



Positive
spaces
Healthy
places

HIV, HOUSING AND HEALTH RESEARCH IN ACTION





Positive
spaces
Healthy
places

HIV, HOUSING AND HEALTH RESEARCH IN ACTION

2005-2015

Acknowledgements

This report has been produced by the OHTN in cooperation with the Positive Spaces Healthy Places Research Team, and is dedicated to the memory of LaVerne Monette, Pius J. White, and Michael J. Hamilton, who have since passed away.

Funding for Positive Spaces Healthy Places was provided by:



The researchers also wish to warmly acknowledge:

The Study's Peer Research Assistants: D. B Hintzen, J. Lauzon, Jim Truax, Marie Kayitesi, Marisol Desbiens, Mary M., Miguel Cubillos, Rob Rollins, Scott de Blois, James Gough, Mary Kato, Jasmine Cotnam, Wayne Bristow, Pius J. White, Michael J. Hamilton, Tim Walker and Stephanie Smith.

The leaders of Positive Spaces Healthy Places: Sean B. Rourke, Saara Greene, Ruthann Tucker, Jay Koornstra, LaVerne Monette, Michael Sobota, Keith Hambly, James Watson, Amrita Ahluwalia, Stephen W. Hwang, Doe O'Brien-Teengs, Glen Walker, Tsegaye Bekele, and Jean Bacon.

Ontario AIDS service organizations who participated in the study:





Contents



Summary...	1
Study Purpose...	3
Methodology...	5
Findings...	7
Impact...	13
Conclusion...	16



Summary

Started in 2005, Positive Spaces Healthy Places, a Canadian Institutes of Health Research-funded, longitudinal community-based research study, was designed to better understand the depth and breadth of housing issues faced by people living with HIV in Ontario, Canada.

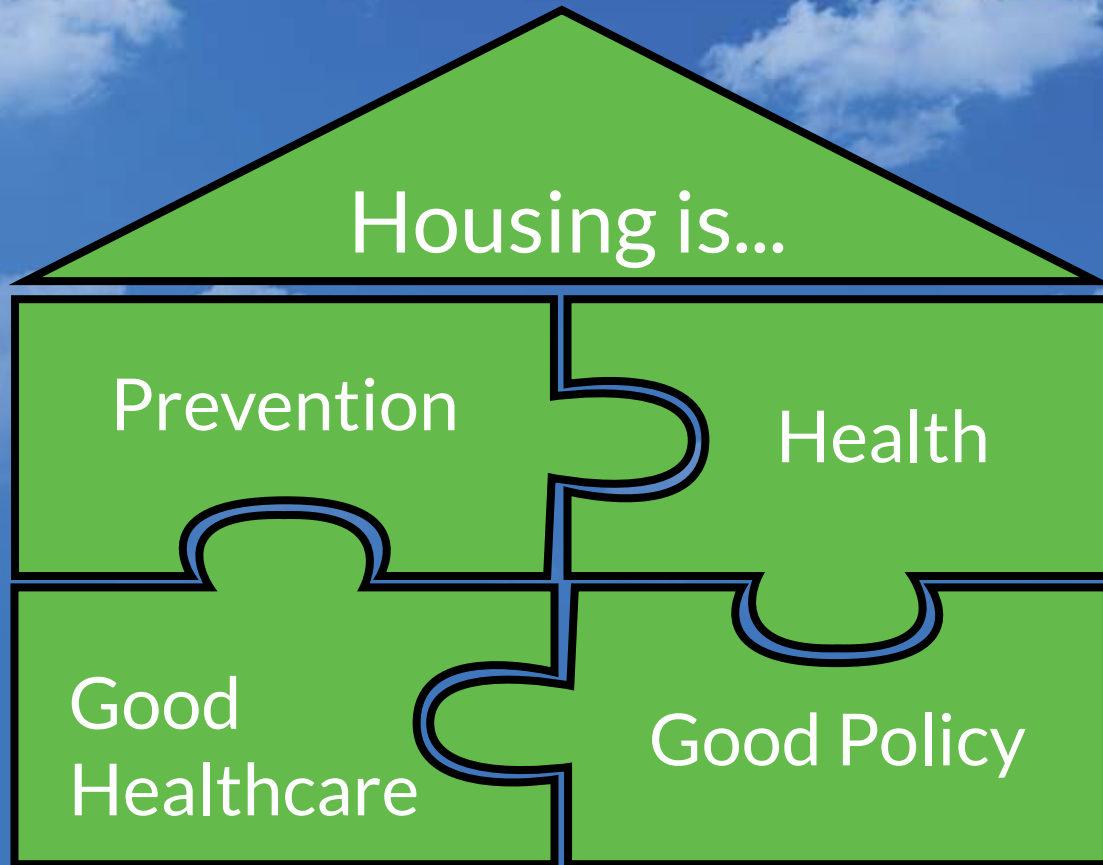
More than 600 people living with HIV were interviewed up to four times about their housing experiences, over a five-year period. The study was one of the first to examine the social determinants of health among people living with HIV and to analyze housing issues faced by parents and families living with HIV.

