

The background is a solid purple color with a dense pattern of white, irregular, scratch-like lines. A white speech bubble with a purple outline is positioned in the upper left quadrant, containing the title text.

## **Your Rights in Research: A Guide for Women**

The information in this booklet  
can help you decide whether  
or not to participate

This project was a collaboration between researchers from 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*.



The team would like to sincerely thank the *Aurora Centre* at BC Women's Hospital and Health Centre; the *BC Coalition of Experiential Women*; the *Intertribal Health Authority*; the *Kettle Friendship Society*; the *Vancouver Area Network of Drug Users* and the *Watari Research Association* for their invaluable help in helping us organise and host the focus groups that made this study possible.



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# Introduction

This leaflet is for women who are past or current drug users and are thinking about taking part in a research study.

If you choose to join a research study it's important that you know your rights and that you have the information you need to decide whether or not to participate.

This leaflet was made by a large group of researchers from the BC Centre of Excellence for Women's Health, the Women's Health Research Institute, UBC and the University of Victoria.

We talked to women in Vancouver who are past or current drug users. We asked about their experiences, their stories and their opinions on research. This leaflet comes from those conversations.

# Your Rights at a Glance

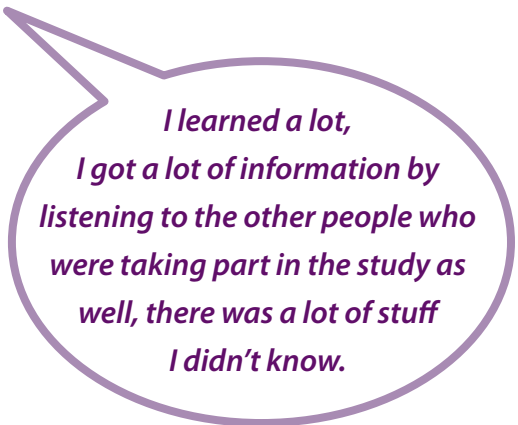
## In any research study you have the right to

- To make your own choice about whether to take part in research or not. Participation in research is VOLUNTARY.
- To have all the information presented to you in a way that's easy for you to understand.
- To understand how the researcher will ensure your confidentiality, and to know if there are any limits to confidentiality.
- To take a consent form home to think about whether you want to participate in the study. You can ask the researcher, or a person you trust, to read the consent form to you, and you can ask for a consent form in your language. You should usually have at least 24 hours to decide if you want to take part in a study.
- To ask any question about the research and have that question answered.
- To understand if, when, and how you will be compensated (or paid) for taking part in the study.
- To choose exactly what and how much you want to say to a researcher.
- To refuse to answer any question, withdraw your consent, or stop participating at any time, even if you have signed a consent form and received payment.
- To be respected for your experiences and opinions.
- To get a free copy of anything that gets produced that includes information you have given to the researchers.

## Why you might want to get involved

- Research studies can make a real difference to what services are available and how they are provided.
- You may find that you learn useful information about a particular subject or about your community.
- Your opinions and experiences are valuable and your knowledge is appreciated by researchers.
- You can let researchers know what you think is important about an issue you care about.
- The payment you might receive from a study recognises your expertise.
- If women understand more about research then there are times when they can be a part of the research team and do studies that they know are important.

*It was good because, actually, the women got 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.*



*I learned a lot,  
I got a lot of information by  
listening to the other people who  
were taking part in the study as  
well, there was a lot of stuff  
I didn't know.*

## Why you might NOT want to get involved

- Researchers can't make action happen, they can only let others know what they find. Taking part in research won't directly be able to get you better health care, housing or any other service.
- Most researchers are not trained counsellors. If you think a topic, or certain questions, may be too distressing for you, then think twice about doing the study.
- If you think the researchers are judging you in any way, or not appreciating your time and expertise, then don't feel that you should take part.

# Trust and Respect

The relationship between you and the research team should always be one of trust and respect. Women we talked to were concerned that some researchers were exploiting them because they use drugs or had addiction, and weren't respecting their expertise or contribution.

If you feel you are being judged or exploited, or if you feel a question is too personal, then remember you can always stop and ask why things are being asked. And if you're still not comfortable then you can just walk away.

