



WELLESLEY INSTITUTE
advancing urban health

Urban Health Research Program Advanced Grant Final Report

1. Executive summary (one page maximum)

(Please provide a brief executive summary describing your project's background, methods, results and discussion/implication).

The partnership for the project developed to address issues related to people living with HIV/AIDS (PHAs) and Housing. Collaborative efforts of the partnership resulted in the successful funding of a three year province wide community-based research(CBR) initiative, with the aim to examine housing and health in the context of HIV; and to assess the current and projected housing needs of PHAs in Ontario. The CBR initiative is funded by Canadian Institutes of Health Research (CIHR), Ontario HIV Treatment Network (OHTN), The Wellesley Institute, the AIDS Bureau, Ontario Ministry of Health and Long Term Care and Ontario AIDS Network (OAN)

The study was launched at the OHTN Conference in November 2005 and the study was branded as “ Positive spaces Healthy places”

This is the first longitudinal CBR initiative in Canada to examine housing and health in the context of HIV. The study is divided into three main stages- Baseline, 12 month survey and a Qualitative study. Participants will complete two face-to-face interviews across the study period, one at baseline and one at 12 months; and a short telephone survey at six months. The first stage has been completed. A total of 605 face-to-face quantitative baseline interviews with PHAs from across Ontario were conducted, fifty of these will participate in a qualitative sub-study aimed at enhancing our understanding of the housing experiences of PHAs.

The investigator group comprise of members from all geographic regions in Ontario and both housing and non-housing providers: AIDS Thunder Bay; AIDS Niagara; Bruce House (Ottawa); Fife House (Toronto); Ontario AIDS Network; Ontario Aboriginal HIV/AIDS Strategy; Community-Linked Evaluation AIDS Resource (CLEAR), McMaster University; School of Social Work, York University; and the Ontario HIV Treatment Network (OHTN).

This CBR initiative aims to identify through its outcomes

- The positioning of PHAs in housing situations that improve access to health care, treatment and social services.
- Safe and stable housing situations for PHAs in communities across Ontario.
- The development of effective and appropriate housing policies and supportive care models that support PHAs throughout their life course.

A research coordinator and seven peers were hired as research assistants. Over 676 calls were received from across Ontario to participate in the study. The study area(Ontario) was divided into four broad regions for the purpose of this study: Northern, Eastern, Central & South West and Greater Toronto Area. The prospective participants were screened and a total

of 605 baseline survey interviews were conducted for the four regions between April 2006-September 2006. The data analysis and interpretation is in progress.

2. Elaborate on each of the following sections:

Background

Since 2002 a partnership was developed between community-based AIDS service organizations (ASOs) and researchers from York and McMaster Universities to study the housing needs of people living with HIV/AIDS (PHAs) as they relate to health and well-being.

This partnership first convened at the Ontario AIDS Network annual retreat for Executive Directors in 2002, when a provincial sub-committee was formed to look at the issues facing PHAs directly related to housing. All geographic regions in Ontario were represented in the partnership and participants included both housing and non-housing providers: AIDS Thunder Bay; AIDS Niagara; Bruce House (Ottawa); Fife House (Toronto); Ontario AIDS Network; Ontario Aboriginal HIV/AIDS Strategy; Community-Linked Evaluation AIDS Resource (CLEAR), McMaster University; School of Social Work, York University; and the Ontario HIV Treatment Network (OHTN).

The partnership identified that housing may be the greatest unmet need among PHAs and that specific housing supports to ensure safety, health and dignity, varied among PHAs. It was also recognized that there was an overall lack of research in the area, particularly in Canada; and this lack of information was seen as a barrier to the adequate understanding of the current situation in Ontario and ability to plan for the future.

Since 2002, the partnership has met regularly to develop a community-based research strategy and to discuss opportunities for networking, information sharing, education and coalition building with local and provincial-level housing organizations. In addition, the Ontario AIDS Bureau's *Proposed Strategy to Address HIV/AIDS in Ontario to 2008* has identified housing as a priority issue for PHAs and reports that increasing numbers of PHA clients are presenting to community-based organizations issues related to their housing.

In 2005 the collaborative efforts of the partnership resulted in the successful funding of a three year province wide community-based research (CBR) initiative, with the aim to examine housing and health in the context of HIV; and to assess the current and projected housing needs of PHAs in Ontario. This CBR initiative is being funded by Canadian Institutes of Health Research (CIHR), Ontario HIV Treatment Network (OHTN), Wellesley Central Health, the AIDS Bureau, Ontario Ministry of Health and Long-Term Care and the Ontario AIDS Network (OAN).

