

# The Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC) Fall 2016/ Winter 2017 E-Update (November 2016)

CUHRRC is an international research collaborative comprised of over 71 people living with HIV, researchers, clinicians, representatives from AIDS service organizations and policy stakeholders in Canada, the United Kingdom (UK), the United States of America (USA), Ireland and Hungary with an interest in HIV and rehabilitation research. Follow us on Twitter @CUHRRC.

#### **New CUHRRC Members**

The CUHRRC welcomes ten new members to the collaborative. **Melanie Bisnauth** is the new CUHRRC Coordinator from University of Toronto in the Department of Physical Therapy in Toronto, Canada. **Charles Emlet** is a Professor of Social Work over at the University of Washington, Tacoma. **Laurie Ringaert** is a Community-Based Research Coordinator for the HIV Collective Impact Network with Nine Circles Community Health Centre in Manitoba, Canada. **Puja Ahluwalia** is the Project Coordinator of the Equitable Access to Rehabilitation Project at *realize* (formally known as the Canadian Working Group on HIV and Rehabilitation) in Ontario, Canada. **Joanne Lindsay** is a Community Investigator at the Canadian Observational Cohort Collaboration in Ontario, Canada. **Adria Quigley** is a PhD student at Dalhousie University in Ontario, Canada. **James Watson** is the Coordinator in Community-Based Research and Peer Training at the Ontario HIV Treatment Network, Canada, **Matthieu Dagenais** is a Masters student in Physiotherapy at the Rehabilitation Sciences Institute at the University of Toronto, Canada. **Saipriya Vajravelu** is a PhD Candidate in Physiotherapy in School of Rehabilitation Science at McMaster University in Ontario, Canada and **Adam McDermott** is a PhD Candidate in Exercise Physiology at Trinity College in Dublin, Ireland.

# **Past and Upcoming Events**

- 1) A **CUHRRC Membership Teleconference Meeting** will be held on **Wednesday November 30<sup>th</sup>, 2016.** The purpose of this meeting is to welcome new CUHRRC members, to exchange knowledge and share updates on HIV and rehabilitation research, and discuss updates to the terms of reference for the collaborative.
- 2) The Canadian Association for HIV Research (CAHR) 2017 Conference will be held on Thursday April 6th, 2017 to Sunday April 9th 2019 in Montreal, Quebec, Canada. Visit the site: <a href="http://www.cahr-acrv.ca/conference/">http://www.cahr-acrv.ca/conference/</a> for more details.
- 3) The **3rd International Forum on HIV and Rehabilitation Research-HIV and Aging** was held on **Thursday May 12**<sup>th</sup>, **2016 in Winnipeg, Canada.** Visit: <a href="http://cuhrrc.hivandrehab.ca/2016-forum.php">http://cuhrrc.hivandrehab.ca/2016-forum.php</a> for more details.
- 4) The Canadian Association for HIV Research (CAHR) 2016 Conference was held on May 12-15<sup>th</sup>, 2016 in Winnipeg, Manitoba, Canada. To see how rehabilitation was featured at the conference, visit: <a href="http://www.cahr-acrv.ca/hiv-rehabilitation-focus-cahr-2016/">http://www.cahr-acrv.ca/hiv-rehabilitation-focus-cahr-2016/</a> For 2016 conference highlights go to: <a href="http://www.cahr-acrv.ca/conference/archives/cahr-2016/">http://www.cahr-acrv.ca/conference/archives/cahr-2016/</a> for more details.
- 5) CUHRRC collaborated with the Canadian Working Group on HIV and Rehabilitation (CWGHR) (now realize) and Canadian Association for HIV Research (CAHR) to host a Special Plenary Session titled Living Longer and Living Well with HIV: Reaching New Heights in Healthy Aging as part of the CAHR Conference on Friday May 13<sup>th</sup> from 12:30pm-2:00pm in Winnipeg, Canada. Visit: <a href="https://www.youtube.com/watch?v=Tb7uiwtF8UU">https://www.youtube.com/watch?v=Tb7uiwtF8UU</a> to view the presentation.
- 6) The World Confederation for Physical Therapy (WCPT) Congress will be held on Sunday July 2<sup>nd</sup>, 2017 to Tuesday July 4<sup>th</sup>, 2017 in Cape Town, South Africa. Please visit: <a href="http://www.wcpt.org/congress">http://www.wcpt.org/congress</a> for more details.



