WHEN RESEARCHERS COME CALLING:

A GUIDE FOR ORGANISATIONS THAT WORK WITH WOMEN

The information is this booklet can help you think about your role in research.

This project was a collaboration between researchers at the *BC Centre of Excellence for Women's Health*; the *Women's Health Research Institute*; the *University of British Columbia*; and the *University of Victoria.*

WOMEN'S HEALTH
RESEARCH INSTITUTE
Women's health, women's lives

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CIHR IRSC
Canadian Institutes of Health Research
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INTRODUCTION

Many community organizations have had positive experiences collaborating with researchers. Other organizations have not had positive experiences, or have concerns about how partnering with researchers might impact the women they serve. This guide is intended to help women-serving organizations make their own informed decisions about whether, and how, they might want to work with researchers in ways that are mutually beneficial.

The team that put together this booklet recognise that women who use substances, particularly those living in the Downtown Eastside of Vancouver are often heavily researched populations and are frequently asked to take part in a wide variety of studies. We were interested in women's experiences as research participants, specifically health research studies, as we have found that there can be a lot of assumptions made by researchers, service providers, and Research Ethics Boards about the needs, values, or concerns of women who use drugs or who have addictions. It can also be the case that these assumptions can result in women being inappropriately excluded from (or included in) research.

We also found that the ideas, perspectives, and opinions of women who use (or have used) substances aren't often included in discussions about what ethical and respectful research practice looks like. Ironically, to do this, we had to conduct our own study to ask women about their experiences with research. To do this, we held a series of focus groups with women from Vancouver who identified as using, of having used, substances. Focus groups were held with young women, women in treatment, women belonging to drug user organizations, women who do sex work, and women with both mental health and substance use issues. We asked women to tell us about:

- what they define as ethical research practice;
- what their experiences have been as research participants;
- why they chose to participate or not participate in research; and
- their perspectives about the risks and benefits of participating in research.

The information in this booklet comes directly what we learned in the focus groups, and the experiences and recommendations that women were so kind to share with us. We hope that their combined knowledge and expertise can be of help to your organisation when you are approached to be part of research in the future.

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WHY SHOULD YOU CARE ABOUT RESEARCH ETHICS?

We understand that as an organisation working for women who use, or have used, substances you most likely have many other things to do than think about research and research ethics. Some of the reasons why it's important for your organization, and the women you work for, to understand more about the research process include:

- When you allow researchers to recruit participants through your organisation, even if that's just a poster on a notice board, then the experience women have could reflect badly on your organization.
- A badly done study can be a truly horrible- even traumatizing- experience for the women you serve. If women feel your organization endorsed the study, may affect their trust in your organization.
- Researchers are sometimes unrealistic when telling potential participants about what they hope their research will achieve. It's very demoralising for people who take part in research to keep repeating the same concerns and never see the changes that they were promised might come from the study. With more information, organizations can help ensure that the women you serve have a good sense of what they can- and should- expect from research and from researchers, and insist that something tangible is given, or communicated, back to the women who took part in the study and the organizations that partnered with it.

> I think sometimes people get the false idea that if you're in addictions then they can do whatever they want with you, that you're something to be observed. Especially depending on how far down the ladder you've gone, the further down the ladder, the more observable you are, the more a side show you are

- When there is a better understanding of research, and what it can achieve, then it is far more likely that organisations like yours can develop equal partnerships with research teams and create studies that are relevant and beneficial to the people you serve.

This booklet includes quick reference boxes with questions you can ask any research team and a checklist to help you evaluate whether or not your organization is comfortable partnering with any study you may approached about.

PAYMENT FOR PARTICIPATION

Issues connected to being paid to take part in research were one of the most frequently raised topics among the women we talked to. Payment to participate in research is sometimes referred to as an **honorarium** or a **stipend**.

Paying for participation is also one of the most controversial topics for researchers themselves. It is sometimes argued that offering cash or honoraria to women who use substances, and who are often struggling for money on a day to day basis, is *coercive* - that offering money compromises a person's ability to make a fully informed and voluntary choice about taking part in a study, and might make someone less likely to weigh any risks the study may carry for them.

