a venue, advertising the Forum, finalizing and distributing participant invitations, establishing opportunities

and implementation plan for student rapporteurs, finalizing the Forum program agenda and interactive workbook, liaising with Forum speakers to meet their needs pertaining to the Forum, developing an evaluation plan, and developing a knowledge transfer and exchange strategy post Forum. Electronic updates were provided to the broader CIHR Dissemination Grant team. In November 2012, the Core Planning Committee met with the CIHR Dissemination Grant Team via teleconference. The meeting goal was to review the overall plan for the Forum and update on initial collaborations with CWGHR in planning this event in conjunction with the CWGHR AGM, and the CWGHR Award of Excellence and 15th Anniversary Celebration.

Invitations and Advertisement of the Forum

The Core Planning Committee in consultation with the CIHR Dissemination Grant Team developed a list of invitees which included, people living with HIV, clinicians, academics, representatives from AIDS Service Organizations (ASOs) and Community-Based Organizations (CBOs) and community members, CWGHR and CUHRRC members, representatives from the HIV National Partners, and representatives from funding organizations. Personal invitations were distributed in February 2012, and invitees were given the opportunity to apply for a subsidy to aid with travel, hotel and/or meal costs while attending the Forum up to April 1st, 2013.

The Forum was further broadly advertised by circulating an E-Blast announcement to the CWGHR, CUHRRC and OHTN membership (French and English) in February 2013. Forum posters and the Forum program at a glance also were displayed at St. Michael's Hospital HIV Rounds, the World Confederation for Physical Therapy (WCPT) website, Canadian Association for HIV Research (CAHR) Spring 2013 newsletter, and in the Department of Physical Therapy, PT Link Newsletter and through posters and PowerPoint advertisements in the 500 University Avenue lobby (University of Toronto).

Invited Speakers and Rapporteurs

Twenty-three researchers, clinicians and community members engaged in the field of HIV, disability and rehabilitation were invited and presented in one of two (2) Plenary and six (6) Research Priority Sessions. Six (6) post-graduate students were invited from the CIHR-funded Universities Without Walls (UWW) program, McMaster University and the University of Toronto to rapporteur the discussion points raised from the research evidence panel session presentations and KTE round table sessions. The Forum registration fee was waived for all speakers and student rapporteurs. Travel and accommodation were provided for speakers as able with funding through the CIHR Dissemination Grant and by partnering the Forum with CWGHR's AGM. Student rapporteurs living outside Toronto were reimbursed for their travel and accommodation expenses.

Forum Workbook

The Core Planning Committee developed a Forum Workbook which contained the title of each speaker's presentation, key messages and publications related to their presentation and work, and their biographies. The Forum workbook also contained two open ended questions asking participants what they thought were 1) new and emerging issues in the field of HIV, disability and rehabilitation

and 2) key research priorities in this area of HIV, disability and rehabilitation essential for moving the field forward. The purpose of the workbook was to give participants the opportunity to familiarize themselves with the work of the speakers, and also prepare them to be involved in discussions held during the Forum. In February 2013, invited speakers were asked to submit these details pertaining to their presentations. The final Forum workbook was available in English and French in hard copy at the Forum. An electronic copy of the Forum workbook in both languages was made available online on a Google Plus folder one week prior to the Forum. Click here to access the electronic Forum Workbook: <http://bit.ly/12fDEha>.

Pre-Forum Planning Teleconferences

Three pre-Forum teleconferences were coordinated for the invited speakers, two for each of the Plenary sessions and one for all six Research Evidence Panel sessions in May 2013. The purpose of these teleconferences was to provide an opportunity for speakers to familiarize themselves with the topics and speakers in their sessions and to review logistics leading up to the Forum. A student rapporteur meeting was conducted via Skype to review the overall goal of the Forum, and to discuss the roles and activities as a student rapporteur at the Forum.

Forum Filming and Media Team

A Forum Filming and Media Team was assembled by the Core Planning Committee in April 2013. The purpose of this team was to enhance the knowledge translation and exchange of the evidence presented at the Forum. The Team created an online folder using Google Plus to house an electronic version of an interactive Forum workbook that included the student rapporteur notes, and provided the opportunity for participants to engage in an online discussion prior to, during and post forum.