The Co-Principal Investigators for the study are Ruthann Tucker, Executive Director, Fife House; Dr. Dale Guenter, CLEAR Unit, McMaster University and Dr. Saara Greene, School of Social Work, York University. The Co-Investigators are Dr. Sean Rourke, Ontario HIV Treatment Network; LaVerne Monette, Ontario Aboriginal HIV/AIDS Strategy; Lea Narciso, Ontario AIDS Network; Jay Koornstra, Bruce House; Steve Byers, AIDS Niagara; Michael Sobota, AIDS Committee of Thunder Bay; Dr. James R. Dunn, Centre for Research on Inner City Health, St. Michael's Hospital and Dr. Stephen Hwang, Centre for Research on Inner City Health, St. Michael's Hospital.

Project personnel include a research coordinator and seven research assistants. The research coordinator and three research assistants are based in Toronto; four research assistants coordinate project activities from Ottawa, Niagara and Thunder Bay. Ethical approval for this study has been jointly granted by the Human Subjects Ethical Review Boards at York and McMaster Universities.

Methods

Preliminary Expert Meeting

Since 2002 a partnership was developed between community-based AIDS service organizations (ASOs) and researchers from York and McMaster Universities to study the housing needs of people living with HIV/AIDS (PHAs) as they relate to health and well-being.

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The following were the goals, objectives and outcomes developed:

➤ Goals

The goal of this CBR initiative is to:

- Increase understanding and awareness about the housing needs and experiences of PHAs and to highlight the ways in which current social policy may impact the housing circumstance and stability of PHAs in Ontario;
- Investigate the relationship between quality of housing and security to the physical and mental health of PHAs;
- Investigate the relationship between quality of housing and security to access health care, treatment and social service utilization;
- Examine how housing characteristics may change for PHAs from diagnosis through their life course and identify possible areas for intervention.

➤ Objectives

The main objectives include:

1. Establish a baseline of the housing status of PHAs in Ontario.
2. Identify the range of housing and supportive housing options currently available to PHAs in Ontario, including those provided by ASOs, community-based health and social service organizations and other housing and/or homelessness agencies.
3. Identify the characteristics of appropriate housing and supportive environments for PHAs applicable at various stages of the *disease course*.
4. Determine the kind of housing options desired or required by PHAs that will ensure access to health care, treatment and social services.
5. Identify the factors that affect the housing status and stability of PHAs; and to understand how such factors may impact the physical and mental health of PHAs and their access and utilization of health care, treatment and social services.
6. Determine possible variations in the housing and/or homelessness experiences of PHAs from specific communities: aboriginal communities, ethno cultural communities, women, families, sexual minorities, youth and ex-prisoners.

➤ ***Expected Outcomes***

Specific outcomes that this CBR initiative aims to achieve include:

- The positioning of PHAs in housing situations that improve access to health care, treatment and social services.
- Safe and stable housing situations for PHAs in communities across Ontario.
- The development of effective and appropriate housing policies and supportive care models that support PHAs throughout their life course.

Role of the Investigator Group

This is the first longitudinal CBR initiative in Canada to examine housing and health in the context of HIV. A total of 605 face-to-face quantitative interviews with PHAs from across Ontario have been conducted for the baseline study, fifty of whom will participate in a qualitative sub-study aimed at enhancing our understanding of the housing experiences of PHAs. Participants are required to complete two face-to-face interviews across the study period, one at baseline (completed) and one at 12 months; and a short telephone survey at six months. Honoraria of \$ 50 for the baseline survey has been provided to the participants of the study and \$ 40 for the 12 month survey will be provided. Honoraria of \$ 40 will be provided to participants for the qualitative interviews.

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The investigator group, to ensure that maximum relevant information was captured through the research met regularly to refine the analytical framework and the survey questions and discuss the literature review.

Literature Review

The literature review supported the need to strengthen the understanding and build upon the little information available about the current housing status of people living with HIV/AIDS(PHAs) in Ontario.

Bonuck and Drucker,1998 suggest that the housing situation of PHAs affects their health, particularly in regard to their morale and ability to aggressively pursue treatment and social options, as well as nutrition, exercise and an ability to utilize family and social supports.