*Drug addicts have first hand experience and this is valuable. We are the key to real experiences.*

*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.*

## QUICK TIPS

- If you're not happy with the researcher's attitude, leave.
- If you want to know more about the researchers' experience and understanding of an issue, ask them.
- Ask the researcher to explain clearly who the study is for and how it intends to benefit your community.

# Consent

This is where you give your permission to the researcher to use any of the information you give in the interview or focus group for their study. Consent is usually given by signing a piece of paper at the beginning of the session.

It is actually called INFORMED CONSENT because you should be given lots of information. You should understand how much you'll be paid, exactly what you're being asked to do, how your information is going to be used, who will be able to see your information, how long your information will be stored for, and any risks there might be to taking part – including any sensitive questions that might be asked.

You also should be informed about all these things in a language you understand and in ways that make sense to you.

**If you are unsure about whether you can give proper consent for any reason (e.g. because of being high or withdrawing), you may want to have someone who really knows you, and your drug use cycle, around to help you decide.**

*Get ongoing consent. Ask the person if they're okay, and ask again a few questions later, but don't be annoying.*

## QUICK TIPS

- The consent process can seem boring, but remember that you are being asked to share your personal information – this shouldn't be taken lightly! Make sure you understand what's going to happen to you and with your information.
- You can WITHDRAW your consent at any time, even if you've signed the consent form and received payment.
- The researcher should keep checking that you're ok to continue with the research.
- You have the right to see anything produced that uses your information. Ask for copies to be sent to you.

# Money

You will almost always be offered either money or something equivalent for taking part in a research study. This might also be called an HONORARIUM, a STIPEND or COMPENSATION.

This payment is given because your time, your knowledge and your expertise are valuable and appreciated by the researchers.

## QUICK TIPS

- You should always know if you will be paid to take part in the study. If you are being paid (or given something else, such as a gift card, reimbursement for transportation, or childcare costs), then you should be told exactly what you will be given and when it will be given to you..
- Once you've been given payment it doesn't mean you have to stay – you can still leave anytime you like.
- Ask what other supports might be available, such as bus tickets, childcare or refreshments to make it easier for you to participate.

*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 lots of square people  
that cash their cheques and  
go buy drugs.*

# Confidentiality

Confidentiality is always a concern for research participants. Women we talked to had concerns about talking in front of people they didn't know, and talking about personal and sensitive issues such as substance use and children.

Researchers would face severe penalties for breaking confidentiality. Information that could identify you- or other people you might talk about during an interview- should be accessible only to members of the research team. Researchers are required to follow rules set by universities that make sure all of your personal information is kept in a secure place.

Researchers should point out that all participants must respect what is said during a focus group. Unfortunately we can never be sure of other people's behaviour, so if there's a question or a topic that you don't feel comfortable sharing, then remember you have the right not to answer.

## QUICK TIPS

- You can ALWAYS refuse to answer a question, even if you've received payment for the study.
- You can ALWAYS stop and ask the researcher about their confidentiality policy and exactly who will see, or hear, your words.
- It's your choice how much you want to say in any research project.

*No matter what, people say at the beginning of the meeting "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.*

## Checklist

Taking a little time to think about the points on this checklist might help you decide whether or not to take part in a research project. Always remember that participation is voluntary, and you can refuse any research project.

- ☐ Do you know why you've been asked to take part in the research, and what you'll be asked to do?
- ☐ Do you know the benefits or risks associated with taking part in the study – including if you will be asked things that might make you feel uncomfortable or upset?
- ☐ Do you know how your information will be used, who will use it, and how it will be stored?
- ☐ Do you know who you can contact if you have a complaint about how you are treated as a research participant?

## Further Contacts

For further information on your rights as a research participant, you can contact:

For research from the University of British Columbia -  
Research Subject Information Line 604- 822-8598

Or for research from Simon Fraser University –  
Office of Research Ethics  
Tel: 778-782-3477

Or for research from the University of Victoria –  
Office of Research Services  
Tel: 250-721-7968

For more information about the project that put this leaflet together –  
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P.A.C.E society has also produced a leaflet called 'Research Participant Tips' which can be accessed on their website at [www.pace-society.ca](http://www.pace-society.ca) under their Resources and Links/Publications section. There is also a lot more information about research on their page.

