

## The Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRRC) Fall 2014/Winter 2015 E-Update (February 2015)

CUHRRRC is an international research collaborative comprised of over 50 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) and Ireland with an interest in HIV and rehabilitation research.

### New CUHRRRC Members

The CUHRRRC welcomes 11 new members to the collaborative. **Ana Brito** is a Chief Sleep Physiologist at Chelsea and Westminster Hospital NHS Foundation Trust. **Victoria Brown** is the Coordinator for the YMCA Positive Health Programme in London, UK. **Paul Decle** is a Web Designer, IT Manager and patient advocate. **Clare Dinham** and **Ambika Kumar** are physiotherapy students at King's College London and recently volunteered at the 2<sup>nd</sup> International Forum on HIV and Rehabilitation Research. **Michael Liddell** is a community member with lived experience with HIV and a member of the Atlantic Interdisciplinary Research Network for Social and Behavior Issues in Hepatitis C and HIV. **Maxwell Madzikanga** is an International Public and Reproductive Health Consultant with experience in international humanitarian affairs and public health and epidemiology. **Alexander Margetts** is a Clinical Psychologist at Central and North West London NHS Foundation Trust. **Kiran Sandhu** is a Medical student studying in Dublin, Ireland with an interest in HIV/AIDS. **Mark Spreckley** is a Student Doctor of Public Health at the London School of Hygiene & Tropical Medicine. Mark has a clinical background in Physiotherapy and his interests include international perspectives on disability and the role of rehabilitation. **Carrie-Ann Wood** is a Senior HIV Physiotherapist at Guy's and St. Thomas' Hospital, NHS Foundation Trust and runs a bi-weekly HIV exercise group, and HIV specialist metabolic clinic.

### Past and Upcoming Events

- 1) A **CUHRRRC Membership Meeting** was held on **Friday January 30<sup>th</sup>, 2015**. The purpose of this meeting was to provide updates since the 2<sup>nd</sup> International Forum on HIV and Rehabilitation Research and welcome new members.
- 2) The **Canadian Association for HIV Research (CAHR) 2015 Conference** will be held on **Thursday April 30<sup>th</sup>, 2015 to Sunday May 3, 2015 in Toronto, Canada**. Visit the site: <http://www.cahr-acrv.ca/conference/abstract-submission/> for more details
- 3) The **Canadian Working Group on HIV and Rehabilitation (CWGHR) Annual General Forum** is **Monday, June 15, 2015** in Toronto, Canada. Stay tuned for more details.

### Knowledge Translation

#### Conferences and Meetings

##### **BHIVA Autumn Conference, London, UK (October 2014) – Special Session on HIV and Rehabilitation**

On Friday October 10<sup>th</sup>, 2014, CUHRRRC and RHIVA conducted a special session at the British HIV Association (BHIVA) Conference entitled: '*A Tale of Rehabilitation in Two Countries: A Snapshot of HIV and Rehabilitation in Canada and the United Kingdom*'. The objectives were to: 1) describe the role and evidence for rehabilitation in the context of HIV; 2) highlight strengths of rehabilitation research and practice in Canada and the UK; and 3) highlight ways in which to recognize the need for rehabilitation, referral and access to rehabilitation for people with HIV. This session was moderated by Esther McDonnell (RHIVA, Chelsea and Westminster Hospital) and speakers Patty Solomon (McMaster University), Kelly O'Brien (University of Toronto), Francisco Ibáñez-Carrasco (Ontario HIV Treatment Network), Darren Brown (RHIVA, Chelsea and Westminster Hospital) and Elizabeth Stevens (Birmingham Hearts of England NHS Trust) presented on HIV and Rehabilitation in Canada and the UK). Click [here](#) to see the BHIVA Special Session Presentation slides.

## 2<sup>nd</sup> International Forum on HIV and Rehabilitation Research, London, UK (October 2014)



On October 11<sup>th</sup>, 2014, the CUHRRC in partnership with the Rehabilitation in HIV Association (RHIVA) in the UK hosted the 2<sup>nd</sup> *International Forum on HIV and Rehabilitation* at the Chelsea and Westminster Hospital.

**Goal of the Forum:** 1) To facilitate knowledge transfer and exchange on HIV and rehabilitation research, clinical practice and service delivery, among people living with HIV (PHAs), researchers, clinicians on HIV, representatives of community organizations, and policy makers; and 2) To foster new research and clinical partnerships in HIV and rehabilitation internationally.

**Attendees:** Fifty-one participants representing a broad range of stakeholders. The majority worked at a hospital (n=19, 37%) or university (n=12, 24%) and identified as clinicians (n=16, 31%), researchers (n=10, 20%) or community members (n=7, 14%).

**Forum Overview:** The Forum was organized into three Clinical Practice and Research Evidence Sessions with 10 presentations (11 speakers) and a Plenary Panel Session with 6 speakers and 1 facilitator. The topics for the three Clinical

Practice and Research Evidence Sessions were: 1) Episodic Health and Disability; 2) Rehabilitation Interventions; and 3) Methodological Advances in HIV and Rehabilitation Research. The Panel consisted of people living with HIV, researchers and clinicians from the community who had the opportunity to comment on bridging research evidence into practice and policy and reflect on the research evidence presented throughout the day.