## **Knowledge Translation**

Upcoming Event - CUHRRC at the Canadian HIV Conference (CAHR 2017) in Montreal, April 6-9<sup>th</sup>, 2017

Special Plenary Session - Advancing HIV, Aging and Rehabilitation: Where Does Rehabilitation Fit in the HIV Care Cascade? CUHRRC is collaborating with *realize* (formerly the Canadian Working Group on HIV and Rehabilitation) and the Canadian Association for HIV Research (CAHR) on this special plenary session (Exact Date and Time – TBC). The session is supported by a CIHR Meeting Planning and Dissemination (MPD) Grant from the Aging Institute. A smaller working meeting will be held prior to the CAHR conference to establish plans for a collaborative operating grant proposal that will address the research priorities on HIV, aging and rehabilitation (details still to be confirmed). Stay tuned for more details. In the meantime, abstracts for the CAHR conference are due Wednesday, December 14<sup>th</sup>, 2017. Click on the link for more details: http://www.cahr-acrv.ca/conference/

#### Research Updates from Charles Emlet (University of Washington)

Charles Emlet is a Professor of Social Work and joined the University of Washington Tacoma Social Work faculty in 1999. Charles et al recently published a journal article titled "I'm happy in my life now, I'm a positive person" which speaks to approaches to successful ageing in older adults living with HIV in Ontario, Canada. Worldwide approximately 3.6 million people aged 50 and older are living and ageing with HIV. Few studies have explored successful ageing from the insider perspective of those living well and ageing with HIV. This study draws upon the lived experience and wisdom of older, HIV-positive adults living in Ontario, Canada in order to understand their views and strategies for successful ageing. Click <a href="here">here</a> to view the article and learn more.

#### Research Updates from David Kietrys, Mary Lou Galantino and Kelly O'Brien

CUHRRC members David Kietrys, Mary Lou Galantino, and Kelly O'Brien are currently concluding a research project titled "Self-Reported Disability in HIV+ Persons with and without HIV-related Distal Sensory Polyneuropathy". Part of this study involves validation of the HIV Disability Questionnaire (HDQ) in sample of people living with HIV in the United States (US). The findings will help elucidate the impact of HIV disease on disability in a U.S. sample, and explore differences in disability in those with and without HIV-related neuropathy. Kelly, David, and Mary Lou have also been collaborating with Dr. Hellen Myezwa from University of the Witwatersrand on "Self-Reported Disability in HIV+ Persons in the United States and South Africa", to explore differences in disability and depression prevalence in people living with HIV between the two countries, and explore factors that contribute to disability.

David Kietrys will present at the 27<sup>th</sup> Annual HIV Medical Update, sponsored by the Francois Xavier Bagnoud Center of Rutgers University, in Cherry Hill, NJ (USA) on **December 7<sup>th</sup>, 2017**. The talk will focus on how to identify and manage HIV-related disability and functional limitations in a clinical setting.

Dave Kietrys and Mary Lou Galantino will be serving as guest co-editors on a special HIV issue of *Oncology Rehabilitation*. Dave and Mary Lou will soon share the call for papers to all CUHRRC members. This special issue is slated for publication in early 2018.

#### Research Updates from Puja Ahluwalia (realize)

The role of rehabilitation in the lives of people living with HIV is one that continually needs to be shared. This short video <a href="http://www.realizecanada.org/resources/video-vault/hiv-and-rehabilitation/">http://www.realizecanada.org/resources/video-vault/hiv-and-rehabilitation/</a> made by <a href="realize">realize</a> (formerly the Canadian Working Group on HIV and Rehabilitation) in collaboration with <a href="Fife House">Fife House</a>, <a href="Saint Elizabeth">Saint Elizabeth</a> and filmed by <a href="Spinster Media">Spinster Media</a> looks at the role of rehabilitation through conversations with occupational therapists and a person living with HIV.