Evans, Barer and Marmor (1994) identify factors such as income, housing and social supports as largely influencing the health of marginalized populations. Health Canada has identified a number of determinants of health related to issues of housing in particular. These include: income status; social support networks; physical environments; and access to health services. They have recognized that issues such as low income, social status, and social support can result in difficulties in finding appropriate housing and, therefore, may contribute to the risk of disease progression. Also the lack of housing for PHAs is reflective of an Ontario-wide issue. Many layers of discrimination faced by PHAs, such as homophobia, racism and discrimination based on PHA's drug use, mental health status or accessibility issues, make it difficult to obtain and maintain affordable housing and thus, may result in additional barriers to PHAs accessing health and social services (Mason Willms, Hayes, & Hulchanski, 1981;Bonuck & Drucker, 1998)

The literature review supported the need to investigate a number of interrelated housing issues for PHAs including the need to establish a baseline of the housing status of PHAs in Ontario; to identify the range of housing options currently available to PHAs in Ontario including those provided by AIDS Service Organizations (ASOs), non-ASOs and the supportive housing available to PHAs through mainstream housing and homelessness agencies; to identify the characteristics of appropriate housing for PHAs throughout the different stages of their disease progression; and to determine the kind of housing options required by PHAs that will ensure access to health and social services.

(Detailed literature review can be provided upon request)

Ethics Approval

The research was reviewed and approved by the Human Participants Review Committee (HPRC) within the context of York University Senate policy on research ethics in September 2005. The ethics approval was renewed in September 2006

Stratification

For the purpose of this study, Ontario was stratified into four regions, Greater Toronto Area, Eastern Ontario, Central & South West Ontario and Northern Ontario. Further stratification was also done on the basis of the epi-data- "Report on HIV/AIDS in Ontario, 2004" by Dr. Robert Remis with minor adjustments. For the purpose of this the four regions were stratified as follows

Region	Target	Targets-Achieved
GTA	376	376
Eastern	93	95
Central & South West	91	94
Northern	40	40
Total	600	605

Data Collection

The survey was developed with the input, participation and feedback of the research team. The survey was pre-tested by the Peer Research Assistants (PRAs) and changes were suggested. The team reviewed the changes and final changes were made. The data collection has been completed. Over 676 calls were received from across Ontario to participate in the study. Total of 605 baseline survey interviews were conducted for the four regions between April 2006-September 2006.

Study Launch at OHTN Conference, November 2006

The study was launched at the Ontario HIV/AIDS Treatment Network Conference in November 2005. A panel discussion was organized to inform and promote the study among the attendees.

Website Development, Promotion Material Development & Printing

The study was titled "Positive spaces Healthy places" and a website was developed to promote the study.

- **Website:** www.healthyhousing.ca (French version available on the website)
- **Posters:** Posters, post cards and discreet cards were forwarded to all AIDS service agencies and others across Ontario.
- **Post Cards**
- **Discreet cards:** 1 866 301 2548

The materials can be downloaded from the website.

Study Promotion & Advertisement

- **Xtra- Call for Participant Ad-** A call for participant ad was posted in the April 13, 2006 issue of XTRA
- **Call for participant Ad-** was circulated to all AIDS Service agencies throughout Ontario
- **Newsletters & E-Newsletters:** AIDS Service Organizations across Ontario carried the call for participant ad for Positive spaces Healthy places in Newsletters and e-newsletters and circulated it amongst their service users.

Hiring and Training of Research Coordinator and Peer Research Assistants

Position of Research Coordinator was advertised on charityvillage.com and filled in July 2005. Position of Peer Research Assistants was advertised on charity village website and was forwarded electronically to various agencies across Ontario. Seven peers were hired as research assistants aimed to cover Greater Toronto Area, Central & South West Ontario, Northern Ontario and Eastern Ontario. A three day training workshop was organized in Toronto for the PRAs.

The PRAs are housed at their local agencies – Fife House, AIDS Niagara, AIDS Thunder Bay and Bruce House.

- Seven Peer Research Assistants were trained to screen participants and administer surveys.
- Promotion for the study was undertaken through newspaper advertisement- Call for participants, distribution of posters, postcards and 1-866 cards to agencies across Ontario.
- Participation and support of the community-based organizations was sought through one to one contact. CBO and ASOs extended their support by promoting the study through their websites and by their support staff forwarding the information to their service users.