Positive Spaces Healthy Places serves as an example of how HIV research can be conducted while respecting the Greater and Meaningful Involvement of People Living with HIV/AIDS principles.

People living with HIV were involved as researchers from the study's earliest stages, and interviews were conducted by Peer Research Assistants. Researchers built strong partnerships with the HIV/AIDS community, as well as policy makers, strengthening the study beyond what could have otherwise been achieved.

Study findings highlight the impact of unstable housing on physical and mental health-related quality of life, the unique challenges faced by Indigenous peoples, and the importance of addressing poverty and inequality in relation to housing issues.

Findings from Positive Spaces Healthy Places have already led to increased funding, collaboration, awareness and policy changes at the local and national level. Positive Spaces Healthy Places' methodology continues to influence other HIV-related studies, and its partners continue to advocate for more responsive housing services for people living with HIV.



Housing is Prevention

People with HIV who face housing instability have significantly poorer physical and mental health and decreased health related quality of life. Housing interventions can lower a person's risk of transmitting HIV.

Housing is Good Healthcare

People with stable housing are more likely to access medical services and adhere to treatment regimens; people who are unstably housed are less likely to initiate treatment or access health care and social services.

Housing is Health

When people with HIV have safe and stable housing, and feel they belong in their neighbourhoods, they are healthier. When they don't have to move more than once in a year or worry about losing their housing, they enjoy better quality of life.

Housing is Good Policy

Policies that increase access to stable, appropriate, affordable and supportive housing improve the overall health of people with HIV and help prevent HIV transmission, thereby reducing overall health and housing costs.

Study Purpose

In the early 2000s, housing was identified by front line leaders as a serious concern for people living with HIV in Ontario. Before 2002, people living with HIV had priority with Housing Connections in the Greater Toronto Area but, when that changed, AIDS service organizations in the province began to report an increase in the number of clients experiencing housing instability.

Although frontline workers already knew that access to stable housing had a significant impact on the health of people living with HIV, Ontario and Canada lacked systematic data on the depth and breadth of housing needs.

Started in 2005, Positive Spaces Healthy Places was the first longitudinal community-based research initiative in Canada to examine the relationship between housing stability and health for people living with HIV. This unprecedented effort to quantify housing needs and impact in Ontario was so successful that, in 2009, Positive Spaces Healthy Places became the first community-based housing-related research project to be re-funded by the Canadian Institutes of Health Research.

Lessons learned from Positive Spaces Healthy Places have the potential to influence research practices as well as policy changes.

“Housing Instability” describes a fluid continuum of homelessness that includes sleeping rough, day and night drop-ins, use of homeless shelters, use of rooming houses, unstable housing, and stable housing.

Tremblay J, Ward J (1998) *Homeless voices: follow-up to the homeless, not helpless report*. Toronto Health City Office, Toronto

The social determinants of health are the social and economic conditions in which people live and age. Positive Spaces Healthy Places collected demographic information related to age, gender, ethnicity, employment, and other social factors.