The team also implemented a social media strategy during the Forum via Twitter:

#hivandrehabforumto. To access the Twitter feed from the Forum go to:

<https://twitter.com/search?q=%23hivandrehabforumto&src=savs>.

The Filming and Media Team was also responsible for filming the Forum sessions. The films were edited and uploaded onto the CWGHR website as part of the Forum Knowledge Translation and Exchange (KTE) Library for further dissemination of research knowledge on HIV, rehabilitation and disability. The Forum Filming and Media Team met two times with the Core Planning Committee via teleconference leading up to the Forum to discuss the development of the online Forum Workbook and strategic planning of capturing the Forum on film. Click on this link to access the current KTE Library development in progress: <http://www.hivandrehab.ca/EN/AGM2013/index.php>.

Post-Forum Teleconference

The Core Planning Committee held a final teleconference following the Forum in June 2013. The purpose of the meeting was to debrief on the overall Forum, and address post Forum activities such as distributing thank you letters, Forum evaluation, and establishing a knowledge transfer plan, including the KTE library.

FORUM OVERVIEW

The two-day Forum held on June 13-14th, 2013 was organized into two plenary sessions and six Research Evidence Panel Sessions, each focused on one of the research priorities. Each panel included 2 to 5 speakers, presenting on research or program evaluation carried out in Canada, UK, Ireland, or the US followed by a question and answer period and group discussion. Participants discussed the implications of presented material for clinical practice, education, policy and research, as well as the cross-applicability of research and practice internationally. Panel sessions were filmed and uploaded into the CWGHR-CUHRRC Knowledge Translation and Exchange (KTE) Library for those unable to attend the Forum, with the aim of broadening the reach of the Forum.

The Forum included a moderator who facilitated question and answer sessions and table discussions over the course of the two days. Six volunteer student rapporteurs took notes during the presentations, which were simultaneously posted online. CWGHR's 15th Anniversary Celebration and Annual General Meeting were hosted in conjunction with the Forum.

Discussion was encouraged through Q&A, table discussions, as well as large group discussions. The Forum included a number of features to enhance knowledge transfer and exchange. Participants were provided an electronic and hard copy workbook which included key messages and relevant publications from each presentation, and provided a space to take notes. In addition to note taking during presentations, rapporteurs also captured table discussions and the Q&A sessions that followed each panel. Participants were also encouraged to capture their thoughts and questions on post-it notes that were gathered at the end of each day. Post-it notes also were used during table discussions on Day One of the Forum. Participants also used Twitter throughout to further translate highlights from the Forum.

Speakers and Participants

There were 23 invited speakers at the Forum, presenting on research and programming carried out in Canada, the UK, the US and Ireland.

Ninety-two participants attended the Forum, representing a broad range of stakeholders, including: academic and community-based researchers, clinicians, representatives from frontline and community-based organizations, funders, and policy makers. Of those who provided additional information, the majority of participants indicated that they worked with organizations that support service providers (23.9%, n=21) or universities (22.7%, n=20). See Table 1 for an overview of characteristics of Forum participants.

| Table 1a: Organization Type of Forum Participants | % | n=88 |
|---|----------|-------------|
| Service Provider Organization Organizations that provide support primarily to service providers including (but not limited to) CWGHR, Canadian Physiotherapy Association, TNN? | 23.9% | 21 |
| University | 22.7% | 20 |
| Frontline Community-Based Organization | 17.0% | 15 |
| Hospital/Health care | 13.6% | 12 |
| Research/Knowledge Production Organization Organizations whose work is primarily focused on research production (may also fund research, but also produce and bring researchers together). Includes but is not limited to the OHTN, ACRIA, and CAHR | 12.5% | 11 |
| Consumer Organization Organizations focused on education, advocacy and establishing consumer rights. Includes but is not limited to, CTAC, Positive Women's Network | 5.7% | 5 |
| Funder | 3.4% | 3 |
| Policy | 1.1% | 1 |

| Table 1b. Position Type of Forum Participants | % | n=86 |
|--|----------|-------------|
| Manager/Director | 22.1% | 19 |
| Researcher | 18.6% | 16 |
| Clinician/service provider | 16.3% | 14 |
| Coordinator (research or program) | 11.6% | 10 |
| Knowledge User | 10.5% | 9 |
| Educator | 7.0% | 6 |
| Student | 7.0% | 6 |
| Other (included consultants, lawyers and media) | 7.0% | 6 |

Many of the participants attended the Forum wearing multiple hats – for instance, they worked as both educators and researchers, or as knowledge users and service providers. Of those participants who indicated their primary position, the majority attended the Forum as a manager/director (22.1%, n=19) or a researcher (18.6%, n=16).

