

COMMUNITY-BASED RESEARCH WITH LGBTQ COMMUNITIES

Since the 1970s, lesbian, gay, bisexual, and trans (LGBTQ) people have become increasingly savvy about the kinds of research they agree to support with their participation. Increasingly, they are demanding greater involvement in research that pertains to them and their health.

Community-based research (CBR) is done in partnership with LGBTQ communities themselves. CBR begins with a research topic of relevance to the LGBTQ community and the research is often carried out in community settings (1). CBR views LGBTQ community members as experts in their own right, whose knowledge is vital to the success of the research. In CBR projects, LGBTQ community members may serve on research teams, help design the study from the ground up, interview participants, analyze data, write reports, and disseminate findings, as well as provide advice and oversight. CBR aims at solving “real world” problems in ways that are meaningful and empowering for LGBTQ communities (1).

WHY USE CBR?

CBR has four significant advantages to offer the researcher:

1. CBR can enhance LGBTQ community capacity for greater advocacy efforts.
2. CBR can increase the relevance and validity of LGBTQ research studies by elevating the status of LGBTQ community knowledge to that accorded to academic knowledge.
3. CBR can enhance theoretical understanding of LGBTQ issues by incorporating lived experience into all aspects of study design.
4. CBR can facilitate action-oriented change, enhance LGBTQ health and improve the quality of life in LGBTQ communities by building very trusting relationships.

THE CONTEXT OF CBR RESEARCH WITH LGBTQ COMMUNITIES

- Community Campus Partnerships for Health (www.ccph.info) argues that CBR has emerged at a time when there is increasing recognition that the complex problems facing communities cannot be solved using mainstream approaches to research.
- LGBTQ communities have good reason to be suspicious of research. Although homosexuality was removed from the Diagnostic and Statistical Manual of Mental Disorders (DSM) in 1973, a mental illness called “ego dystonic homosexuality” remained in the DSM until 1986, allowing psychiatrists to treat people’s discomfort with their same sex attractions, rather than focussing on the cause of that discomfort.
- Many non-CBR research studies have damaged LGBTQ communities. Laud Humphries’ 1970 study of men who sought sex in public bathrooms, for example, did not obtain informed consent. Humphries used men’s licence plates to trace their home address and interviewed them without revealing the nature of his research (2). More recently, a 2005 study reported that in terms of their arousal patterns, bisexual men were indistinguishable from gay men, leading them to speculate that male bisexuality was not

rooted in sexual response (3). That study was covered by the New York Times under the heading “Gay, Straight or Lying,” and contributed to the invisibility and erasure of bisexual men (3-4). A uniquely bisexual pattern of arousal in men has since been found, although with less broad media reportage (5).

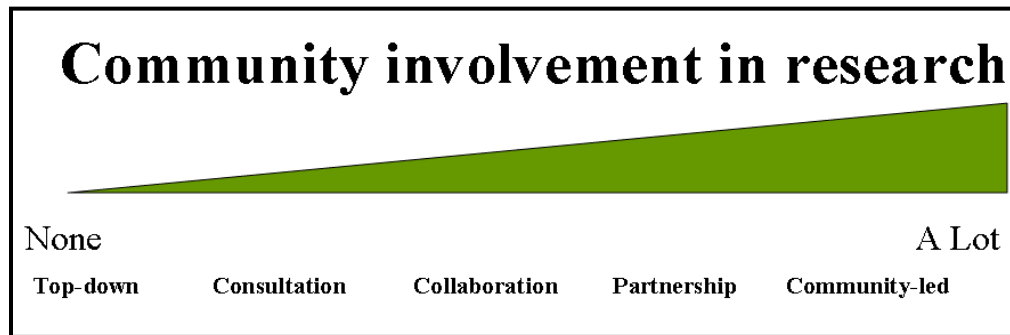
- Drawing on activist roots, LGBTQ community members began to demand that research expose the social conditions that create health disparities, and address the local needs of LGBTQ community members.
- Increasingly, health care practitioners, researchers and policy-makers have begun to accept that the local knowledge that community members bring to CBR can lead to the most scientifically sound research. A systematic review of the academic literature prepared for the Agency for Healthcare Research and Quality of the U.S. Department of Health and Human Services countered criticism that CBR was not objective, rigorous, or effective as a tool for social change (6). A 2008 study of LGBTQ researchers by Rainbow Health Ontario found that CBR projects increased research capacity, generated new knowledge, fostered community inclusion, and benefitted the LGBTQ community (7).
- CBR projects help students develop skill at researching LGBTQ populations by enabling them to translate theory into practice. Researchers have found that students who participate in CBR projects exhibit greater proficiency at research (8).

