

Web Only Content

about the conduct of research to be completed were daunting. The long standing relationship of the academic and community partner co–leads prevented this from happening as the academic partner worked closely with the community team members to successfully complete the research training.

While it is clear the necessity of assuring all members of the research team are held to the highest standards of research ethics, our non-academic community partner felt that their team was at a distinct disadvantage. The research conduct course appeared to be derived from graduate level material about the conduct of research including complex policies about the ethical conduct of research with which they did not have previous experience. The expectation that community partners from various backgrounds, different areas of expertise, and academic achievement must complete the CITI training prior to the project beginning can create a major obstacle. We believe that that academic partner and funders must reach out to community partners and provide more direction and help with this expectation or the expectation of the training needs to be re–considered as does who really needs such training. We realize that this is a universally accepted and utilized training requirement, academia needs to understand that what was developed within the academic community, when applied to the greater community, puts the greatest burden on the community and quickly places the community at a disadvantage and diminishes egalitarianism so important for building team. While our team was able to support each other as we completed the CITI training requirements, there may be other partnerships that fail or never begin because of this onerous expectation.

Summary

The collaborative nature of the CBPR worked extraordinarily well in our project. It led to a greater sense of collaboration and understanding, not only between the staff members of our community partner and the faculty of our academic partner but also between staff, faculty, and this remarkable group of Senior Companions who were the focus of study. It certainly left us with the goal of continuing our

partnership. The disadvantages were relatively minor, usually associated with trying to impose programs designed for academic settings, for example the CITI training requirement, to the community settings. We look forward to continuing our work together.

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A Belgian Story of CBPR Among People with a Migration Background

Charlotte De Kock

About three years ago, I decided I was in need of a new professional challenge. At the time I had been working as a practice oriented researcher in the social work field for about four years. My previous projects were practice based and policy oriented and involved studying people with a migration background, acceptance of difference in society and fair integration of these people in elderly care and education. These projects also involved amplifying the voices of vulnerable people with a migration background, to open communication about inequalities in general society. In 2015, the Institute of Social Drug Research (Ghent University, Belgium) hired me to conduct and help coordinate a community–based participatory research project on substance use and treatment for addiction in people with a migration background. A challenge indeed because this type of research had never been conducted in Belgium and the topic of the research is understudied in Belgium. We worked with a team of four researchers, each

one based in a different university department and working with a sub target group of 'people with a migration background'.

We mainly chose the CBPR design because substance use is often a taboo topic among people with a migration background. Additionally, it is not easy for researchers to reach substance users in these populations. Maybe we chose the design because of the wrong reasons, prioritizing target group reach, over empowerment and equity. However, the design did allow us to work with over 40 community researchers to collaboratively conduct four case studies in and with the Turkish community in the Ghent municipality, the Eastern European communities in the Ghent Municipality, the Congolese communities in Brussels and undocumented migrants and refugees across target groups and municipalities.

The idea was to reach the target groups better by working with community organizations and researchers and finally to build a bridge between research and the lived experience of addiction care, general welfare social work as well as communities of people with a migration background. The study was based in a collaboration between four project assistants (one per case study and myself as coordinating staff member and researcher in the Turkish community), a community organization per case study and a community advisory board. The selected community organizations differed substantially: first, one of the organizations did not receive any structural funding which made it hard to build up a structural working relation, second, three out of four organizations did not want to be affiliated too much with the topic of substance use and third, the target groups of the organizations differed: one aimed at a single 'ethnic group', another aimed at several 'ethnic groups' and a last aimed at vulnerable drug users, including those having a migration background. This illustrates that the CBPR method, as devised in a North American research context requires significant cultural adaptation in a European context.

The community advisory board consisted of people from the socio-cultural work field, local policy makers and practitioners in drug prevention and treatment. The involvement of a community

advisory board facilitated the identification of missing populations in the study sample and dissemination of practice-oriented recommendations to treatment and welfare organizations. All actors were involved in refining the research questions, guiding the project and finding participants from the target groups and disseminating the research results. Nevertheless, the main research question was quite rigidly defined before the project had started: What is the nature of substance use in the four 'communities' and which needs do target groups have towards addiction treatment facilities?

The project consisted of four consecutive stages: (1) finding suitable community organizations and forming the community advisory boards, (2) finding and training community researchers, (3) gathering semi-structured interviews, doing field work and (4) analyzing the data and disseminating it in academia, the professional field and the target groups. This project took 15 months.

Each project assistant contributed to finding community researchers by means of personal contacts, mail shots, flyers, posters and the organization of info sessions in the community organizations. Eligibility criteria for community researchers were that (1) they could recruit at least 10 respondents, (2) they participated in a nine-hour training to recruit an interview respondent and to make the interview transcripts and (3) they demonstrated sufficient social skills and willingness to learn about interviewing techniques. About 15 community researchers were selected per target group: trained by the project assistants per target group. About half was highly educated, having obtained a College or University degree and the majority of community researchers was unemployed. Their training included the basics of quantitative and qualitative research, ethical dilemmas, the deontology of this type of research and skills for conducting semi-structured interviews. A session was also dedicated to refining the research questions and creating an interview guide. During the training sessions, community researchers gave each other insights about how to approach respondents: some for example switched potential respondents to avoid confidentiality issues. After the training, we started the data collection period.

We planned for this to take up about three months but eventually extended this period with an additional two months because during the holiday period most of the potential respondents returned to their home country to visit family. We conducted an average of 55 interviews per target group. The community researchers themselves determined what type of respondents they approached via snowball sampling.