Of those participants who indicated the location they primarily work, most were located in Canada (87%, n=79), with the majority working in Ontario; 10% (n=9) were from the UK, 2% (n=2) Ireland, and 1% (n=1) the US.

Forum Presentation Topics and Discussion

The Forum was organized into two plenary and six research evidence panel sessions. Plenary sessions provided an overview of HIV and rehabilitation research and clinical practice in Ireland, the UK, and Canada as well as specific examples of programming informed by current research evidence. Each research evidence panel session was focused on one of the six research priorities, three on each day of the Forum. Speakers were asked to present on current research studies, interventions, and/or programming content areas.

Day 1

Day one began with a plenary session with three presentations illustrating the state of research evidence related to HIV and aging in Canada, Ireland and the UK. This included presentations focused on HIV service delivery and research in Ireland, HIV and rehabilitation research and service delivery in the United Kingdom, and neurocognitive screening and behavioural interventions for HIV-associated neurocognitive disorders.

The first research evidence panel session following the plenary focused on ***disability and episodic disability*** and included two presentations aimed at understanding disability as experienced by people living with HIV. The first presentation provided an overview of the *HIV, Health and Rehabilitation Survey*, a survey instrument developed to establish a profile of comorbidities, disability, rehabilitation service use, and living strategies of adults living with HIV in Canada. The second presentation provided an overview of programming and patients who access the HIV rehabilitation clinic at the Royal London Hospital, in the UK.

The second research evidence panel session focused on ***concurrent health conditions, aging with HIV***. This panel included a presentation on the contribution of uncertainty in the lives of older people living with HIV, drawing from a qualitative study carried out in Canada. A second presentation shared findings from a knowledge synthesis project of evidence-informed recommendations in rehabilitation for older adults. A third presentation provided an overview of findings related to an environmental scan of in-process research activities in Canada related to health, HIV and aging.

The final research evidence panel session on day one was focused on ***HIV and the brain***. The three presentations in this panel all focused on clinical practice or programming. The first presentation

focused on the use of assessment scales for HIV associated neurocognitive disorder (HAND) as part of the Annual Health Check program at Heartland Hospital in the UK. A second presentation introduced the Assessment of Motor and Process Skills (AMPS) to help detect the presence of HAND and differentiate between severity levels. A third presentation provided an overview of findings from a Canadian needs assessment survey of service providers who work with people living with HIV related to their support and training needs in mental health.

Day 2

Day two began with a plenary session with four presentations illustrating the implementation of research into practice. This included a presentation focused on aging and HIV and the role of rehabilitation in retention to care and adherence to medication, and a study of self-screening of STIs as a method of reducing barriers and improving the sexual health care. A third presentation focused on a supervised group exercise class offered in the UK, and the fourth presentation focused on the development of a clinical tool, the HIV Clinical Checklist, to assist practitioners in assessing broad needs related to HIV as a chronic and episodic condition.

Research evidence panel session four focused on research related to **labour force participation and income supports**. There were three Canadian presentations in this panel. The first presentation focused on findings from the *Employment Change and Health Outcome* (ECHO) study. A second presentation provided an overview of the development of the *HIV and Employment Framework*, which included online and print resources for people and organizations engaged in employment work with people living with HIV. The final presentation shared CWGHR's recent work developing a business case for employers to hire people living with episodic disabilities

Presentations in research evidence panel session five focused on **access to and effectiveness of rehabilitation**. The first presentation shared experiences with a 10-week exercise program at St. Thomas Hospital, London, UK. The second presentation focused on the development of a day health program in Toronto, as a means of responding to the health care needs of medically complex patients. The third presentation looked at the uptake of the CWGHR's e-module of evidence-informed HIV rehabilitation. The fourth presentation provided an overview of an HIV primary care facility in Winnipeg that includes Occupational Therapists as part of the health care team. The final presentation in this panel provided a review of Canadian policy related to aging, HIV and rehabilitation.