WORKING WITH COMMUNITY PARTNERS

- The role of community members in a CBR project will vary, depending on the resources available to a community, the degree of organization within an LGBTQ community, and the level of trust between community and academic partners. In some instances, community members play advisory roles, while in others they are co-investigators, and research partners (9).
- There may not always be a clear distinction between community members and researchers, as LGBTQ people themselves are increasingly entering the research field. In the Risk & Resilience project, a CIHR-funded study of the mental health of bisexual people in Ontario, the majority of members on the research team met the project’s definition of bisexual, yet the study also had a community advisory committee made up of people with experience in bisexual community building, support and activism.
- Using an equity-based approach, community partners should play roles in research studies that are based on their existing knowledge and skills, and their desire to build or strengthen individual and community capacities (10).
- Partnership agreements are invaluable tools for CBR teams. They provide the “glue” that keeps teams together through the challenges that partnerships inevitably face. Research teams should spend time up-front discussing what each partner needs from being involved in a study—(e.g. data to drive funding applications and programming; publications to help secure tenure). Partnership agreements should include these points so that all partners feel their needs are being met in a study.
- Partnership agreements should outline the study’s guiding principles, identify its intended outcomes (e.g., policy changes), define the roles and responsibilities of the partners, and provide clear criteria for accessing and publishing study data. Moreover,

teams should think about the roles that students can play in CBR studies and spell out supervisory relationships in their partnership agreements (10).

- How involved community partners are can vary, even within a CBR framework. As this visual from Access Alliance 2007, adapted from Winer and Ray (11), shows:



- Trans PULSE (www.transpulseproject.ca) is an example of a community-led project, since it was initiated by members of the Trans Working Group at the Sherbourne Health Centre, which then interviewed researchers for the investigator roles. Researchers should be wary, however, of assuming that community-led projects are always preferable over projects with less community involvement. Not every community has the time, resources, or interest to lead a research project. Researchers should work together with community members to select a level of community involvement that is appropriate to the project and to the community involved.

FORGING CONNECTIONS WITH LGBTQ COMMUNITIES

- There are not enough LGBTQ researchers to do all of the work that needs to be done, so allies can make invaluable contributions in CBR with LGBTQ communities. In research that is not LGBTQ-specific, allied researchers can include questions about sexual orientation and gender identity, ensuring that their studies make LGBTQ communities visible and contribute important knowledge about LGBTQ needs.
- Ethical researchers should turn to LGBTQ researchers and community members with a history of CBR and seek advice and direction on how to conduct research that is ethically sensitive and has action outcomes. Outreach to LGBTQ advocacy groups, community centres, health centres, student groups, and research networks can also put allies in touch with people who need help with research.
- Historically, members of LGBTQ communities have not benefitted from the research in which they participated. There remains a significant risk today of being pathologized by researchers, especially for trans people. Trust may be an issue, and LGBTQ community groups will expect you to be able to justify your interest in working with them.
- When researchers fail to place research findings into a context that is inclusive of a history of LGBTQ pathologization and current systems of oppression, researchers breach ethics and put LGBTQ individuals and communities at risk. Kurt Freund's research, for example, labelled trans women as homosexual or heterosexual men, disregarding their self-identity (12). Ray Blanchard's studies argued that those trans

women who were not attracted to men were aroused by imagining themselves as women, rather than by the partners they choose—a condition he called “autogynephilia” (13). In both cases the ability of trans people to consent to participating in research is compromised when study participants rely on those same researchers to approve their hormonal or surgical therapies.

