



Establishing a Community-Based Participatory Research Partnership to Examine HIV Prevalence and Related Risk Factors Among People Who Use Drugs in Ottawa: *The PROUD Cohort Study*



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BACKGROUND

Community-based participatory research (CBPR) prioritizes community inclusion throughout the research process, with community members bringing their knowledge and lived experience to the research with the goal of combining education and action to achieve social change [1-3]. There has been a growing recognition of the need to more meaningfully involve community members and organizational partners, alongside academic researchers in public health research [4]. Peer-led drug user advocacy groups have themselves been calling for more meaningful involvement through the promotion of the practice “Nothing For Us, Without Us” [5].

Although there have been efforts to more meaningfully engage communities in research, community is still rarely involved in every stage of the development, design, and dissemination of research projects. Grounded in a community-based participatory research (CBPR) framework, the PROUD (Participant Research in Ottawa: Understanding Drugs) Study aims to better understand HIV risk and prevalence among people who use drugs in Ottawa, Ontario.

This study relies on peers' expertise stemming from their lived experience to guide all aspects of the project. From the planning stages of this proposal through to implementation and action for community change, we ground our process in a community-based participatory research approach.



METHODS

In partnership with the Drug Users Advocacy League (DUAL), a Community Information Session was held in March 2012. Individuals who self-identified as having lived experience with drug use and/or stakeholders completed an application form describing their experiences with drug use and their interest in the project. Twenty-one applicants were interviewed, and fourteen were selected to join the Community Advisory Committee (CAC), comprised of eight people with lived experience, three allies and three ex-officio.

The CAC has been meeting bi-monthly since May 2012 to develop the research design, data collection, analysis, and knowledge translation stages of the PROUD Study and will continue to meet throughout all phases of the research process. CAC members receive an honorarium for their work on the project (\$25/meeting), recognizing their role as expert consultants.

In September 2012, eleven medical student applicants from the University of Ottawa were recruited to work alongside peers as interviewers. Training was provided to the CAC and medical students on CBPR; HIV and harm reduction; interviewing skills; and research ethics. Through partnership with Ottawa Public Health, both groups underwent rigorous training on the administration of HIV point-of-care (POC) tests, along with training in pre- and post-test counselling, and were certified to administer testing. Trainings aimed to prepare the research team to take on more active roles in data collection and to provide opportunities for peers and students to build relationships.

RESULTS

From March – December 2013, the PROUD Study recruited 862 people with drug use experience into the PROUD cohort. 597 participants were recruited from Ottawa's downtown core, where the majority of drug use is concentrated. A further 265 participants have been recruited from other known areas within Ottawa where people who use drugs are more typically located. All participants were 16 years or older, had injected or smoked drugs other than marijuana in the past 12 months, and had lived in Ottawa for at least three months at the time of enrolment.

Participants completed a one-time questionnaire administered by a trained peer or medical student, who then administered an HIV POC test. Prospective follow-up will occur through linkages to health care records available through the Institute for Clinical and Evaluation Sciences (ICES). Consent was obtained for each element of the study and participants could choose to opt-in to the HIV POC test and/or data linkages. Consistent with other cohort research projects, a cash honorarium (CAN \$20.00) was offered to participants after completing the survey portion of the study, regardless of whether participants choose to opt-in to the HIV POC test and/or data linkages.

CONCLUSION

The PROUD Study uniquely applies CBPR principles to engage the communities of people who use drugs in the development of a large-scale prospective cohort study. Along with developing new models of CBPR among people who use drugs, the PROUD Study will also advance knowledge of the epidemiology of HIV among people who use drugs in the Ottawa area and develop novel community-based strategies for HIV testing.

The PROUD Study meaningfully engaged the communities of people who use drugs in Ottawa through the formation of the CAC, the training of peers as community-based researchers, and integrated KTE throughout the research project. This project successfully supported skill development across the team and empowered people with drug use experience to take on leadership roles, ensuring that this research process will promote change at the local level. It is expected that the CBPR methods developed in this study will impact similar research projects with people who use drugs in other settings, and contribute to new knowledge of successful approaches to CBPR which take into account the meaningful engagement and self-determination of people most affected by HIV.

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