The sixth research evidence panel session focused on **HIV measurement tools**. This panel included two presentations, one focused on Patient Reported Outcome Measures (PROMS), and the second focused on the new HIV Disability Questionnaire (HDQ).

To access the Forum Speakers' presentation slides go to

<http://www.hivandrehab.ca/EN/AGM2013/index.php>. To view the discussion points captured during the Forum, access the rapporteur notes through the electronic workbook: <http://bit.ly/12fDEha>.

International Forum on Rehabilitation Research Agenda (June 2013)

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|---|
| Day 1 – Thursday June 13, 2013 |
| Welcome and Official Opening to the Forum and CWGHR's 15th Anniversary Celebration Greg Robinson (Canadian Working Group on HIV and Rehabilitation) |
| Setting the Context: Why Canada, United Kingdom and Ireland? Francisco Ibáñez-Carrasco (Ontario HIV Treatment Network (OHTN)) |
| Overview of CWGHR and Key Research Priorities in HIV and Rehabilitation Elisse Zack (Canadian Working Group on HIV and Rehabilitation) |
| Goal of Forum and Overview of CUHRRC Kelly O'Brien (University of Toronto) |
| Plenary Session - HIV and Aging: State of the Evidence in Canada, UK, and Ireland - Advancing the Field of HIV, Aging and Neurocognitive Rehabilitation <u>Keynote Speakers:</u> Colm Bergin (St. James's Hospital, Dublin, Ireland) Simon Rackstraw (Mildmay Mission Hospital, London, England) & Will Chegwiddden (National Hospital for Neurology and Neurosurgery University College Hospitals London NHS, London, England) Sean Rourke (OHTN, St. Michael's Hospital, University of Toronto, Toronto, Canada) |
| Research Evidence Panel Session 1 – Disability and Episodic Disability <ul style="list-style-type: none">Establishing a Profile of Disability and Rehabilitation Services Use Among People Living with HIV in Canada: Lessons Learned from Piloting the HIV, Health and Rehabilitation Survey (HHRS)Disability experienced by people living with HIV attending a rehabilitation clinic in the UK <u>Speakers:</u> Stephanie Nixon (University of Toronto, Toronto, Canada) Will Chegwiddden (National Hospital for Neurology and Neurosurgery University College Hospitals London NHS, London, England) |
| Research Evidence Panel Session 2 – Concurrent Health Conditions Aging with HIV <ul style="list-style-type: none">HIV and Aging – Experiences of disability among older adults living with HIVEvidence-Informed recommendations for rehabilitation for older adults with HIVHIV and Aging (CWGHR)– Environmental Scan of research on HIV and aging (HIV and Aging sector) <u>Speakers:</u> Patty Solomon (McMaster University, Hamilton, Canada) Larry Baxter (CWGHR, Halifax, Canada) Glenn Betteridge (CWGHR, Toronto, Canada) |
| Research Evidence Panel Session 3 – HIV and the Brain <ul style="list-style-type: none">Functional Impact of HIV Associated Neurocognitive Disorder and strategies for rehabilitationUsing a measure of everyday performance to assess the presence and severity of HIV associated neurocognitive disordersPositive Outlook: A Needs Assessment of Front-line Care Providers Working With People Living With HIV and Depression <u>Speakers:</u> Elizabeth Stevens (Heartland Hospital, Birmingham, England) Brenda Merritt (Dalhousie University, Halifax, Canada) Le-Ann Dolan (CWGHR, Toronto, Canada) |
| Knowledge Transfer Exchange (KTE) Round Table Break Out Sessions |

Day 2 – Friday June 14, 2013

Plenary Session—Implementing HIV and Rehabilitation Research into Practice

Keynote Speakers:

Stephen Karpiak (AIDS Community Research Initiative of America (ACRIA), New York, USA)

Siobhan O’Dea (St. James’s Hospital, Dublin, Ireland)

Darren Brown (Chelsea and Westminster Hospital, London, England)

Gordon Arbess (St. Michael’s Hospital, Toronto, Canada)

Facilitator:

Patty Solomon (McMaster University)

Research Evidence Panel Session 4 – Labour Force and Income Support

- Employment status, job quality and health in people with HIV: The Employment Change and Health Outcomes (ECHO) study¹
- ‘Getting to Work’ – Creating Evidence-Informed Learning Tools to Enhance Labour Force Participation Options for PHAs in Canada²
- Different But Equal – Enhancing Labour Force Participation for People Living with Episodic Disabilities – an update on CWGHR’s research on employment and episodic illness