Process

- The participants interested in the study call the number assigned to the study 1 866 301 2548 or 416 642 0181 for Toronto.
- Voice mail has been set up for prospective participants to leave their contact information.
- The information is entered into a database by the Research Coordinator.
- The Research Coordinator then assigns the call backs to the peer research assistants across Ontario.
- The PRAs call back the prospective participants to screen them for eligibility to participate in the research study. A date/venue/time is finalized for a survey interview.
- The data is initially stored at the local locations identified for the study and then forwarded to the Research Coordinator to be stored centrally at Fife House.

Project Timelines

- All activities and progress of the project are reported in the monthly team meetings with the principal investigators and co-investigators. This ensures that the project is meeting the timelines and moving in the right direction.

- Regular updates by the Research Coordinator to the supervisory group comprising of the Principal Investigators ensures the same.

Current positioning of the research project

The project has completed its first phase of data collection and we are in the process of data analysis and interpretation.

Results

This is a longitudinal study over a period of three years. The project is at the stage of baseline Data Analysis. The interim data from the baseline survey will become available by October 2006. In keeping with the guiding principles of CBR, quantitative and qualitative data analysis will include community-feedback initiatives; dissemination of research findings and action-outcome activities will be directed towards established relationships with relevant policy makers, community leaders and program providers in the areas of housing and supportive care.

Discussion/Implications

Full Participation of community in identifying the issue:

Implication- This led to recognizing the urgent need for the research and enthusiasm among the community for information about correlation between housing status of PHAs and Health outcomes.

Participation of Community in study design and proposal submission:

Implication- This led to developing a study approach, which was accepted by the community and would strengthen the community.

Participation of community in recruitment and capacity building:

Implication- This led to ability of the project to recruit, identify and train peers to participate in the study process.

Development of instrument through community input, tested in the community and by the community members:

Implication-This helped in developing an instrument sensitive to the issues of this community and increased reliability and validity of the data.

Community members participate in the interpretation and data analysis:

Implication-This led to the information translation in a manner more relevant to the community and generation of data that can be effectively used to inform policy change.

3. Project Outcomes

(Please describe any program, policy or partnership outcomes that have resulted from your research initiative).

The analysis of the data for the baseline study are not yet available. The outcomes of the project will be presented at the end of the three year period.

4. Dissemination

The project outcomes will become available at the end of three years period and the dissemination of the final outcomes will be reported at that time. The results of the baseline data will be presented at various conferences and meetings. Presentations made so far for the study are:

Conferences, Forums and Meetings:

i) Ontario HIV Treatment Network (OHTN) Research Conference, 2005

Plenary Session: Positive spaces Healthy places: a model of community-based research aimed at influencing HIV, Housing and Health practice and policy.

ii) International Urban Health Conference, 2005

Poster Presentation: Social Inclusion, Social Justice and HIV/AIDS: A community-based research approach to examine the link between HIV/AIDS, Health and Housing.

iii) Annual Canadian Conference on HIV/AIDS Research (CAHR), 2006

Poster Presentation: Whose capacity are we building through HIV/AIDS community-based research?

iv) Canadian Association of Schools of Social Work (CASSW) Conference, 2006

Panel Presentation: Social Inclusion, Social Justice and HIV/AIDS: A community-based research approach to examine the link between HIV/AIDS, health and housing.

v) Ontario AIDS Network- Annual General Meeting, 2006

Presentation: Positive spaces Healthy places-Encouraging participation in community-based research

vi) The Ontario HIV outpatients Clinic Network Quarterly Meeting, June 2006

Presentation: Positive spaces Healthy places-Making a difference through participation in community-based research.

vii) XVI International AIDS Conference, August 2006

Presentation: Building Community-Based Research Capacity Through Exploring the Impact of Housing Status on People Living with HIV/AIDS in Ontario

viii) XVI International AIDS Conference, August 2006

Satellite Symposium-Presentation: Innovations and Partnership to Improve Health Outcomes for People Living with HIV/AIDS and Communities at Risk

5. Next Steps

How will you use this research to further your work? How will you sustain the initiatives and partnerships developed? What are the next steps for your collaborative?

Data Analysis: The data from the baseline survey is being screened for the following information:

1. The housing status of PHAs in Ontario.
2. Identify the range of housing and supportive housing options currently available

to PHAs in Ontario, including those provided by ASOs, community-based health and social service organizations and other housing and/or homelessness agencies.