Money and honoraria is one of the main reasons- but not the only reason- women who use substances choose to participate in research. This is also true of most research participants in general. Offering payment for participation can be made much less coercive if researchers hand out payment before the study begins, and if they stress that women can leave (or stop participating) at absolutely any time, without an explanation. That way, women might be less likely to continue participating when they don't want to because they are waiting for their honorarium.

While it is less coercive to offer money upfront each research project will have different rules about when people receive their honorarium or stipend. Some will offer it before the study starts, while others offer it in increments (especially if women need to meet with a researcher more than once), and some offer it after the participant has finished the study. Before agreeing to take part, women should be very clear about if, when, and how they will be compensated.

> I am being consulted so I should be paid like others. I am an expert in my life, even though I am economically challenged, both us and the interviewer should be paid. No-one asks what they *(researchers)* do with their money and I know lot of square people that cash their cheques and go and buy drugs.

The women in our focus groups were very clear that payment for research participation is an ethical practise that acknowledges the time, effort and expertise women contribute. Not paying was considered to be an unethical practise that dismisses and disrespects women, particularly those who are marginalized.

Cash payments were preferred by the women we spoke to, as it provides the most flexibility. The argument that payment will be spent on drugs was countered in many ways. Firstly, women stated that it is very judgemental and offensive to assume that their honorarium would be spent on drugs. Here, they noted that no other groups are asked how they spend their honoraria, or have their honoraria withheld on the basis that they might make a "bad" decision about what to do with the money. Secondly, women told us that if they need money to buy drugs, then there are more effective ways of getting it than taking part in research studies. This is because research studies often entail a large time commitment, as well as some inconvenience. 'Desperate' women are unlikely to sit through an hour and a half of focus group for $20.

If cash isn't offered for research participation, then women told us that honoraria should still be appropriate and meaningful. This is something a community organisation could be consulted on.

> Yeah, like, you give out a Future Shop gift card when the person's fridge is empty...I'll fill it with a DVD.

QUICK QUESTIONS TO ASK RESEARCHERS

- **How, and at what point in the study, will women be compensated for taking part in the study?**
- **What other supports can you provide for women who participate in the study? (e.g. bus tickets, childcare, refreshments)**
- **How will you ensure that women know they can leave or withdraw from the study, even after they've received a payment/ honorarium?**

RELATIONSHIPS WITH RESEARCHERS

> - What do researchers owe the people they ask questions to?
> - Total and utter respect

The women we talked to told us that an encounter with judgemental or insensitive researchers can be very distressing. Women have left research studies feeling they are being judged unfairly as “addicts”, as mothers or as people living in poverty. These encounters can erode respect and trust built up with other researchers, but they can also reflect poorly on the organisation that might have set up, or helped in recruitment for, the study.

As a community organisation, you could have a role in reducing these negative encounters by ensuring that research teams who approach you, in any capacity, have an appropriate awareness of the needs, concerns, and circumstances of women you may be introducing them to. You have the right to ask for evidence of any previous experience the researchers have in this field. Reviewing things the researcher has published before might give you an idea of whether their approach is consistent with your organisation’s philosophy or values.

> I felt, after it, very degraded. It’s funny to see how far people, when they’re working trade, how far they can get, how much they can get out of us. For, like, twenty bucks they want to ask us our whole life story, whatever they think they can get. They make us feel like we have to answer the question. They pressure us, or they make you feel like it’s not a good enough answer, or that you’re stupid

Not surprisingly, women we spoke to stated that they feel uncomfortable when questions or topics become too intrusive and personal. Questions that often caused concern were those about money, the specific details of their drug use, and about their family. Researchers should be able to clearly justify the need for every question they ask. It helps to warn potential participants if sensitive questions will be asked. This way, they can choose not to take part if they suspect it will be too stressful or upsetting. Women should also be very aware that they can choose not to answer any question asked by a researcher, and that they can walk away at any time, even if they've already received an honorarium. Your organisation can help by asking to see all the materials the research team will be using, and highlighting anything you suspect might be distressing.