Positive Spaces Healthy Places was committed to bolstering connections within the HIV community and driven by unique research questions related to the social determinants of health. Its goals were to:

- 1** Identify the range of housing options available in Ontario
- 2** Determine how housing and homelessness experiences vary
- 3** Investigate the relationship between housing quality/security and physical/mental health, and access to healthcare, treatment, and social services
- 4** Examine how housing changes for people living with HIV over time
- 5** Increase understanding and awareness about housing needs and experiences
- 6** Identify the characteristics of healthy housing

Using collaborative and respectful research methods was just as important to the Positive Spaces Healthy Places research team as answering the study's research questions. Researchers placed high value on:



Interconnection between evidence-based practice and practice-based evidence



Research as a culture, not just an activity



Solving problems together, through partnership and collaboration



Methodology

Positive Spaces Healthy Places succeeded, in part, because of the values shared by the team, and because of the strong relationships and collaboration between academic, community and policy partners. Each group provided unique skills and knowledge that strengthened the study as a whole, allowing it to achieve what none of its partners could have accomplished alone. As a partner in Positive Spaces Healthy Places, the Ontario HIV Treatment Network provided continuity, infrastructure and material support in addition to its researchers and analysts.

Our diverse stakeholders played key roles in the study by:



- connecting with key stakeholders
- providing strategic advice to influence programs and services



- building a rigorous evidence-based case for investing in housing
- publishing findings in peer-reviewed journals to build knowledge base



- engaging and involving the community
- enhancing community morale
- sharing personal experiences
- showing leadership by moving research into action

From the beginning, Positive Spaces Healthy Places was unusually ambitious in its goal to gather province-wide data. Over 600 participants were interviewed up to four times as part of the study. The sample was selected to reflect the diversity of people living with HIV in Ontario, both in terms of region and social demographics.

Researchers were able to engage hard-to-reach and underrepresented populations by ensuring that all aspects of the research, including recruitment, study design, data collection and analysis involved the participation of community partners.

In addition to involving people living with HIV as Co-Investigators in the study, Positive Spaces Healthy Places also adhered to the Greater and Meaningful Involvement of People Living With HIV/AIDS principle by employing Peer Research Assistants.

Peer Research Assistants were involved in every stage of the research process, and the study benefited through:

- **Enhanced engagement of participants**
- **More complete data collection**
- **Better participant retention**
- **Stronger connections between people living with HIV and the research.**

“The experience changed my life because I felt like I gained some control and power back; moving from the experience of being a [person living with HIV] as being negative to very positive.”

– Positive Spaces Healthy Places Peer Research Assistant

Peer Research Assistants also benefited through their involvement by:

- **Developing their research skills**
- **Securing gainful employment**
- **Improvements in their quality of life**
- **Helping to shape research that directly affects them.**

This model proved so effective that the Ontario HIV Treatment Network established an interactive educational environment for peer researchers in The Learning Place for Community-Based Research in HIV/AIDS (<http://tlp.ohtn.on.ca>) to support Peer Research Assistants across Canada. The OHTN has also continued to build its research studies around this approach.

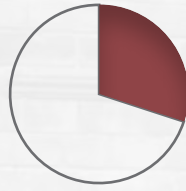


Findings

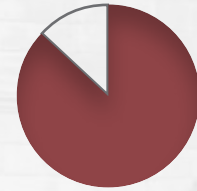
Findings from Positive Spaces Healthy Places highlight the complex range of social and economic factors related to housing instability, as well as the need for equally-complex solutions.



Approximately **50%** of participants experienced housing instability



Over **30%** were at risk of losing their homes



87% were unable to meet their basic needs (e.g., food, clothing, housing)

Positive Spaces Healthy Places demonstrated that housing instability, including inappropriate and unsafe housing, is significantly associated with poorer mental and physical health among people living with HIV. Participants with unstable housing were more likely to:

- Have substance use issues
- Experience depression and higher levels of stress
- Have lower CD4 counts
- Have higher viral loads
- Have higher mortality rates

People living with HIV who face housing instability are less likely to:

- Access medical and social services
- Access antiretroviral therapy
- Adhere to antiretroviral medications

“When I wake up every day I’m just like every other mother. And when my child looks at me, I’m the best thing she has in the whole world. But in case something happens — we are living in this house, she’s just under my umbrella. She’s under me; my umbrella. But if something happens to me, then she doesn’t have her home. That’s my main concern... What happens to our kids?”