**Forum Evaluation:** The majority of participants agreed that the Forum achieved its goal of translating recent research evidence on HIV and rehabilitation. Strengths of the Forum included: high quality of evidence presented, passionate and informative presentations, supportive group environment, diverse nature of attendees and perspectives and a great opportunity for networking and collaborations. Challenges of the Forum included: lots of information provided in a short amount of time and not enough discussion time.

### More Information and Knowledge Translation Materials on the Forum:

Forum Twitter feed: <https://twitter.com/search?q=%23RehabHIV14&src=typd>

Forum photographs: [http://cuhrrc.hivandrehab.ca/conference\\_2014.php](http://cuhrrc.hivandrehab.ca/conference_2014.php)

Forum films and slide presentations, please visit the 2<sup>nd</sup> Forum Knowledge Translation and Exchange (KTE) Library: <http://cuhrrc.hivandrehab.ca/kte.php>

Forum Report, please visit <http://cuhrrc.hivandrehab.ca/docs/kte/Forum-ResearchReport.pdf>

Forum Fact Sheet, please visit: <http://cuhrrc.hivandrehab.ca/docs/kte/Forum-FactSheet.pdf>

### Building a Research Proposal to Evaluate the Effect of a Rehabilitation Intervention with Adults with HIV in the UK, London, England (October 2014)

Following the Forum on October 12<sup>th</sup>, 2014, 22 researchers (36%), clinicians (32%), community members (18%), educators (9%), and a student (5%) met to discuss the development of a collaborative **research proposal** that will address research priorities in HIV and rehabilitation. The group discussed an outline for an intervention study to assess the effect of exercise interventions on health outcomes for adults living with HIV. CUHRRC members in the UK are leading the next steps in preparing a proposal for submission in the UK. For more information contact Ayesha Nayyar.

### Irish Chartered Society of Physiotherapists (ISCP): The Paul Wagstaff Commemorative Lecture, Dublin, Ireland (November 2014). *Fiche bliain ag fás: Living with HIV: Experiences in Ireland and Canada*

Kelly O'Brien and Colm Bergin presented at Trinity College Dublin on November 6<sup>th</sup>, 2014 on the emerging issues in HIV and rehabilitation, role and evidence for rehabilitation (and physical therapy) and the future opportunities highlighting the CUHRRC collaboration.

## Publications

Solomon P, O'Brien K, Wilkins S, Gervais N. Aging with HIV: A Model of Disability. *Journal of the International Association of Providers in AIDS Care*. Published online. August 2014. DOI: 10.1177/2325957414547431  
<http://www.ncbi.nlm.nih.gov/pubmed/25149413>

Gallagher S, Biro S, Creamer E, Della Rossa E, Collins E, Rourke S, Nixon SA. "It's a Hidden Issue": Exploring the Experiences of Women with HIV-Associated Neurocognitive Challenges Using a Disability Framework. *Disability and Rehabilitation*. 2013;35(1):36-46. DOI: 10.3109/09638288.2012.687029  
<http://www.ncbi.nlm.nih.gov/pubmed/22621682>

Hawkins C, Eva G. Understanding HIV Management. *OT News*. 2014; 22(12): 44-45.

Hopcroft L, Bester L, Clement D, Quigley A, Sachdeva M, Rourke S, Nixon SA. "My body's a 50 year-old but my brain is definitely an 85 year-old": Exploring the Experiences of Men Aging with HIV-associated Neurocognitive Challenges. *Journal of the International AIDS Society* 2013;16:18506  
<http://www.jiasociety.org/index.php/jias/article/view/18506>

O'Brien KK, Ibáñez-Carrasco I, Solomon P, Harding R, Cattaneo J, Chegwidde W, Gahagan J, Baxter L, Worthington C, Gayle P, Merritt B, Baltzer-Turje R, Iku N, Zack E. Advancing research and practice in HIV and rehabilitation: a framework of research priorities in HIV, disability and rehabilitation. *BMC Infectious Diseases*. 2014;14:724. DOI: 10.1186/s12879-014-0724-8  
<http://www.biomedcentral.com/1471-2334/14/724>

## Webinars

### Adherence to Exercise and Medication for People Living with HIV (November 2014)

Carrie-Ann Wood and Rebecca Mullin presented a webinar hosted by the World Confederation for Physical Therapy on November 20<sup>th</sup>, 2014.

- To access the Webinar, visit the following link. *Note: The ARF player needs to be downloaded to view this webinar*  
<https://oakland.webex.com/oakland/lsr.php?RCID=2423f10242ba9d893777945993a6506a>

## Social Media

### CUHRRRC Launched on Twitter (October, 2014)

CUHRRRC launched its' official Twitter page @CUHRRRC. Follow us at <https://twitter.com/@cuhrrc>

### World AIDS Day Twitter Chat (December 1<sup>st</sup>, 2014)

'HIV and Rehabilitation: What does  
Physiotherapy have to do with it?'  
Join us to find out!