> The lady who interviewed me before, she had not used. I left, and I felt insecure and I shut down and never talked, at all.

In most cases, it seems women feel more comfortable if their interviewer, or the facilitator of the focus group, is someone they already know and trust. It may be possible for someone within your organisation to ask the questions; this is something you could ask about. When the research team prefer to have a 'neutral' person to facilitate, then that person should still have experience and understanding of the issues they'll be discussing.

As women have the right to withdraw at any time, your organisation also has the right to withdraw your support if you feel the relationship you have with the research team is not one of mutual trust, respect and sensitivity.

QUICK QUESTIONS TO ASK RESEARCHERS

- **What experience do you have working with women who use substances?**
- **How will your team demonstrate sensitivity and non-judgemental attitudes to women who are already marginalised?**
- **Can we see all the materials you'll be using for this research? (e.g. surveys, scales, interview questions, etc.)**
- **Can you explain, if asked, why each question you are asking women is necessary?**
- **What support can you provide if participation is triggering or re-traumatising?**
- **Who can we talk to if we have a complaint about the way you conduct the study?**

INFORMED CONSENT

Informed consent means that the women participating in a study should be provided with all the information they need about the benefits and risks of participating (and not participating) in order to make an informed choice on whether or not to take part. This means that potential research participants should understand:

- why the research is being done;
- what they will be asked to do;
- how their information will be obtained;
- how their information will be protected; and
- how they can withdraw their consent, or complain, at a later date.

In practice, this often means signing a consent form at the beginning of the study. Everything potential participants need to know about the study should be contained in the consent form. Reviewing consent forms can be a boring and laborious process, but it is the researcher's responsibility to ensure ways are found to engage women at this time. Community organisations, as well as researchers, should emphasise that the experiences women choose to share in research are valuable, and what happens to this knowledge is important.

The women we talked to in the focus groups had a number of suggestions for enhancing the practise of obtaining informed consent, which good researchers should already be following. Women spoke about making informed consent **an ongoing process**, rather than a one-time requirement at the beginning of the research encounter. For example, researchers may want to ask for consent again if sensitive questions arise, or if they want to take photos. Women should be very aware when choosing to answer that most researchers are not trained counsellors and neither will they be able to change a woman's housing, medical care, benefits etc.

> ...get ongoing consent. Ask if the person is okay and ask again a few questions later, but don't be annoying!

> ...she actually had tears come down her face, and I just went "you don't have to answer these you know". I guess she felt obligated

Women said that researchers should very explicitly present the **option to withdraw their consent**, and that this should be done a number of times throughout the research process. Women have the right to withdraw their consent at any time, regardless of compensation, including after the encounter. Sometimes a research study has a time limit after which participant can no longer withdraw their consent. If this is the case, participants should be told about this in advance, and reasons for this limit should be given.

> [What do researchers owe women who take part in their studies?]...To not give us a bullshit story about what they're going to do with the research material, 'cause a lot of times they'll have this research and surveys that they want us to be involved in, but yet when the outcome comes out, it's got fuck all to do with helping us and basically, a lot of the time, it actually hurts us

The focus group conversations also connected informed consent to include *how* information is used by the researchers. Women spoke of how their consent was given on the understanding that the information would not be used to further harm or marginalise women who use substances. It's not always the case that researchers feel obliged to consult any community organisations involved in the study before disseminating their results. If this is something you feel strongly about, it is important to discuss it with the research team when you are first approached, and make this a condition of your partnership.

Women in the focus groups, and researchers themselves, are divided about whether informed consent can be given when someone is high or withdrawing from drugs. Some women we spoke to felt that the better a researcher knows a community and is familiar with people who use drugs, the more likely they are to be able to accurately assess the wellness and comfort of a participant during the research encounter. One suggestion for making sure that women in this situation are able to make a good decision about taking part in research is for them to have someone who knows them, and their drug use cycle, present to help them decide whether or not this is a good time for them to be making a choice about taking part in research.