Speakers:

Sergio Rueda (OHTN, Toronto, Canada)¹

Tammy Yates (CWGHR, Toronto, Canada)

Research Evidence Panel Session 5 – Access to and Effect of Rehabilitation

- Exercise and Adherence in People Living with HIV in the UK
- Living with HIV: Designing and evaluating the new Casey House Day Health Program
- An Innovative Rehabilitation Health Care Delivery Model – Accessing Rehabilitation for people living with HIV/AIDS (PHAs)
- Evaluating the uptake of an electronic e-module for rehabilitation professionals on HIV
- What’s Policy Got To Do With It?: An Exploration of HIV Rehabilitation Policy Approaches in Canada and the UK

Speakers:

Rebecca Mullin (St Thomas' Hospital, London, England)

Soo Chan Carusone (Casey House, Toronto, Canada)

Tara Carnochan (Nine Circles Community Health Centre, Winnipeg, Canada)

Nancy Salbach (University of Toronto, Toronto, Canada)

Jacqueline Gahagan (Dalhousie University, Halifax, Canada)

Research Evidence Panel Session 6 – HIV Measurement Tools

- Patient-reported outcome measures in HIV care: What Matters Now?
- Developing and assessing the measurement properties of the new HIV Disability Questionnaire (HDQ) with adults living with HIV

Speakers:

Richard Harding (King’s College London, London, England)

Kelly O’Brien (University of Toronto, Toronto, Canada)

Bringing it all Together –Review of All Six Research Priorities and KTE Large Group Discussion

¹Presentations 1 and 2 in Research Evidence Panel Session 4 were presented by Sergio Rueda

ESTABLISHING NEW RESEARCH PRIORITIES IN HIV, DISABILITY, AND REHABILITATION: THE PROCESS

The Forum provided an excellent opportunity for a broad range of stakeholders to respond to current research evidence and reflect on the original six research priorities. The goal of updating the priorities was announced during the promotion and beginning of the event; participants were aware that their discussion and feedback over the two days would inform a renewed or revised set of research priorities. Comments, ideas and recommendations related to the priority areas were documented through the following five mechanisms:

1) Speakers' Notes

Before the Forum, speakers (n=23) were asked to submit answers to two questions:

- What are 2 new and emerging Issues in the field of HIV, disability and rehabilitation?
- What are 2 – 3 key research priorities in the area of HIV, disability and rehabilitation essential for moving the field forward?

Speakers notes from all speakers were collated by individual and question in an excel spreadsheet.

2) Forum Workbook (Electronic and in print)

The Forum Workbook in print included a tear-away page that for participants to provide their answers to the same two questions listed above. Although participants were encouraged throughout the Forum to fill out the page, only two responses were collected.

3) Rapporteur Notes

Six student rapporteurs took notes during the forum (2 rapporteurs per panel). Rapporteur notes were simultaneously posted online in the electronic Workbook, and included the Q&A session that accompanied each panel. Student rapporteurs also took notes during the table discussions that took place at the end of each day.

4) Post-it Notes

Participants were encouraged to write down their thoughts and questions related to the presentations and discussions throughout the two days.

5) Evaluation Form

Evaluation forms were circulated with the Forum Workbook and participants were encouraged to complete it at the end of the Forum. A link to the online evaluation form was circulated one week after the forum for those participants who were not able to complete a paper copy. Forty-three participants completed both the online and paper evaluation. Their feedback was analyzed and an evaluation report of the Forum completed in August 2013. The evaluation form included one question related to the research priorities (*Q13. In your opinion, what are 1 or 2 new and emerging issues that were not covered in the forum?*). Answers to this question were included as an information source in this process. Twenty-two participants provided answers to this question.

These different mechanisms for capturing participant feedback, ideas, and recommendations formed the primary information sources for revising and updating the research priorities. Information captured from each mechanism was formatted as a document, and reviewed and analyzed using content analytical techniques. Two reviewers read through and coded the material, developing a coding framework to capture key themes. Because the original six priorities provided the primary content of the Forum, the themes that emerged are informed by those original priorities. However, the six priorities did not provide the starting point for the coding framework – any groupings that had been used in the context of the Forum (Q&A related to specific panel presentations, post-it notes organized by research priority) were removed before the coding process began.

