

**The Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC), in partnership with the Rehabilitation in HIV Association (RHIVA) hosted the 2nd International Forum on HIV and Rehabilitation Research on October 11, 2014 in London, England.**

**Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC):** CUHRRC is an international research collaborative comprised of over 50 researchers, clinicians, people with HIV, and representatives from community organizations, from Canada, the UK, Ireland and USA to advance research ideas and activities related to HIV and rehabilitation research.

**What is rehabilitation?** Any services or providers who address or prevent the physical, cognitive, mental, emotional or social health challenges experienced by people living with HIV which can include (but is not limited to) physiotherapy or occupational therapy.

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

**How Can I Access the Forum Presentations?** Go to the Knowledge Translation and Exchange (KTE) library at <http://cuhrrc.hivandrehab.ca/kte.php>

**How Many Attended the Forum?** 51 participants including: clinicians (31%); researchers (19%); community members (16%); service providers (10%); media team members (8%); volunteers (6%); students (6%); and educators (4%) from the UK, Canada and Ireland.

## **2nd International Forum on HIV and Rehabilitation Research - Summary of Evidence**

The following is a brief synopsis of the research evidence presented at the Forum. For more detail please visit the KTE Library at <http://cuhrrc.hivandrehab.ca/kte.php>

### **Episodic Health & Disability - HIV and Aging**

- **Aging and Uncertainty:** Results from a qualitative study with 49 older adults with HIV in Canada found that uncertainty related to aging with HIV is related to sources of health challenges, appropriate long term housing, seeking a caregiver, transitioning to retirement, the episodic nature of HIV, financial uncertainty and health care providers' knowledge and skills (Solomon).
- **Episodic Disability and Resiliency:** A qualitative study with 12 adults with HIV in Ireland, reported that disability was episodic in nature with fluctuating periods of wellness and illness. PHAs experienced challenges with memory and concentration, stress, depression, and loneliness due to loss of social support and the fear of HIV disclosure. Resiliency and positive outlook helped to minimize perceived health challenges experienced by adults with HIV (O Dea).
- **Future Research:** The GUIDE Clinic at St. James's Hospital, Dublin is conducting a pilot study to assess issues related to aging and the impact of exercise with people with HIV and neurocognitive challenges (Bergin).

### **Rehabilitation Interventions**

- **Interventions to Enhance Coping:** A systematic review (Harding et al., 2011) indicated that the majority of interventions focused on enhancing coping among PHAs aim to improve mental health, reduce psychological symptoms, or achieve stress reduction. Out of the interventions appraised, 60% reported significant positive changes in these areas (Harding).
- **Exercise Interventions:** Exercise can help to address disability experienced by PHAs (Cochrane Collaboration, 2010). The Kobler Rehabilitation Class at the Chelsea and Westminster Hospital (UK) aims to improve health and social well-being. Evaluation with 92 participants found improvements in flexibility, strength, quality of life scores and the six minute walk test after the program. Participants reported improved physical fitness and self-management following participation (Brown).
- **Reasons for people with HIV not engaging in exercise** may include: belief based reasons (e.g. exercise is pointless), internalized justifications related to exercise (e.g. embarrassment), physical barriers independent of exercise (e.g. sickness) and external reasons independent of exercise (e.g. busy) (Mullin).

# 2<sup>nd</sup> International Forum on HIV and Rehabilitation Research- Summary of Research Evidence

## Methodological Advances in HIV and Rehabilitation

- **Outcome Measures:** Patient reported outcome measures (PROMs)/patient reported experience measures (PREMs) aim to promote quality of life and equity of access to care. Researchers are creating structures to enable measurement and ensuring that clinical priorities are mapped (Harding & Platt).
- **HIV, Health and Rehabilitation Survey (HHR):** Preliminary findings suggest 72% of participants were living with two or more health conditions in addition to HIV. Seventeen (17%) accessed physical therapy and 6% accessed occupational therapy in the past year (O'Brien et al, in progress).
- **HIV-Associated Neurocognitive Disorders (HAND):** HAND occurs in 30-50% of PHAs however it is under-recognized. A systematic review by Zipsursky et al (2013) found that few studies focused on milder forms of HAND – there is a need for tools that can measure milder forms of HAND. (Rourke).

## Bridging HIV and Rehabilitation Evidence with the Real World: Response from the Community and Clinical Perspective.

- The Canadian Working Group on HIV and Rehabilitation participates in research that is evidence based and establishes partnerships across sectors to influence policy and practice using a cross-disability (or episodic disability) approach (Porch). <http://hivandrehab.ca/EN/index.php>
- A needs-approach towards practice and management of the complex multi-dimensional challenges of HIV is important for clients with HIV (Hawkins). An increase in available rehabilitation services is needed for older adults with HIV (Josh).
- High level evidence is needed to demonstrate the effect of rehabilitation in order to make the case for enhancing access (Nelson).
- The Kobler Rehabilitation Class allows participants to exercise at their own pace towards goals and gain a sense of social support (Dunne).
- To translate evidence into action, we need to direct results to local service organizations and HIV clinics (Baxter).

## Developing a Research Proposal

On Sunday October 12<sup>th</sup>, 2014 the CUHRRC Core Planning Team held a 1 day meeting whereby 22 stakeholders met to develop a joint international collaborative research proposal focused on assessing the effect of a rehabilitation intervention for people with HIV in the UK.

## In Summary...

As people live longer and age with HIV and other health conditions, there is an increasing role for rehabilitation. The field of HIV and rehabilitation research is evolving with Canada and the UK as leaders in HIV rehabilitation research. More high quality evidence is needed to document the impact of disability and determine the effectiveness of rehabilitation interventions to enhance overall health of PHAs.

## How Can I get more information?

Contact Ayesha Nayar (CUHRRC) Coordinator at [ayesha.nayar@alum.utoronto.ca](mailto:ayesha.nayar@alum.utoronto.ca), visit <http://cuhrrc.hivandrehab.ca/> and follow us @CUHRRC

## 2<sup>nd</sup> International Forum Group Photo



## Acknowledgements

**CIHR Grant and Forum Planning Team:** Kelly O'Brien (University of Toronto), Francisco Ibáñez-Carrasco (Ontario HIV Treatment Network), Elisse Zack / Stephen Tattle (Canadian Working Group on HIV and Rehabilitation (CWGHR)), Darren Brown (Chelsea and Westminster Hospital NHS Trust), Colm Bergin (St. James's Hospital, Dublin), Siobhán O Dea (St. James's Hospital, Dublin), Catherine Worthington (University of Victoria), Patty Solomon (McMaster University), Richard Harding (King's College, London), Larry Baxter (Community Member) & Patriic Gayle (Three Flying Piglets (3FP)), Nkem Iku and Ayesha Nayar (Research Coordinator).  
**Forum Filming and Communications Media Team:** Patriic Gayle (3FP), Paul Sugars (3FP), Jim Spring (3FP), Tammy Yates (CWGHR) & Jo Josh (Commsbiz).  
**Student Volunteers:** Helen Seaman (King's College London (KCL)), Clare Dinham (KCL), Ambika Kumar (KCL).

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