QUICK QUESTIONS TO ASK RESEARCHERS

- **What are your consent procedures?**
- **How will you ensure that women remain comfortable with their consent at all times?**
- **How, and when, will you make clear that participants can withdraw their consent?**
- **Will you consult, or obtain consent, from us and the community before disseminating findings? How will you seek this consent?**
- **How will you ensure women understand the limitations of the researchers and the study?**

CONFIDENTIALITY

Confidentiality is always a concern, and was one of the main issues discussed by the women we spoke to. Women were concerned about information being given to the media, their families, or future employers as well as a lack of confidentiality among researchers and services providers.

All researchers should see confidentiality as a fundamental right of participants, and the duty to maintain confidentiality as a professional obligation. In all but a few circumstances, researchers face serious professional consequences if they breach confidentiality. Information that could identify an individual participant can only be accessed by the research team, and researchers are required to follow rules set by research ethics boards that make sure all information is kept in a secure place. Most data also needs to be destroyed after a set amount of time (usually 5-10 years).

There is one exception to total confidentiality: if information comes to a researcher that suggests a child is in danger, or if someone makes threats toward another the safety of another person, researchers (like all adults) have a duty to report that information to the appropriate authorities. These limits to confidentiality should always be made very clear to research participants as part of the consent process.

> Especially some research programs, there's a mix of people. Like there's rich people and it's like poor you....and you do feel exploited if you're a little different, people are judging you. No matter what people say at the beginning of the meeting like "everything here is going to be confidential" but you don't know that. Like that person won't take it seriously and will walk out of the room and will go and exploit your shit on the street

Women also talked about confidentiality concerns they had when they were in focus groups with people they didn't know, particularly when the discussion included personal and sensitive issues such as substance use or children. Researchers, unfortunately, cannot guarantee that confidentiality will be maintained by other participants in focus groups, so again it is the researchers responsibility to ensure that women know they don't have to answer anything they don't feel comfortable sharing with others. Participants can always choose how much they want to say in any research study.

‘Community confidentiality’ was also discussed by the women we spoke to. Women worried that given the homogenization of severely stigmatized groups of women (e.g. sex workers in Vancouver’s Downtown Eastside who use drugs) that information shared by one woman could have consequences for a whole community. As a community organisation this is something you can mitigate by knowing more about the research team and the aims of their study as well as developing relationships only with researchers you feel comfortable with.

> I was asking her [the researcher] and she wasn’t answering me on half of them...like certain questions that were actually quite important she was manoeuvring around, and so, she wasn’t giving me the answers that I wanted to, answering what I wanted to be answered

QUICK QUESTIONS TO ASK RESEARCHERS

- **How will you protect women’s confidentiality?**
- **Who will be handling the information provided by individuals?**
- **How will you ensure women know about their rights with regards to confidentiality?**
- **What are the potential consequences for women participating in your study? How will you mitigate those consequences?**

RECIPROCITY AND CHANGE

The women we spoke to had lots of reasons for taking part in research. A central reason for their decisions about participating in research was that they thought it might be able to help other people dealing with the same issues, that it would make things better for their community, and make a difference to other, and future, communities.

There is often, unfortunately, a large gap between a participant's expectation of the research and the reality of implementing a study's findings. The researchers who conduct studies are usually very separate from the people who can make change happen. Researchers are often confined to simply trying to get the people who matter to listen to their results. This is something both individual women and community organisations should be aware of when agreeing to participate in a study. Conversely, change, and particularly policy change in health and social care often relies on research studies to suggest and monitor new approaches. Research *can* make the difference women hope it does when they agree to participate.

> People participating in research projects who have health issues or who are criminalized always absorb an undue proportion of risk and receive the least benefit

When change that people hoped would come from research is not happening and women's situations are not improving, then it is understandable that some women, and community organisations, become sceptical and suspicious of researchers, as well as exhausted from repeating the same concerns over and over again. Researchers can often seem to 'disappear' after completing their data collection, and analysis can seem to take an inordinately long time. To keep women and other community partners more engaged, you can ask to be given regular updates on the progress of the study and to be given interim results.

> They research violence and talk about stuff but they don't give us housing or real help for drugs.