# **Knowledge Translation**

#### A) Rehabilitation Featured at the Canadian Conference for HIV/AIDS in Winnipeg in May 2016

3rd International Forum on HIV and Rehabilitation Research – HIV and Aging, Winnipeg, Canada, Thursday May 12<sup>th</sup> 2016



On May 12, 2016, CUHRRC, in partnership with Realize and the Canadian Association for HIV Research (CAHR) hosted the 3rd International Forum on HIV and Rehabilitation Research – Advancing HIV, Aging and Rehabilitation Research and Practice in Winnipeg, Manitoba. The Forum was supported by a Meeting, Planning and Dissemination Grant from the Canadian Institutes of Health Research (CIHR) Aging Institute.

Goals of the Forum: 1) To facilitate knowledge transfer and exchange (KTE) on HIV and aging research, clinical practice and service delivery, among people living with HIV, researchers, clinicians on HIV, representatives of community organizations, and policy makers in Canada, UK, Australia and the United States; 2) To establish new research and clinical partnerships in HIV and aging internationally; 3) To foster mentorship and training in HIV and aging research and; 4) To identify new and emerging research priorities in HIV, aging and rehabilitation.

**Attendees**: 69 stakeholders, including community leaders, clinicians, researchers, students and people living with HIV from Canada, the United Kingdom, Australia, and the United States.

**Forum Overview:** The Forum included a series of dynamic and interactive research evidence panel sessions focused on HIV, aging and multi-morbidity, rehabilitation interventions and models of service delivery. The sessions aimed to a) translate emerging research evidence related to HIV, aging and multi-morbidity in the context of disability and rehabilitation, b) profile innovative models of rehabilitation interventions and living well strategies for older adults living with HIV, c) highlight concrete strategies for enhancing access to rehabilitation for people aging with HIV, and d) identify key research priorities in the field and discuss opportunities to enhance service delivery.

More Information and Knowledge Translation Materials on the Forum: Launch of the KTE Library Forum films and slide presentations, visit the 3rd Knowledge Translation and Exchange (KTE) Library: http://cuhrrc.hivandrehab.ca/2016-forum.php

Forum Program, please visit: <a href="http://cuhrrc.hivandrehab.ca/docs/3rd-Forum-Program-FINAL-May-6-16.pdf">http://cuhrrc.hivandrehab.ca/docs/3rd-Forum-Program-FINAL-May-6-16.pdf</a>
Forum Report, please visit: <a href="http://cuhrrc.hivandrehab.ca/docs/3rd-International-Forum-Final-Report-FINAL-CIRCULATED-Sept-2-16.pdf">http://cuhrrc.hivandrehab.ca/docs/3rd-International-Forum-Final-Report-FINAL-CIRCULATED-Sept-2-16.pdf</a>

Forum Fact Sheet (Summary of Evidence), please visit: <a href="http://cuhrrc.hivandrehab.ca/docs/3rd-Forum-HIV-Aging-Rehabilitation-Summary-of-Evidence-FINAL-CIRCULATED-Sept-2-16.pdf">http://cuhrrc.hivandrehab.ca/docs/3rd-Forum-HIV-Aging-Rehabilitation-Summary-of-Evidence-FINAL-CIRCULATED-Sept-2-16.pdf</a>

**Acknowledgements**: CUHRRC acknowledges support from Three Flying Piglets for filming the Forum, the Department of Physical Therapy, University of Toronto, and the Ontario HIV Treatment Network. CUHRRC gratefully acknowledges the financial support for coordination by *realize* (formerly known as CWGHR).



#### Living Longer and Living Well with HIV: Reaching New Heights in Healthy Aging

CUHRRC in collaboration with *realize* conducted a special plenary session at Canadian Association for HIV Research (CAHR) Conference on Friday, May 13th, 2016 entitled: 'Living Longer and Living Well with HIV: Reaching New Heights in Healthy Aging'. This session was moderated by Patty Solomon (McMaster University) and speakers Richard Harding (Cicely Saunders Institute, Kings College), Stephanie Nixon (University of Toronto, International Centre for Disability and Rehabilitation), Darren Brown (Chelsea and Westminster Hospital, Rehabilitation in HIV Association), Chris Lucas (Nine Circles Community Health Centre) and Kate Murzin (*realize*) presented on HIV and healthy aging across the contexts of Canada, UK and Sub-Saharan Africa. Please <u>click here</u> to see the CAHR Special Plenary Session Presentation Video.

