Developing International Partnerships in HIV and Rehabilitation Research: The Canada-United Kingdom HIV and Rehabilitation Research Collaborative (CUHRRC)

Kelly O’Brien1,2, Will Chegwidden3, Patty Solomon1, Catherine Worthington4, Francisco Ibanez-Carrasco5, Elisse Zack6, Kirsti Duke2

McMaster University1, University of Toronto2, Barts and the London NHS Trust3, University of Calgary4, The Ontario HIV Treatment Network5, Canadian Working Group on HIV and Rehabilitation6

Background

- People living with HIV/AIDS (PHAs) in Canada and the United Kingdom (UK) face similar disability issues, such as challenges accessing rehabilitation services, social participation issues, income and employment, concurrent health conditions faced by those aging such as diabetes, osteoarthritis, and cardiac disease.
- UK - well established HIV and rehabilitation clinical system. Canada - well established research foundation fostered by the Canadian Working Group on HIV and Rehabilitation (CWGHR) and researchers.
- Forming partnerships with individuals experiencing similar types of disability is a first step in bridging widespread clinical knowledge in the UK with the strong research foundation on HIV, disability and rehabilitation in Canada.

Purpose

To develop an international collaborative research agenda to address the research priorities in HIV and rehabilitation by establishing partnerships with researchers, clinicians, community organizations, and people living with HIV in Canada and the United Kingdom.

Key Research Priorities in HIV and Rehabilitation

- Disability & Episodic Disability
- Concurrent Health Conditions Aging with HIV
- HIV & the Brain
- Labour Force & Income Support Issues
- Access to and Effect of Rehabilitation
- Measurement Tools

Description

- We coordinated a three day research meeting in London, UK at Mile End and St. Bartholomew’s Hospitals (October 15th – October 17th, 2009).
- First half of the meeting was aimed to facilitate knowledge transfer on HIV and rehabilitation and service delivery.
- Second half of the meeting was dedicated to developing an international research agenda and formalizing sustainable plans for a research group called the Canada-UK HIV and Rehabilitation Research Collaborative (CUHRRC)

Participants (n=25)

18 participants (13 from the UK and 5 from Canada) attended the three day meeting in person.
7 participants joined via videoconference in Toronto (n=5) and Halifax (n=2).
Researchers, rehabilitation professionals (occupational therapists, physical therapists), physicians, people living with HIV, and representatives from community organizations from the UK and Canada.

Meeting Preparation

- We circulated invitations to the meeting electronically and included details of the six research priorities in HIV and rehabilitation identified by a scoping study, presented nationally and internationally, and supported by CWGHR as key emerging issues for PHAs.
- We asked participants to indicate which of the 6 research areas they would like to focus and expand on the top 3 areas they felt should be addressed in the CUHRRC meeting to help guide our discussion.

Ranking Results for Research Priority Focus (n=17)

<table>
<thead>
<tr>
<th>Research Priority</th>
<th>UK Score (Rank)</th>
<th>Canada Score (Rank)</th>
<th>Overall Mean Score</th>
<th>Overall Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability and Episodic Disability</td>
<td>3.78 (3)</td>
<td>2.75 (2)</td>
<td>3.00</td>
<td>2</td>
</tr>
<tr>
<td>Concurrent Health Conditions Aging with HIV</td>
<td>3.00 (2)</td>
<td>3.25 (3)</td>
<td>3.12</td>
<td>3</td>
</tr>
<tr>
<td>HIV and the Brain</td>
<td>2.33 (1)</td>
<td>4.50 (5)</td>
<td>3.35</td>
<td>4</td>
</tr>
<tr>
<td>Labour Force and Income Support</td>
<td>4.67 (4)</td>
<td>5.75 (6)</td>
<td>4.82</td>
<td>6</td>
</tr>
<tr>
<td>Access to and Effect of Rehabilitation</td>
<td>3.00 (2)</td>
<td>2.62 (1)</td>
<td>2.82</td>
<td>1</td>
</tr>
<tr>
<td>Development and Evaluation of Measurement Tools</td>
<td>3.78 (3)</td>
<td>3.38 (4)</td>
<td>3.59</td>
<td>5</td>
</tr>
</tbody>
</table>

- Note: many priorities overlap with one another, and participants identified the importance and opportunity to address more than one research priority in a given research study.