- Where time is lacking to fully engage LGBTQ communities in CBR, researchers will have to first engage in strategies to ensure that trust is built with LGBTQ communities and will have to show that their research intentions support community needs. Researchers may want to designate someone on their team as a liaison to the LGBTQ communities, or to a community agency that serves LGBTQ people. Both parties should still utilize a partnership agreement specifying their roles, their intentions, desired outcomes, and strategies for achieving these outcomes.

BENEFITS AND CHALLENGES OF CBR

- The high points of CBR are innumerable—they include witnessing studies that have achieved community empowerment, social change, policy change, program development, and community capacity building. The real world value of CBR is evident in community agencies use of data gleaned from CBR studies for program funding applications and other advocacy efforts. When community agencies are able to apply research findings in their work, and when community members themselves are situated as policy change agents, we see the value of CBR.
- If you are the kind of researcher who is not patient with process, building trust, meeting outside of the university, sharing power, and in engaging community partners as invaluable partners on a research team, CBR is not for you.
- Many researchers continue to produce research studies that sit unused on a shelf, thus wasting valuable resources. Because CBR projects engage community partners and other decision-makers from the inception of a study, the data produced by a team will invariably have real world value.
- Community Based Research Canada has a list of useful resources for people considering taking on a CBR project: <http://communityresearchcanada.ca/?action=links>.
- In smaller communities it may be difficult to separate the role of researcher and participants, and researchers must work with their research ethics boards, research teams and advisory committees to establish processes for ensuring and protecting participants’ confidentiality. If consent is to be kept free and informed researchers must be wary of the pressure community members may exert on others to participate (14).
- By getting community members, activists, and policy and decision makers invested in the project from the start, data produced by CBR projects have a greater likelihood of uptake than those created by more mainstream approaches to research. Moreover, CBR studies that engage community partners in sharing the knowledge gathered in a study, reach broader audiences with their messages. CBR studies also build the capacities of communities to mobilize knowledge and create change for themselves. A pilot study of bisexual people’s experience with mental health services demonstrated the need for bisexual identity support (15). This evidence was then used to create the B-Side, a recurring ten-week program at the Sherbourne Health Centre for people coming out as bisexual.

FUNDING & ETHICS REVIEWS FOR CBR

- One challenge facing CBR teams is the competitive nature of research funding environments along with the time-consuming nature of CBR, given its focus on trust and partnership development.
- CBR is not yet understood by some funding and review agencies (16). The RHO study found that 44% of researcher identified lack of staff resources and 41.7% named a scarcity of funding sources as significant barriers to CBR research with LGBTQ communities (7).
- A review of Canadian research ethics boards and US institutional review boards found that studies are assessed based on risk to individual participants rather than to communities, and that the review process is often inappropriate for CBR projects (17-18).
- Funders like the Canadian Institutes of Health Research have funded CBR projects through the Institute of Infection and Immunity and the Institute of Gender and Health. Framing determinants of health broadly can help funding agencies understand how to fit CBR research into their current framework.