# Rapporteur Summary of the HIV and Rehabilitation Research Content presented at the 25<sup>th</sup> Annual Canadian Conference on HIV/AIDS Research at CAHR 2016

CUHRRC developed a rapporteur summary to provide an overview of HIV and rehabilitation content presented at the 25<sup>th</sup> Annual Canadian Conference on HIV Research at CAHR 2016. The Summary is organized according to six research priorities in HIV, disability and rehabilitation: 1) episodic health and disability; 2) aging with HIV across a lifespan; 3) concurrent health conditions; 4) access to rehabilitation and models of rehabilitation service provision; 5) effectiveness of rehabilitation interventions; and 6) enhancing outcome measurement in HIV and rehabilitation research. Please click <a href="here">here</a> to access the 2016 Rapporteur Summary of HIV and Rehabilitation Evidence at the CAHR Conference.

### B) Community Knowledge Translation and Exchange Events

# 'More to Life than Medications! Research & Community Mobilization on Healthy Living for People Living with HIV'

Researchers, clinicians and community members came together to discuss updates on findings from research about living well and living longer with HIV on **Thursday, October 20<sup>th</sup>, 2016** at St. Paul's Hospital in Vancouver, BC.

The session included key updates from the HIV, Health and Rehabilitation Survey Study, HeadsUp! Study, and *realize* with a panel discussion with clinicians and community members who discussed what the research meant for people living with HIV, health providers and community-based organizations. This was collaborative KTE event with the Dr. Peter AIDS Foundation, Positive Living Society of British Columbia, *realize*, and the HIV Health and Rehabilitation Survey (HHRS) and HeadsUp! Study teams. The HIV Health and Rehabilitation Survey and HeadsUp! Studies are funded by the CIHR, HIV/AIDS Research Initiative.

For more information on Discussions on Episodic Disabilities and Employment, check out the following link from realize: http://www.realizecanada.org/en/?s=employment







# HIV, Health and Rehabilitation Survey Update-Launch of Fact Sheets

The HIV, Health and Rehabilitation Survey (HHRS) is a CIHR-funded Canada wide online survey with the overall goal to establish a comprehensive profile of the range of health conditions people with HIV in Canada live with, the health-related challenges they experience (disability) and the rehabilitation services and living strategies that they use to deal with their health related challenges.

With *realize* (formerly CWGHR) as the Principal Knowledge User, the HHRS is a collaboration with over 30 AIDS Service and Community Based Organizations, clinics and health centres across the country. The HHRS includes 941 responses from adults living with HIV across Canada. The HHRS team is in the analysis phase of the study.

The **HIV**, **Health and Rehabilitation Survey Fact Sheet** was launched in September 2016 at the *realize* Annual General Forum. The aim of this summary was to highlight the key findings of the HHRS to the broader community including people living with HIV, knowledge user and collaborator organizations, clinics and community-based organizations. Click here to access the **English** and **French** versions of the HHRS Fact Sheet.

For more information on the HHRS please visit the HHRS webpage on the CUHRRC website <a href="http://cuhrrc.hivandrehab.ca/current\_studies.php">http://cuhrrc.hivandrehab.ca/current\_studies.php</a> or contact Kelly O'Brien (Principal Investigator) at <a href="mailto:kelly.obrien@utoronto.ca">kelly.obrien@utoronto.ca</a> or Melanie Bisnauth (Research Coordinator) at <a href="mailto:melanie.bisnauth@utoronto.ca">melanie.bisnauth@utoronto.ca</a>. The Health and Rehabilitation Survey is funded by the CIHR, HIV/AIDS Research Initiative.



## **CUHRRC Website Updates**

http://cuhrrc.hivandrehab.ca/index.php

Updates to the CUHRRC website are made throughout the year. Please feel free to send updates from your work on HIV and rehabilitation research you wish to share on the CUHRRC website or in the newsletter.

# **CUHRRC Steering Committee**

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If you are interested in becoming a member of the CUHHRC Steering Committee, please contact Kelly O'Brien.

# **Stay Tuned!**

Next Issue of CUHRRC E-Update ~ May 2017

For more information on these activities and/or the CUHRRC, please contact Melanie Bisnauth, CUHRRC coordinator, at <a href="cuhrrc@utoronto.ca">cuhrrc@utoronto.ca</a> or visit the CUHRRC website at <a href="http://cuhrrc.hivandrehab.ca/">http://cuhrrc.hivandrehab.ca/</a>

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