— Positive Spaces Healthy Places Participant

Indigenous participants faced unique challenges compared to Caucasian participants. Indigenous participants were more likely to:

- Have a history of incarceration
- Have a history of homelessness
- Report perceived housing discrimination
- Live in unstable housing
- Live in supportive housing, or receive rent subsidies

Positive Spaces Healthy Places was one of the first studies to examine housing for parents and families living with HIV. Researchers conducted qualitative interviews with HIV-positive parents, which revealed concerns about:

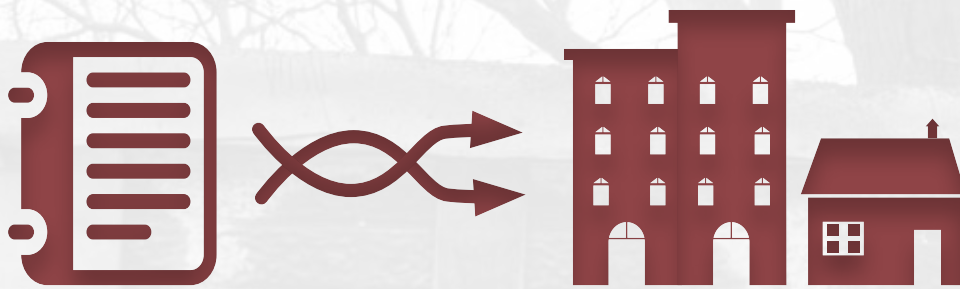
- Adherence to their medication
- Living in inappropriate or unsafe neighborhoods and housing situations
- Stigma, discrimination, and the need for privacy surrounding their HIV status
- Poverty and finances
- What would happen to their children in the event of an emergency



Data from Positive Spaces Healthy Places were also used to form a picture of what healthy housing looks like, emphasizing safety, housing and economic security, and social inclusion as facilitators to well-being. Housing solutions for people living with HIV must:

- Address financial and social concerns to ensure stability
- Attend to the physical and emotional safety of people living with HIV
- Be non-stigmatizing
- Foster social support and a sense of community

Results show that housing is a building-block to better living, thereby reducing stress, and forming the foundation for long-term economic security.



Moving Research into Action

Research became a form of action in Positive Spaces Healthy Places. As a community-based study, every step was guided by the needs of people living with HIV, who took an active role in leading and shaping the process.

The research process itself was transformative, in ways that can't be expressed through numbers. Positive Spaces Healthy Places was a study by and for people living with HIV that served as a model

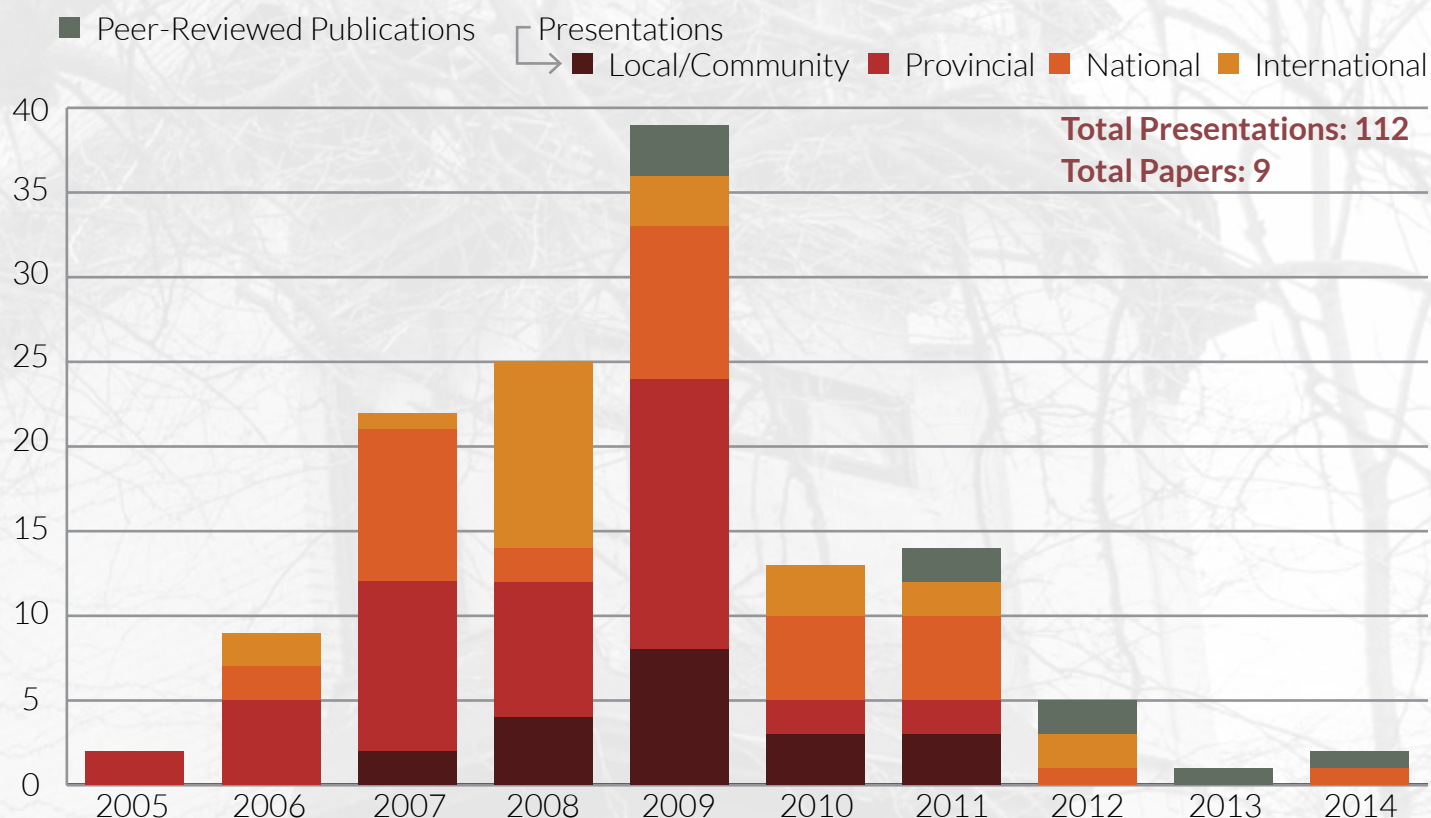
for how to conduct collaborative research, and helped build skills and relationships that have a life beyond its end.

