The Methadone Project: Part 1 of 3

What does it mean to be truly a community-based research project?

For a project to be truly community-based it must be run by and for the community that is under study. At best, the findings should improve the situation for the people being studied and those doing the studying. At the very least, it should provide relevant information that the community can use. The Methadone Project used its funding to hire people already on methadone, train them to interview the participants (providing them with a new skill) and, in return for the expert knowledge that only methadone clients could provide, paid those who agreed to participate $15 each.

The interview topics, which were determined by the research team, were chosen principally by the methadone interviewers themselves along with assistance from at least two staff members: one who has used methadone for 14 years and another who specializes in work with drug-using folks with mental illnesses. Their collective goal was to “expand our understanding of people’s experiences on methadone and to work to create changes to enhance [the] well-being and equity for people on methadone” – fantastic goals, don’t you think?

To accomplish this they decided to examine three very important areas from the many topics on which they could have focused:

a) “experiences with doctors and clinics”
b) “experiences with pharmacists and pharmacies”
c) “experiences with the criminal justice system”

In the next issue of the newsletter, part two of this three part look at the study will deal with the main findings in each of the three areas.

This study was a participatory research project. Those who participated were given a choice about whether or not they wanted to be a part of the study, rather than being somehow made to feel that they had to participate (coercion) or that failing to participate would make them part of the problem instead of the solution (peer pressure) – especially since the interviewers were all on methadone themselves.

The study states that “[w]e surveyed 47 people, including 16 women and 31 men. Interviews were confidential [which means that those who agreed to answer the questions of the interviewers were provided with a safe space, closed off to other clients of the program] and people were compensated $15 for sharing their knowledge with us”. This is key be-

Author’s Note: Whenever you see quotation marks (“ ”) that means that I’m quoting directly from the published findings of the study. Whenever you see no quotation marks or you see square brackets [ ] it means that I am adding something to the direct quotes, like a comment or a grammatical change to make the sentence easier to read.

1. The study is available through the COUNTERfit HR Program at 955 Queen St. East, Toronto, ON, M4M-3P3
cause many researchers coming from outside the community just study the subjects (in this case those on methadone) without compensating them, and, just as importantly, without acknowledging that the participants are providing expert information which can come only from those with direct, lived experience in the areas under study. Where appropriate, studies can include subject names and background information, and, attendance subsidies can be made available thus allowing subjects to participate in presentations.

It’s essential to conduct truly participatory, community-based research that empowers the participants who provide the information needed to support effective change within a system. And, it’s necessary to use members of the group being studied to collect the information because people are more likely to be honest and give more truthful answers when they know they are talking to others who are also going through what they are going through (that’s why peer programs work). It also gives back to the community by giving the community-based researchers/interviewers new skills that look good on a résumé and can help them to qualify for similar jobs as well as other kinds of employment.

Community-based research is so important and it can be, and is being, done by those of us who have the skills and who believe in empowering others by sharing those skills.

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**Patient Advisory Group Update**

- A PAG member has been asked to contribute the patient’s perspective at CAMH’s Opioid Dependence Treatment Certificate Program for physicians and pharmacists. The PAG will be working together to brainstorm for topics and ideas for the patient presentation for the upcoming course this fall.

- The women of the PAG are participating in a survey as well as focus groups in conjunction with the CPSO and the Jane Tweed Centre on the impact of methadone on women’s lives including their health and experiences with substance use treatment. This anonymous feedback will also be presented at the 2011 Methadone Prescribers Conference.

- All the data compilation and analysis on the PAG assisted Research Project Changing Needs of Long Term Methadone Patients on MMT (for 5 Years or more) has been completed. Dr. Carol Strike PhD. and her research assistant Medical Student, Justyna Bartoszko, are now in the stages of writing and revising a paper that is to be presented at the 2011 Methadone Prescribers Conference. The data collection from in depth interviews of both patients who have been on the program for 5 years or more as well as interviews with the physicians that treat them suggests that long term stable methadone patients may benefit from being transitioned into primary care by a GP. The paper will focus on improving the access to primary care for stable methadone patients.