Lessons Learned

- Meeting was the first step in formally establishing the CUHRRC.
- Combination of clinical and research expertise between Canada and UK.
- Involvement of people living with HIV in developing the research agenda, and CUHRRC.
- Benefits of a face-to-face dedicated 3 day meeting with structured and unstructured time to share knowledge, develop new partnerships, capacity build, and generate research questions that alight with the priorities in HIV and rehabilitation.

CUHRRC Research Agenda – Current Research Activities

Research priorities identified by CUHRRC to pursue included:
1) Determining prevalence study of disability and health and rehabilitation services use among people living with HIV (in Canada and mirrored in the UK for international comparisons) = currently underway.
2) Conducting a policy analysis of rehabilitation access between Canada and the UK = currently underway.
3) Establishing a ‘research bank’ of ideas for future work.
4) Broadening membership to successfully develop and carry out research on HIV, disability and rehabilitation.
5) Setting up a CUHRRC website on Canadian Working Group on HIV and Rehabilitation (www.hivandrehab.ca).

Conclusions

- Overall, the meeting was a success in developing a research agenda and building a foundation for a sustainable Canada-UK HIV and Rehabilitation Research Collaborative.
- CUHRRC represents the first formalized international research collaborative on HIV and rehabilitation between Canada and the UK.
- New partnerships from this international collaborative will help to address the key research priorities on HIV, disability and rehabilitation. This process may be of interest to others wishing to develop international rehabilitation research networks.

Acknowledgments: This meeting was funded by the Canadian Institutes of Health Research (CIHR). Kelly O’Brien is supported by a Canadian Institutes of Health Research, HIV/AIDS Research Program and McMaster Michael DeGroote Postdoctoral Fellowship.

1) Determining prevalence study of disability and health and rehabilitation services use among people living with HIV (in Canada and mirrored in the UK for international comparisons) = currently underway.
2) Conducting a policy analysis of rehabilitation access between Canada and the UK = currently underway.
3) Establishing a ‘research bank’ of ideas for future work.
4) Broadening membership to successfully develop and carry out research on HIV, disability and rehabilitation.
5) Setting up a CUHRRC website on Canadian Working Group on HIV and Rehabilitation (www.hivandrehab.ca).

CUHRRC Research Agenda – Current Research Activities

Research priorities identified by CUHRRC to pursue included:
1) Determining prevalence study of disability and health and rehabilitation services use among people living with HIV (in Canada and mirrored in the UK for international comparisons) = currently underway.
2) Conducting a policy analysis of rehabilitation access between Canada and the UK = currently underway.
3) Establishing a ‘research bank’ of ideas for future work.
4) Broadening membership to successfully develop and carry out research on HIV, disability and rehabilitation.
5) Setting up a CUHRRC website on Canadian Working Group on HIV and Rehabilitation (www.hivandrehab.ca).

Conclusions

- Overall, the meeting was a success in developing a research agenda and building a foundation for a sustainable Canada-UK HIV and Rehabilitation Research Collaborative.
- CUHRRC represents the first formalized international research collaborative on HIV and rehabilitation between Canada and the UK.
- New partnerships from this international collaborative will help to address the key research priorities on HIV, disability and rehabilitation. This process may be of interest to others wishing to develop international rehabilitation research networks.

Acknowledgments: This meeting was funded by the Canadian Institutes of Health Research (CIHR). Kelly O’Brien is supported by a Canadian Institutes of Health Research, HIV/AIDS Research Program and McMaster Michael DeGroote Postdoctoral Fellowship.