Community engagement was the heart of the study. The process of coming together and taking constructive action — to gather information, to build a case, to solve a problem — has had as much lasting impact as any other study result.

“My mental health changed and also my physical health changed. Yes, I started to look better physically and mentally I start to think clear, I have my own space, I have my own time. I became more focused and I started to look for other problems like how to deal with my HIV rather than housing... I start to think of the future.”

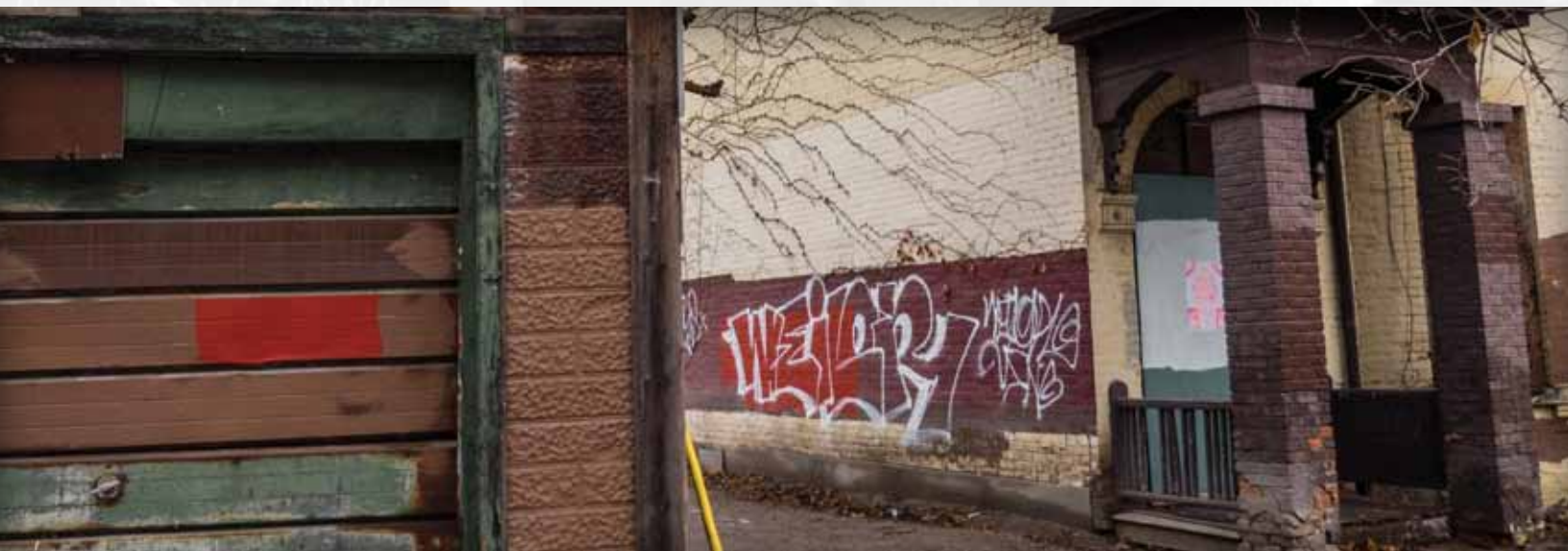
— Positive Spaces Healthy Places Participant