This method came with considerable challenges. For example, the community researchers did not have any contact with certain subgroups such as heroin users. I therefore supplemented the respondent pool by means of purposive sampling in heroin substitution centers. The involvement of researchers and community organizations at every stage of the research did also not appear to be evident because it presupposes a lot of time, expertise and motivation. By extending the data collection phase we were not able to organize extra training for data analysis and noticed that some of the community researchers had lost motivation to collaborate. Consequently, the academic team conducted the data analysis while regularly contacting community researchers for clarifications of statements during the interviews. Also, the community researchers were paid to conduct interviews but not for attending training courses, participating in peer sessions or collaborating in the process of data analysis. As the project primarily built on their intrinsic motivation, we lost about one third of the researchers during the period of data collection.

Monitoring and coaching community researchers appeared to be much more time-consuming than we expected. However, this guidance is necessary to preserve both the quality of the data as well as the involvement and motivation of the community researchers. This close contact between the project assistants and community researchers also lead to better understanding the content of the interviews during data analysis.

During the interviews we also noticed that a certain degree of identification between the community researcher and the participant lead to the fact that not all interview themes (e.g. religious aspects) were elaborated upon sufficiently. Moreover, there

were a lot of users who did not want to talk about substance use with people with a same migration background because they feared that community researchers would gossip about the content of the interview.

Working with community researchers did offer us the advantage of better access to the target audience and the ability to conduct interviews in the native language of the participants. Moreover, the community researchers as well as the respondents gained awareness of the research topic. The dissemination of research results also happened in part through community researchers and members of the community advisory board. These new networks allowed me to disseminate the results of the project in over ten local municipal networks concerned with substance use, treatment and general welfare; they in turn. Several attendees proactively incorporated these recommendations in their organization by creating new partnerships to reach more people with a migration background, or by installing a task force to address these issues in their organization.

The CBPR design thus allowed for the research not to be confined to the academic world but also had a considerable impact on the studied groups, in the field of addiction care, in the socio-cultural work field as well as on local municipal policy. However, if I had the chance to do it all over again I'd change many things in this project design, most importantly: we'd pay the community researchers better and extend the total project period for proper training of community researchers and follow-up. It would also be better to base project assistants in a welfare organization, close to the studied neighborhoods, instead of the university. This would make the research truly participatory by means of the researcher getting out of his or her safe environment and really getting to know the lived world of the welfare organization.

Although the team of community researchers, academic researchers and members of the advisory board rushed through the project phases in these 15 months, overall, we did a fine job taking into account the limited resources. While running from one house of a community researcher to another, while searching respondents and keeping in touch

with the community organizations, I pondered about how true equity could be realized in such a project, and to what degree communities should be empowered to deal with substance use problems and I found the answer to this question to be quite complex. Therefore, in future research, I'd particularly prefer to work with a general welfare organization or a treatment center instead of an organization linked to or aimed at a group of people with specific migration backgrounds: because after all, are we studying epidemiology and health inequity of an ethnic group, or is it rather inequity in welfare, health and treatment organizations we want to study?



Developing Trust, Multiple Identities, and Participatory Research: Select Examples

Scarlett Hopkins

In community-based participatory research (CBPR), trust among participating individuals and groups is paramount to achieving goals. Trust is an ever-changing and evolving concept implying increasing willingness to take risks with potentially delicate information, an assumption that promises will be kept, and a belief in the good will of the other. When outside researchers enter a community, they are greeted by community members and organizations who have often had prior experience with outside researchers. A critical aspect of this process is the value of outside researchers developing what clinical psychologist James Kelly called an "eco-identity" or a way of becoming known in the local community that helps community members "locate" the researcher in the community context and provides a basis for relationship development and subsequent trust. In this paper, I will describe the development of trusting relationships involving genetic studies with Alaska Native communities.

The Center for Alaska Native Health Research (CANHR) located at the University of Alaska

Fairbanks was funded in 2001 by the National Institutes of Health (NIH) as a Center of Biomedical Research Excellence (COBRE) focusing on obesity and cardiometabolic disease in Yup'ik Alaska Native people in rural southwestern Alaska. Initially, it was comprised of three multidisciplinary research studies including genetics of obesity, nutrition and physical activity, and cultural understandings of health. Now, CANHR includes behavioral health and nutritional research as well as epigenomic and pharmacogenomic research to address health disparities in Alaska Native people.

As a Registered Nurse, I am interested in health disparities in Alaska Native people and the influence of culture on health beliefs, behavior and outcomes. I began working with CANHR in 2002, first as a graduate student in cultural anthropology, then as a research coordinator, and now leading the Community Engagement and Clinical Support Core. One of my responsibilities as a graduate student was initial contact with potential communities who had been selected by the Yukon-Kuskokwim Health Corporation (YKHC), the native health entity providing medical services and overseeing health research in this region. These initial contacts included several visits to the communities to meet with Tribal Governments and community members to discuss the research and gain approval. These first visits were the beginning of trusting and sustained partnerships spanning a 15-year period with over 1,800 Yup'ik participants in our genetic studies.

It is important to reflect on and document how trust develops in community research, particularly when it involves basic science rather than community interventions intending to have direct community impact. In the 15 years that I have been involved in multiple projects involving multiple communities, my primary role has been to facilitate the relationship between the university research project team members while simultaneously being involved in recruitment of participants, data collection and dissemination of research progress and findings. During these years, I have come to understand how my various identities have played a role in allowing and promoting relationships with community members. These identities involve my