As a community organisation working with women who use substances, you can make researchers as accountable as they can be for any action suggested by their studies. When approached to participate you can discuss the resources they've allocated to disseminate their findings, you can make sure that this dissemination is the most appropriate for your community, and ask how they will help advocate on behalf of your community. Often, change comes as a result of combined pressure from researchers, community organizations, front-line workers, and the people they serve. Partnering with researchers and people who participate in the research to advocate for change can be one way to bring the research findings into action.

> Do the action on the research. If it recommends to do something for drug addicts then do it!!!!!

QUICK QUESTIONS TO ASK RESEARCHERS

- **What will change or improve as a result of this research?**
- **What are the risks and benefits for women and communities participating in this research?**
- **How will you use the resources you have to advocate for improving women's situation based on the results to your study?**

GETTING INVOLVED

The women we talked to were very clear that they felt more comfortable, and safer, participating in research if the facilitator was someone who had lived experience of the issues being studied. They also suggested that women with lived experience of substance use may be more likely to establish a rapport with participants and have a greater understanding of the complexities and nuances of the issue being studied. Descriptions of positive research experiences given by the women included instances where women who use drugs were involved in the research process and/or designing parts of the study. All of which point to the benefits of community organisations and women who use substances being an active partner in research studies.

These types of partnership-based research studies, where individuals and community groups most affected by the issues being studied take a lead role in designing and carrying out the study, are often called **participatory action research projects.** It is felt by many that these projects can produce more relevant and beneficial research to improve the situations of women who use substances.

Getting actively involved in research studies gives a chance to women who use substances, and community organisations who work with them, to minimise some of the difficulties discussed in this booklet. This s not always easy, but it does give an opportunity for the unique knowledge and experiences of women who use substances to be recognized and utilized, and women to be fairly paid for their expertise. Having women who use drugs, and organizations who support them, involved in designing and carrying out their own research can improve the research process in many ways, including producing a more equal balance between the needs of the researcher and those of the researched.

> It was good because actually women got asked the questions and were treated respectfully and were asked questions that meant something to them, and was from them. And the research is actually, as best we can, is being used to help them. So I think that's the best thing that could possibly happen in something like that.

QUICK QUESTIONS TO ASK RESEARCHERS

- **How are women who use substances involved in this research process?**
- **Could women who use substances be more actively involved in this study?**
- **How can you help us research the issues we know to be important and relevant to women who use substances?**

CHECKLIST

Taking a little time to think about the points on this checklist might help you as a community organisation to be more confident that the women you work with have respectful and beneficial research encounters. Always remember that you can refuse to participate in any research project.

- ☑ **Can you see any benefit to women who use substances in the proposed research?**
- ☑ **Are women being paid fairly and ethically for the study?**
- ☑ **Do you feel the research team are capable of being sensitive and non-judgemental at all times with the women they hope will take part in their research?**
- ☑ **Is the consent process an ongoing one and does it make clear the option of withdrawing consent at any time?**
- ☑ **Will all aspects of women’s confidentiality be protected?**
- ☑ **Will you be consulted before the findings are publicly disseminated?**
- ☑ **What plans and resources do the researchers have to help put findings into action?**
- ☑ **Are there any opportunities for women who use substances to be a more active partner in this research project?**

FURTHER CONTACTS

- For information about research from the University of British Columbia -

  Research Subject Information Line 604- 822-8598

- For information about research from the University of Victoria -

  Tel: 250-721-7968

  e-mail: nforcada@uvic.ca

- For information about research from Simon Fraser University -

  Tel: 778-782-3477

  Website: http://www.sfu.ca/vpresearch/ethics/ where the current research officer's e-mail is in the "contact us" section.

- For more information about the project that put this leaflet together -

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- The PACE Society also have a document for community groups that might participate in research, it covers similar issues in more detail that are specific to the concerns of sex workers. This can be accessed at their website www.pace-society.ca under their *Resources and Links/Publications* section.

- National guidelines for research ethics that are to be followed by all researchers at Canadian universities can be found in the Tri Council Policy Statement: Ethical Conduct for Research Involving Humans, at their website www.pre.ethics.gs.ca/english/policystatement