Positive Spaces Healthy Places Publications and Presentations Since 2005



The study's researchers built national and international credibility for Positive Spaces Healthy Places by sharing their findings early, and with a wide audience. They have been presenters at HIV/AIDS-focused conferences, such as the Canadian Association for HIV Research conference, as well as at conferences focussed on housing (such as the Baltimore and North American Housing Summits), urban health, social work, homelessness and the health of Indigenous people. The researchers also placed high priority on grounding their work at the local and provincial level, sharing their findings in the communities that helped the study grow.

Looking toward the future, researchers from Positive Spaces Healthy Places will keep developing relationships with local, national and international organizations, publishing peer-reviewed papers, and updating healthyhousing.ca with new information. Although the study has ended, the work to improve housing for people living with HIV continues.





List of Peer-Reviewed Publications

Positive Spaces Healthy Places researchers have published nine papers based on study data. Copies may be requested through info@ohtn.on.ca.

“Under My Umbrella”: The housing experiences of HIV positive parents who live with and care for their children in Ontario

Saara Greene • Ruthann Tucker • Sean B. Rourke • LaVerne Monette • Jay Koornstra • Michael Sobota • Steve Byers • Stephen Hwang • James Dunn • Dale Guenter • Amrita Ahluwalia • James Watson

Published online in *Archives of Women’s Mental Health*, 2009.

Housing Status and Health Outcomes in Aboriginal People Living with HIV/AIDS in Ontario: The Positive Spaces, Healthy Places Study

LaVerne Monette • Sean B. Rourke • Ruthann Tucker • Saara Greene • Michael Sobota • Jay Koornstra • Steve Byers • Amrita Ahluwalia • Tsegaye Bekele • Jean Bacon • Christine Johnston • Stephen Hwang • James Dunn • Dale Guenter • the Positive Spaces Healthy Places Team

Published in *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research*, 2009.

Between skepticism and empowerment: the experiences of peer research assistants in HIV/AIDS, housing and homelessness community-based research

Saara Greene • Amrita Ahluwalia • James Watson • Ruthann Tucker • Sean B. Rourke • Jay Koornstra • Michael Sobota • LaVerne Monette • Steve Byers

Published in the *International Journal of Social Research Methodology*, 2009.

Inequalities in Determinants of Health Among Aboriginal and Caucasian Persons Living With HIV/AIDS in Ontario: Results From the Positive Spaces, Healthy Places Study

Laverne E. Monette • Sean B. Rourke • Katherine Gibson • Tsegaye M. Bekele • Ruthann Tucker • Saara Greene • Michael Sobota • Jay Koornstra • Steve Byers • Elisabeth Marks • Jean Bacon • James R. Watson • Stephen W. Hwang • Amrita Ahluwalia • James R. Dunn • Dale Guenter • Keith Hambly • Shafi Bhuiyan • the Positive Spaces Healthy Places Team

Published in *Canadian Journal of Public Health*, 2011.

Social Determinants of Health in HIV/HCV Co-infection Compared to HIV Infection Only: Results from the “Positive Spaces, Healthy Places” Study

Sean B. Rourke • Michael Sobota • Ruthann Tucker • Tsegaye Bekele • Katherine Gibson • Saara Greene • Colleen Price • Jay Koornstra • LaVerne Monette • Steve Byers • James Watson • Stephen W. Hwang • Dale Guenter • James Dunn • Amrita Ahluwalia • Michael G. Wilson • Jean Bacon • the Positive Spaces Healthy Places Team

Published in *Open Medicine*, 2011.