Recommendations for research were compiled into a ‘Research Bank of Questions on HIV, Disability and Rehabilitation’ (Appendix A). Development and refinement of the new research priorities in HIV, disability and rehabilitation is underway and will be published in the KTE Library when available.

STRENGTHS AND CHALLENGES OF PLANNING AND IMPLEMENTING THE FORUM

The evaluation of the Forum highlighted specific strengths and successes for this event. Feedback from evaluation forms indicated that the Forum was an enjoyable and useful event for participants. Respondents left positive and thoughtful comments, suggesting they were meaningfully engaged with the event goal, organizers, content, and other attendees. Evaluation indicated that both the content and structure of the Forum offered opportunities to reflect, connect and collaborate on issues related to HIV and rehabilitation, with 97.3% of evaluation respondents indicating that they would be able to apply the content from the Forum to their work. Respondents highlighted a number of event features that supported or enabled engagement and collaboration, including: the venue and food, the skillful event facilitator, table discussion, the Forum Workbook, and Rapporteur Notes.

Invited speakers and participants represented a broad range on interdisciplinary and international stakeholders. Feedback from the evaluation indicated that respondents were able to create connections with other participants. For instance, 95.2% (n=40) agreed or strongly agreed that they were able to make new contacts that will be helpful in their work, and 95.3% (n= 40) of respondents agreed or strongly agreed that it was useful to learn about the rehabilitation research and programming carried out in other countries. Feedback from open-ended questions also indicated that respondents were able to make useful connections with other relevant stakeholders, and that learning about rehabilitation programs and models in different countries was valuable (*Awesome conference, I really learned a lot and was able to network. I highly respect the work of CWGHR and think that the collaboration with UK and Ireland and Canada is great to learn, share practices, and research. Very high caliber presenters, leading edge, most appropriate.*)

The Forum required a great deal of organization and planning, as well as some logistical challenges related to scheduling large international teleconferences. The Forum agenda was ambitious with 24 presentations covering an immense amount of information. Evaluation feedback indicated that some participants felt there was too much information covered over the two days. Participants

recommended less reliance on presentations as the key method of disseminating information, suggesting that papers or summaries be circulated before the Forum, or discussants be used to pull out common themes and/or the practical or regional relevance of any presented material. Some participants also recommended including workshops or other practice-based learning tools as a means of translating research evidence, particularly in relation to assessment tools or outcome measures. Finally, although participants indicated they liked the use of social media and other online tools as a means of engaging with the Forum and its content, they also suggested the use of these tools could be enhanced. These recommendations have been reviewed and will be considered in the planning and implementation of future events.

Lessons Learned

Overall, some important methodological lessons were learned in the process of planning, promoting and implementing an International Forum with such a diversity of researchers, intersectoral and interdisciplinary perspectives that may be of help to future organizers of similar events.

- *Intersectorality in action is complex*: harmonizing the interests, strategic agendas, monies, and funder requirements of groups of persons across public and academic sectors was challenging; it is key for an organizing team to dispose of ample time and interaction space to distribute opportunities equally. Even though the Forum had a clear research objective, it had to be implemented in ways that provided community members, non-profit organizations, policy makers, students as well as researchers ample opportunities to move their agenda forward.
- *Inter-nationality and intersectorality, and interdisciplinarity imply logistical as well as methodological flexibility (in format and delivery)*. The integration of technology, the flexibility of the sessions, the extensive written and audiovisual documentation (speaker's notes, video, electronic Workbook), and some changes on-the-go required great attention to detail and cooperation between organizers. Indeed, these electronic and pedagogical tools were layered over the program grid to give the Forum greater accessibility to others and various levels of depth for different participants. The Forum was tailored so a well-established researcher could draw material for his/her current program of research and a community leader could draw key ideas for programming from the contents and proceedings of the Forum.

CONCLUSION

The need for research in HIV, disability and rehabilitation continues to increase as people live longer and age with HIV. This report summarizes the process, content and lessons learned of the first *International Forum on HIV and Rehabilitation Research*. Overall, the Forum was successful in translating research evidence, and fostering new research partnerships among stakeholders in HIV, disability and rehabilitation across Canada and internationally. A key outcome of the Forum will include the *Framework of New Research Priorities in HIV, Disability and Rehabilitation*. These priorities will serve as a future plan for HIV, disability and rehabilitation research that will help increase our knowledge to enhance practice, programming and policy for people living with HIV. Overall, a number of important lessons were learned in the planning, promoting and implementation

process for the Forum. These lessons will be particularly useful in planning future events with diverse stakeholders from HIV research, programming and policy sectors.