**WORLD AIDS DAY TWITTER CHAT**

**December 1<sup>st</sup>, 2014**

**12:00 – 1:00pm EST**

**#HIVandPhysio**

On December 1<sup>st</sup>, 2014 CWGHR in partnership with CUHRRRC, RHIVA and the Canadian Physiotherapy Association held a one hour World AIDS Day Twitter Chat. The three questions posed were: 1) What challenges in rehabilitation do you see as a clinician, patient or advocate? 2) How do these challenges relate to episodes of disability? 3) What is your vision for the future of rehabilitation in the context of HIV? The Twitter chat had over 10 participants including Darren Brown, Larry Baxter, and Greg Robinson. To access the Twitter feed, please visit #HIVandPhysio at:

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

Twitter Chat Partners:



### 3 Minutes with ... Darren Brown (December 3<sup>rd</sup>, 2014)



On December 3<sup>rd</sup>, 2014 Darren Brown in partnership with the Chartered Society of Physiotherapy, was interviewed by Frontline Magazine. Darren explained how he developed the skills needed to be a specialist physiotherapist in HIV. To read the full article, please visit <http://www.csp.org.uk/frontline/article/3-minutes-darren-brown>

### HIV, Health and Rehabilitation Survey Update



The *HIV, Health and Rehabilitation Survey* (HHR) 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. Launched in October 2013, the HHR team has

collaborated with over 30 AIDS Service and Community Based Organizations, clinics and health centres across the country to invite over 4000 adults living with HIV to participate in the study. The data collection phase closed on August 5<sup>th</sup>, 2014. We received **941** valid and complete responses to the survey and are now in the analysis phase of the study. For more information on the HHR please visit the HHR webpage on the CUHRRRC website [http://cuhrrc.hivandrehab.ca/current\\_studies.php](http://cuhrrc.hivandrehab.ca/current_studies.php) or contact Kelly O'Brien (Principal Investigator) at [kelly.obrien@utoronto.ca](mailto:kelly.obrien@utoronto.ca) or Ayesha Nayar (Research Coordinator) at [ayesha.nayar@alum.utoronto.ca](mailto:ayesha.nayar@alum.utoronto.ca). The HHR Team met by teleconference on December 15<sup>th</sup>, 2014 to discuss the descriptive findings from the survey. The HHR Face-to-Face meeting will be held on June 16<sup>th</sup>, 2015. The HIV, Health and Rehabilitation Survey is funded by the CIHR, HIV/AIDS Research Initiative.



### A Survey on the Canadian Working Group on HIV and Rehabilitation's (CWGHR) E-Module

The Canadian Working Group on HIV and Rehabilitation (CWGHR) is conducting a preliminary survey about the access to and use of, the "E-Module for Evidence-Informed HIV Rehabilitation". The E-Module is a resource for practicing rehabilitation professionals to increase their knowledge about rehabilitation in the context of HIV.

The E-Module is openly accessible at:

[http://www.hivandrehab.ca/EN/information/care\\_providers/documents/CWGHR\\_E-moduleEvidence-InformedHIVRehabilitationfinal.pdf](http://www.hivandrehab.ca/EN/information/care_providers/documents/CWGHR_E-moduleEvidence-InformedHIVRehabilitationfinal.pdf)

If you have ever accessed the E-Module, we invite you to complete this short 5 minute survey questionnaire at the following link: <https://www.surveymonkey.com/s/CWGHREModule> by February 15, 2015

Please contact Ayesha Nayar (CUHRRRC Coordinator) at [cuhrrc@utoronto.ca](mailto:cuhrrc@utoronto.ca) if you have any questions.



## CUHRRC Website Updates

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

Updates to the CUHRRC website are made 7 times per 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

Kelly O'Brien [kelly.obrien@utoronto.ca](mailto:kelly.obrien@utoronto.ca)

Esther McDonnell [Esther.McDonnell@chelwest.nhs.uk](mailto:Esther.McDonnell@chelwest.nhs.uk)

Patty Solomon [solomon@mcmaster.com](mailto:solomon@mcmaster.com)

Cathy Worthington [worthing@uvic.ca](mailto:worthing@uvic.ca)

Francisco Ibáñez-Carrasco [fibanezcarrasco@ohrn.on.ca](mailto:fibanezcarrasco@ohrn.on.ca)

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

## Stay Tuned!

Next Issue of CUHRRC E-Update ~ July 2015

For more information on these activities and/or the CUHRRC, please contact Ayesha Nayar, CUHRRC coordinator, at [cuhrrc@utoronto.ca](mailto:cuhrrc@utoronto.ca) or visit the CUHRRC website at [cuhrrc.hivandrehab.ca](http://cuhrrc.hivandrehab.ca)

**ACKNOWLEDGEMENTS:** CUHRRC gratefully acknowledges the support of the Canadian Institutes of Health Research, and the Canadian Working Group on HIV and Rehabilitation (CUHRRC Coordination).