Housing Characteristics and their Influence on Health-Related Quality of Life in Persons Living with HIV in Ontario, Canada: Results from the Positive Spaces, Healthy Places Study

Sean B. Rourke • Tsegaye Bekele • Ruthann Tucker • Saara Greene • Michael Sobota • Jay Koornstra • LaVerne Monette
Jean Bacon • Shafi Bhuiyan • Sergio Rueda • James Watson • Stephen W. Hwang • James Dunn • Keith Hambly • the
Positive Spaces Healthy Places Team

Published online in *AIDS and Behaviour*, 2012.

Direct and indirect effects of perceived social support on health-related quality of life in persons living with HIV/AIDS

Tsegaye Bekele • Sean B. Rourke • Ruthann Tucker • Saara Greene • Michael Sobota • Jay Koornstra • Laverne Monette
Sergio Rueda • Jean Bacon • James Watson • Stephen W. Hwang • James Dunn • Dale Guenter • the Positive Spaces
Healthy Places Team

Published in *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV*, 2012

Unmet Basic Needs in HIV: The Moderator Effect of Age on Poor Health-Related Quality of Life

Phan Sok • Sergio Rueda • Sandra Gardner • Ruthann Tucker • Saara Greene • Michael Sobota • Jay Koornstra • LaVerne
Monette • Keith Hambly • Stephen W. Hwang • James Watson • Tsegaye Bekele • Glen Walker • Sean B. Rourke • the
Positive Spaces Healthy Places Team

Published in *AIDS Patient Care and STDs Journal*, 2013

Not Just “A Roof over Your Head”: The Meaning of Healthy Housing for People Living with HIV

Lori A. Chambers • Saara Greene • James Watson • Sean B. Rourke • Ruthann Tucker • Jay Koornstra • Michael Sobota •
Stephen Hwang • Keith Hambly • Doe O’Brien-Teengs • Glen Walker • the Positive Spaces Healthy Places Team

Published online in *Housing, Theory and Society*, 2014

Four additional papers will be published in 2015. These papers address food insecurity and mental health as they relate to housing, as well as the effects of housing on survival. There are also plans to publish a summary paper that will address housing instability issues over a five-year period, and discuss how housing issues relate to health and well-being. More details will be available at healthyhousing.ca.



Impact

Findings from Positive Spaces Healthy Places have already led to increased funding, collaboration, awareness and policy changes. Data have been used to secure additional funding and support for local, national and international organizations, and researchers have built relationships with partners worldwide.

Local Highlights:



More Funding for Housing

- FIFE House secured **\$19 million** for supportive housing
- Positive Living Niagara secured an additional **\$200,000 in annual funding** for supportive housing
- FIFE House and LOFT Community Services secured **\$500,000 in ongoing funding** for the Addiction Supportive Housing Program
- The Canadian Mental Health Association and the Sandy Hill Community Health Centre (Oasis) received **funding for an Intensive Case Management Program using a Housing First Model** with rent supplements for 96 individuals including people with HIV and having mental health/addiction issues
- HIV/AIDS Regional Services secured **\$350,000 for five HIV housing units** in Belleville, the last of which will be in place in 2017



Policy Changes

- People with HIV and substance use issues are now **eligible for new supportive housing** developed for people with addictions in Ontario
- The **strategic plans of FIFE house and Bruce House** were both influenced by Positive Spaces Healthy Places
- Study data have been cited in the **Ontario Human Rights Commission report** Right At Home: Report on the Consultation on Rental Housing and Human Rights
- After reviewing the data from Positive Spaces Healthy Places, Thunder Bay **added a fifth pillar, concerning housing, to its Municipal Drug Strategy.**

“The funding is really important. ... These buildings... they’re so essential to people. They’re a source of community, they’re a source of support, they’re a source of shelter. They’re not just, like, a roof over your head – it’s more than that.”