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APPENDIX A- RESEARCH BANK OF QUESTIONS

The following examples of research questions were derived from the discussions throughout the Forum. The questions are organized within six theme areas and are in no particular order of priority or preference.

Content Area One: Episodic Health and Disability across the Lifespan

1) Episodic Health and Disability

- What impacts adherence to HIV medication?
- How do people move from uncertainty to place of mastering (HIV and disability)?
- How is uncertainty constructed in the context of liberal notions of the individual? In this context, what does the move from uncertainty to mastery involve?
- What is the episodic nature of HIV over time?
- As realities of HIV change, what are the implications of defining HIV as a disability?
- What is the influence of extrinsic and intrinsic contextual factors, such as stigma, social supports and living strategies, as well as triggers, on dimensions of disability? What interventions can prevent or mitigate disability experienced by adults living with HIV?
- What dimensions of disability are experienced as episodic over time? What dimensions might fluctuate on a daily basis opposed to larger fluctuations in health over time?
- What are the gendered consequences of living with an episodic illness in Canada?
- How do people living with HIV understand and experience disability?
- How is disability experienced over time?
- What is the experience of living with an episodic illness?
- How can we account for differences in perception of health and disability between different populations of PHAs?:
 - Long term survivor for whom being alive is good health
 - Individuals more recently diagnosed who may place more importance on challenges long term survivors might see as minor.
- How is uncertainty experienced by people living with other chronic conditions?
- How is uncertainty experienced episodically?
- How might uncertainty and fear relate to each other as a health challenge?

Social Engagement and Employment

- What are the main predictors of return to work and job retention? What is the interplay between medical, financial/legal, psychosocial and vocational factors?
- What are the main drivers of intention to work for people with HIV?
- How does social isolation impact the health and well-being of people living with HIV?
- Does employment play a role in prevention?

2) Aging with HIV across the Lifespan

Youth

- What is the experience of living with HIV from birth, particularly in terms of neurocognitive and mental health? What assessment tools and outcome measures could be used with children living with HIV?
- What is the impact of episodic disabilities on the lives of youth 15-24 years of age in Canada?

- Children developing with HIV – how can early interventions from rehabilitation, particularly Occupational Therapy, help improve longer-term outcomes?

Older Adults

- Can we parse out or separate length of time living with HIV and chronological age in research on HIV and aging? How are these processes different?
- Does HIV and HCV co-infection further amplify or accelerate aging?
- How are issues of financial insecurity impacting the experience of aging with HIV, particularly in terms of uncertainty?
- How engaged is the larger aging infrastructure around issues of HIV and aging?
- What are the everyday functional abilities across the lifespan of persons who are living and aging with HIV?
- What is the gendered nature of ‘healthy aging’ with HIV?
- What are the qualities and attributes that contribute to successful aging in older adults living with HIV?
- What is the current state of knowledge on social participation and sexual wealth of older adults living with HIV, (with specific focus on specific sub-populations among older PHAs) including examination of strengths-based perspectives and resiliency?
- As persons age with HIV, is advanced physiological age associated with a sharper decline in daily life performance?
- What are the particular experiences of women aging with HIV?
- What HIV prevention strategies work with older adults?
- Is uncertainty diminished among older adults living with HIV compared with younger adults living with HIV? What strategies for uncertainty work?

3) Concurrent Health Conditions

Mental Health

- What are effective interventions to address mental issues for adults living with HIV?
- Can we tease out distinctions between trauma, depression, and other mental health issues for adults living with HIV?
- What are the psychological determinants of health for adults living with HIV?
- What is the relationship between trauma, post-traumatic stress disorder, isolation and HAND, within the context of living and aging with HIV?