REFERENCES

- (1) University of Victoria. 2011. What is CBR? Available at: <http://communityresearchcanada.ca/download.php?id=3380>.
- (2) Humphries L. *Tearoom Trade: Impersonal Sex in Public Places*. Chicago: Aldine Press; 1970.
- (3) Rieger G, Chivers M, Bailey J. 2005. Sexual arousal patterns of bisexual men. *Psychological Science* 16 (8): 579-584.
- (4) Carey B. July 5, 2005. Straight, Gay or Lying? *Bisexuality Revisited*. New York Times.
- (5) Rosenthal A, Sylva D, Safron A, Bailey J. 2011. Sexual arousal patterns of bisexual men revisited. *Biological Psychology* 88 (1): 112-115.
- (6) Viswanathan M, Ammerman A, Eng E, Gartlehner G, Lohr K, Griffith D, et al. 2004. Assessing the Evidence. Evidence Reports/Technology Assessments: Community-based Participatory Research: Assessing the Evidence. 99T. <http://www.ahrq.gov/downloads/pub/evidence/pdf/cbpr/cbpr.pdf>
- (7) Abelsohn K. 2009. For us, by us, with us: A needs assessment of LGBTQ Community Based Research in Ontario. Toronto: Rainbow Health Ontario..
- (8) Bach R, Weinzimmer J. 2011. Exploring the Benefits of Community-based Research in a Sociology of Sexualities Course. *Teaching Sociology* 39 (1): 57-72.
- (9) Stoecker R. 1999. Are Academics Irrelevant? : Roles for Scholars in Participatory Research. *American Behavioral Scientist* 42 (5): 840-854. http://web.unbc.ca/~kitchena/EDUC_610_2012/Stoecker_1999.pdf
- (10) Travers R, Wilson M, Flicker S, Guta A, Bereket T, McKay C, et al. 2008. The greater involvement of people living with AIDS principle: theory versus practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care* 20 (6): 615-624.
- (11) Winer M, Ray K. *Collaboration Handbook: Creating, sustaining, and enjoying the journey*. St. Paul, MN: Amherst Wilder Foundation; 2000.
- (12) Freund K, Steiner B, Chan S. 1982. Two types of cross-gender identity. *Archives of Sexual Behavior* 11: 49-63.
- (13) Blanchard R. 1989. The concept of autogynephilia and the typology of male gender dysphoria. *Journal of Nervous and Mental Disease* 177: 616-623.
- (14) Poff D, McGillivray B. 2009. Setting the Stage: The Landscape of CBR and Research Ethics Review. Ontario HIV Treatment Network. www.ohtn.on.ca/Documents/Programs/Poff_OHTN_CBR_Ethics.pp
- (15) Dobinson C, MacDonnell J, Hamopson E, Clipshan J, Chow K. 2003. Improving the access and quality of public health services for bisexuals: A position paper and resolution adopted by the Ontario Public Health Association. Toronto: Ontario Public Health Association.
- (16) Flicker S, Wilson M, Travers R, Bereket T, McKaye C, van der Meulenc A, et al. 2009. Community-based research in AIDS-service organizations: what helps and what doesn't? *AIDS Care* 21 (1): 94-102.
- (17) Flicker S, Travers R, Guta A, McDonald S, Meagher A. 2007. Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards. *Journal Of Urban Health* 84 (4): 478-493.

(18) Guta A, Wilson M, Flicker S, Travers R, Mason C, Wenyev G, et al. 2010. Are We Asking the Right Questions? A Review of Canadian REB Practices in Relation to Community-based Participatory Research. *Journal of Empirical Research on Human Research Ethics* 55 (2): 35-46.

Acknowledgements

This fact sheet was co-written by staff at Rainbow Health Ontario and Dr. Robb Travers, Assistant Professor in Community Psychology at Wilfrid Laurier University. Dr. Travers is a leader in the community-based research movement in Canada. His research focuses on social exclusion and the health and well-being of trans communities and LGBTQ youth.

Feedback on this document is welcome. Comments and questions can be addressed to Lorelee Gillis:
lgillis@RainbowHealthOntario.ca



RHO Factsheet: Community-Based Research with LGBTQ Communities is licensed under a [Creative Commons Attribution-noncommercial-sharealike 3.0 Unported License](https://creativecommons.org/licenses/by-nc-sa/3.0/)

Last updated: August 2012