– Positive Spaces Healthy Places Participant



More Research

- Positive Spaces Healthy Places’ study **model is being replicated across Canada**, in BC and Quebec, adding to the body of research
- The Canadian Aboriginal AIDS Network has established **new studies to investigate appropriate housing options for Indigenous people** living with HIV
- Positive Spaces Healthy Places helped inspire the Ontario **Housing Measures Project**, which seeks to measure the impact of supportive housing on quality of life and independence for people living with HIV

National and International Highlights:



- A satellite session on Poverty, Homelessness and HIV/AIDS was held at the **International AIDS Society meetings** in 2013
- A Knowledge-to-Action Symposium was jointly held by the Ontario HIV Treatment Network, Positive Spaces Healthy Places, and the North American Housing Coalition at the **Canadian Association for AIDS Research conference** in 2008
- Several presentations using study data were delivered at **International AIDS Housing Roundtables** in North America and Europe
- More than 150 delegates endorsed **a declaration asking policy makers to “recognize housing as a human right** and address the lack of adequate housing as a barrier to effective HIV prevention, treatment, and care.”

The study’s partners continue to advocate for more responsive housing services and hope to build even more ambitious data collection systems in the future.



National Housing Collaborative



One further impact of Positive Spaces Healthy Places was the formation of a National Housing Collaborative, first developed at the Canadian Institutes of Health Research Research to Action Symposium. Through building partnerships with service providers, and experts in research, policy and education, the collaborative is able to pool knowledge and resources related to housing issues.

RESEARCH, POLICY AND EDUCATION

Canadian Aboriginal AIDS Network, *Ottawa*
Canadian AIDS Society, *Ottawa*
Canadian Association of HIV Research
Canadian Housing & Renewal Association
Columbia University, *New York*
CIHR Centre for REACH, *Toronto*
COCQ-SIDA, *Montreal*
McMaster University, *Hamilton*
National Aboriginal Housing Association
Ontario HIV Treatment Network, *Toronto*
Pacific AIDS Network, *Vancouver*
San Francisco Department of Public Health, *San Francisco*
SHARP Foundation, *Calgary*
University of Victoria, *Victoria*
York University, *Toronto*

SERVICE PROVIDERS

AIDS Committee of Newfoundland & Labrador, *Newfoundland*
Elevate NWO, *Thunder Bay*
AIDS Vancouver Island, *Vancouver*
ASK Wellness (AIDS Society of Kamloops)
Alberta Health Services, *Edmonton*
Bruce House, *Ottawa*
Blood Ties Four Directions, *Whitehorse*
Catholic Social Services, *Edmonton*
Dr. Peter Centre, *Vancouver*
Fife House, *Toronto*
John Gordon Home, *London*
LOFT Community Services, *Toronto*
Maison D'Herelle, *Montreal*
McLaren Housing Society, *Vancouver*
Positive Living BC, *Vancouver*
Positive Living Niagara, *Niagara*
Positive Women's Network, *Vancouver*



Conclusion

Positive Spaces Healthy Places was a ground-breaking study that provided quantifiable data about housing issues for people living with HIV in Ontario. Its partners, researchers and participants have laid the foundation for ongoing research into housing and HIV, and provided a wealth of knowledge to inform policy decisions. Looking toward the future, the research team strongly recommends:

- Increasing the availability of housing for people living with HIV, both inside and outside of supportive housing
- Increasing the availability of appropriate housing support services
- Improving non-HIV housing service providers' responsiveness to and understanding of the housing needs of people living with HIV
- Increasing collaboration and partnerships to support capacity building
- Undertaking more focussed housing policy development, advocacy, and research initiatives, in partnership with governments, decision-makers, and provincial organizations

Complex issues such as housing stability can only be addressed through the sustained cooperation of researchers, policymakers, and community members, including people living with HIV. The success of Positive Spaces Healthy Places shows what we can accomplish when we work together to support change, create lasting policy, and improve the lives of people with HIV.

A Special Thank You

The researchers would like to take this opportunity to thank all of the participants who contributed their stories and personal information in the hopes of establishing the link between the social determinants of health, housing, and personal well-being. Without them, there would have been no opportunity to move this field of study forward in Canada. Their contributions are helping others affected by HIV across the nation.

More details about the data from Positive Spaces Healthy Places, including fact sheets and slide decks for use in the HIV sector, are available at healthyhousing.ca.