3. Identify the characteristics of appropriate housing and supportive environments for PHAs applicable at various stages of the *disease course*.
4. Determine the kind of housing options desired or required by PHAs that will ensure access to health care, treatment and social services.
5. Identify the factors that affect the housing status and stability of PHAs; and to understand how such factors may impact the physical and mental health of PHAs and their access and utilization of health care, treatment and social services.
6. Determine possible variations in the housing and/or homelessness experiences of PHAs from specific communities: aboriginal communities, ethno cultural communities, women, families, sexual minorities, youth and ex-prisoners.

Final Outcomes: The final outcomes will be used to establish

- The positioning of PHAs in housing situations that improve access to health care, treatment and social services.
- Safe and stable housing situations for PHAs in communities across Ontario.
- The development of effective and appropriate housing policies and supportive care models that support PHAs throughout their life course.

The outcomes of this research will be available to pursue further research, within and outside Canada

Knowledge Transfer/Dissemination of Results

Stakeholders

- Research Participants
- Community Members, PHA's
- AIDS Service Organizations (ASO's) across Ontario
- Community Based Organizations (CBO's) across Ontario related to HIV, Housing or Homelessness
- Researchers (Academic and Community-Based)
- Key Decision Makers/ Policy Makers- Ministry of Health & Long Term Care

Methods Of Dissemination (Final Outcomes)

Stakeholders: Research Participants, Community Members, ASOs, CBOs, Housing Providers (within and outside Ontario)

- Research findings posted on the website www.healthyhousing.ca
- Links to the healthy housing website through website of various ASOs, CBOs & Funding Agencies
- Research findings to be circulated through E- Newsletter to ASOs & CBOs
- The information will further be forwarded to the service users of these agencies
- Newsletter Articles
- Reports- Self published Reports
- Press Releases
- Presentations, Workshops at Conferences
- Community Forum/Briefings
- OHTN-Knowledge Transfer Exchange Program
- Think Tank Workshop

Stakeholders: Researchers

- Scientific Journal Articles
- Newsletter Articles
- Academic Conferences
- Press Releases
- Reports-Self Published
- OHTN-Knowledge Transfer Exchange Program
- Website
- Think Tank Workshop

Stakeholders: Key Decision Makers/Policy Makers- Ministry of Health & Long Term Care

- Report Submission- Hard Copies, E-Reports, Fact Sheets
- Presentations, Workshops at Conferences
- Think Tank Workshop (Attendees: Community Members, PHA's, Researchers, Investigators, Policy Makers, Funders, ASO's, CBO's)
- Community Feedback
- Press Releases

6. Lessons learnt/ Challenges/Barriers

Lessons Learnt

- This partnership has brought together the best of skills, ideas and experiences from all areas. This we believe has led to a well grounded research. The research team comprising of various AIDS Service Organizations, academic researchers and PHAs has given the study the sight, enthusiasm and impetus that is essential for a community-based research.
- Collaboration improved quality of the procedures developed and questionnaire designed.
- Support from ASOs and CBOs is crucial to the success in meeting the targets of this study. Community agencies provided the most effective way to reach the study participants.

- Partnerships enhance the quality and broaden the scope of the research.
- Data Analysis with inclusivity and team effort of the community members, service providers and researchers led to insights which could easily have been ignored in the absence of any of the representative groups.
- Interpretation of data in a manner relevant to the community by the participation of community members has projected different insight and learning.
- Collaboration in this instance has led to more useful data generation.

Challenges/Barriers

- Study Design: The designing of the survey took longer than planned.
- Training: More, In-depth training and constant support is required to guide and build capacity of the Peers as Research Assistants of the study as they do not have research related backgrounds.
- Recruitment and Retention: Recruitment and retention of Peer Research Assistants has been a constant challenge. Due to personal challenges, the peer research assistants had to take time off the study, new assistants were hired and trained on an ongoing basis.
- Team Coordination: Coordinating the team activities of the Investigator group also presented some challenges. The process also required extra mutual learning and negotiation.

Addressing Challenges

- Although it took longer to design the survey but the research approach and the instrument became much more acceptable to participants after the input from the community members.
- Training and constant support to the peer research assistants enhanced their skills and met one of the most important objective of the community-based research i.e. building capacity of the community
- Understanding the personal challenges of the peers as research assistants and providing support to them led to a feeling of ownership for the study among this group. Some of the peer research assistants even returned to the study after having addressed their personal issues.
- Greater learning and understanding of the process of research, of community and of the value of this research were outcomes a team consisting of partnership between service providers, community members and researchers.

7. Budget vs. Actual

Attached