HIV and the Brain

- What are the mechanisms/predictors of Asymptomatic Neuropsychological Impairment and Mild Neurocognitive Disorder?
- Can early identification of subclinical medical comorbidities (e.g., cardiovascular disease (CVD)) lessen/prevent development and progression of milder forms of HAND?
- What is the impact of CVD on aging and HAND?
- What are the ‘real life implications’ of neurocognitive impairment?
- How do we identify, support and rehabilitate individuals with cognitive impairment?
- How do quantitative measures of HAND match (or mismatch) with the lived experience?

Content Area Two: Rehabilitation

4) Access to Rehabilitation and Models of Rehabilitation Service Provision

- What is the role of palliative and end of life care for people living with HIV and other chronic conditions?
- How are we evaluating reducing barriers, introducing policy-based measures for optimal care for people living with HIV?
- How can evaluation be included as part of rehabilitation programming?
- How engaged is the larger aging infrastructure around issues of HIV and aging?
- What models of service delivery have organizations in Canada been using (one size fits all vs. specific)? What has been working well?
- How does the climate of reduced HIV specialist services impact access to rehabilitation services?
- How does complexity/concurrent health conditions impact access to, and retention in care?
- Why do referrals to rehabilitation specialists (e.g., OT, PT) primarily occur after a major health crisis? Early identification of functional challenges could serve to prevent poor health outcomes of those who are living and aging with HIV.
- What is happening in other sectors/related to other chronic illness in terms of access to rehabilitation services?
- What is the self-perceived knowledge and ability of rehabilitation professionals to facilitate evidence-informed rehabilitation working within a HIV-specific healthcare program?
- What is the role of a self-management program in adherence to exercise and self-efficacy in managing HIV as a long-term condition?
- Maintaining adherence with exercise at home/around work commitments- how do we maintain adherence without supervision?
- What are the self-attributed and implicit (outside conscious control) barriers, along with motivators of sustained exercise behavior?
- How might a person living with HIV manage the episodic nature of HIV with an exercise intervention?
- What strategies might successfully enhance the ability for people with HIV to live in the community, safely, for as long as possible?
- How might we effectively incorporate established and promising rehabilitation practices into HIV care, given the field of research is evolving?
- What are the current attitudes (including stigma) and behaviors towards rehabilitation in the era of both aging with HIV and enhanced treatment outcomes?
- How can rehabilitation services reach people living with HIV when fewer are accessing ASO services and having fewer HIV clinical visits? What strategies might promote self-managed HIV rehabilitation prevention and treatment services?
- How is rehabilitation for people living with HIV perceived and delivered?
- Can interdisciplinary rehabilitation teams intervene early to prevent poor health outcomes (e.g., comorbid health conditions, functional decline, cognitive decline, unemployment)?
- What is the role of rehabilitation services in HIV self-management programs?
- What knowledge translation strategies can facilitate the application of comprehensive and lengthy evidence-informed guides to HIV rehabilitation into clinical practice?
- How can programs and services better meet the needs of the episodic and chronic nature of the disease?
- What is the potential impact of changes in employment policies for people living with HIV?

- What is the role of rehabilitation in terms of issues like addiction and substance use?
- What percentage of people living with HIV access rehabilitation services in Canada?
- How are client-centered or client-driven goals used in rehabilitation programs?
- What is the cost benefit of having people living with HIV accessing rehabilitation services?
- How do people living with HIV experience and understand rehabilitation programs and services?
- What are the key lessons learned in setting up a rehabilitation outpatient program for people living with HIV?

5) Effectiveness of Rehabilitation Interventions

- What are effective interventions to address mental issues for people living with HIV?
- What interventions improve the physical and psychological well-being of older PHAs? (include evaluation of existing programs and pilot-testing new programs)
- What is the relationship between physical/mental health and treatment outcomes?
- How can research best support evidence-based employment services for people living with HIV?
- How can the expertise of people living with HIV be used in research and programming?

Content Area Three: Methodological Advances in Rehabilitation and Disability Research

6) Enhancing Outcome Measurement

- What assessment tools and outcome measures could be used with children living with HIV?
- What is the interpretability (what do the HDQ scores really mean?) and the responsiveness (is the HDQ able to detect change in disability when change actually occurs?) of the HIV Disability Questionnaire (HDQ) for adults living with HIV in Canada and internationally.
- What are the measurement properties of the HDQ when administered online or electronically (currently validation work has been done using pen-paper self-administration)?
- How can we best measure engagement for people living with HIV in care?
- How can we ensure the comprehensiveness and rigor of our research studies?