

“Me, I’m Living it”

The Primary Health Care Experiences of Women who use Drugs in Vancouver’s Downtown Eastside

Summary of Findings from the
VANDU WOMEN’S CLINIC ACTION
RESEARCH FOR EMPOWERMENT Study



Prepared by
The VANDU
Women CARE Team
FEBRUARY 2009

Dedication

The VANDU Women CARE team would like to dedicate this report to the memory of Marilyn, Fran and Veronica who participated in the project, and died before it was completed.

The VANDU Women Clinic Action Research for Empowerment Team are:

Principal Investigators:

Amy Salmon, PhD (Women's Health Research Institute and UBC School of Population and Public Health)
Ann Livingston (Executive Program Director, Vancouver Area Network of Drug Users)

Co-investigators:

Annette Browne, PhD, RN (UBC School of Nursing)
Ann Pederson, MSc (British Columbia Centre of Excellence for Women's Health)

Research Staff:

Laurel Dykstra, MA (Community Research Facilitator, Vancouver Area Network of Drug Users)
Julie Ham, MSW (Research Assistant, Women's Health Research Institute)
Tessa Parkes, PhD (Technical Writer)

VANDU Women's Group Steering Committee Members and Peer Interviewers:

CD
Jewels Chapman
Fern Charlie
Fran Dawson
Florence Hodgson
DJ Joe
Debra Leo
Juanita Mayes
Sharon Message
Jackie Robinson

Acknowledgments

The VANDU Women CARE team would like to extend our gratitude to all of the women who shared their life experiences and insights with us throughout the past two years of this project. We would also like to thank the Michael Smith Foundation for Health Research's Health Services and Policy Research Support Network, which provided the operating grant that made this work possible.

The British Columbia Centre of Excellence for Women's Health and its activities and products have been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent those of Health Canada.

Introduction

Background and Context: A Focus on Women and Primary Care in the Downtown Eastside

Preventing and reducing the harmful consequences of drug use has been identified as a key priority in Canada at all levels of government. Initiatives to reduce barriers to care for marginalized women who use drugs are currently underway. However, despite the significant national and international attention paid to the health and social conditions of women in Vancouver's Downtown Eastside (DTES), women who use drugs in this community report persistent health inequities and barriers to accessing a wide range of services, including primary health care, harm reduction services, mental health care, and addictions treatment. **These inequities and barriers to care result from a complex interplay of social, political and economic factors.** In order to provide effective, empowering, compassionate, and respectful care for women who use drugs it is crucial to understand how these factors influence health and well-being.

Vancouver's Downtown Eastside is known as a neighbourhood where the incomes, living standards, and education levels are the lowest in Canada, and health service utilization rates, including hospitalization, are the highest (Vancouver Coastal Health Authority, 2005). The disproportionate representation of Aboriginal women among Canada's most disenfranchised is also evident in the DTES. Although only about 7% of Vancouver's population is Aboriginal, Aboriginal people represent approximately 40% of the population in the DTES (Joseph,

1999)¹. Among women who use drugs in this community, women who inject drugs have mortality rates almost 50 times higher than women in the rest of British Columbia (Spittal, 2006). Surveys and studies in the DTES also show that crack cocaine use has become increasingly common over the past 10 years (SCORE, 2008). One BC survey of youth in custody found that young women were significantly more likely to use crack cocaine than young men (Buxton, 2007). Persistent inequities in health and social indicators evident among women who use illicit drugs in the DTES (particularly Aboriginal women) are manifestations of the complex interplay of social, political and economic determinants that influence health status and access to health care. Analysis of those determinants as they interact with women's access to health services is urgently needed to inform an evidence-based strategy to address the needs of women who use drugs.

Primary health care services provide the first point of contact with a health care provider for prevention, diagnosis, treatment, follow-up and long-term management of health concerns (RNABC, 2002; Shah et al., 2003). As such, primary care services are the foundation for community-based health services in most Canadian jurisdictions. In BC, women report lower rates of satisfaction with community-based health services than do men, and the satisfaction ratings reported by women and men decreased between 2000 and 2003 (BC Ministry

1 Aboriginal women are also over-represented among survival sex trade workers in the DTES, an indication of the highly gendered and systemic poverty, racism, and marginalization which Aboriginal women encounter across Canada (Anderson et al., 2001; Hull, 2001). Seventy percent of sex trade workers in the DTES are Aboriginal women and mothers of at least one child (Burgelhaus & Stokl, 2005).

of Health Services 2004). Gender informs “needs and expectations regarding health care services” (Gijsbers Van Wijk, et al 1996:708). For example, women more often than men change doctors because of dissatisfaction with the quality of communication; and women’s primary care tends to be split between multiple providers (Pollard and Hyatt 1999; Gonen 1999; Weisman 2000; Wilde Larsson, Larsson, and Starrin 1999). Moreover, women’s expectations may be shaped not only by their own health care

needs and experiences, but by their experiences of obtaining care for others. However, most indicators of “quality” in health care concentrate on technical aspects of care, clinical guidelines, or clinical outcomes (Smith et al. 1997). As such, the role of gendered social, economic, and political contexts are rarely analyzed in studies of relationships between “accessibility”, “quality” and “satisfaction” in health care for marginalized women.



The VANDU Women CARE Project

We are a group of women who are current or former users of illicit drugs. We are here to enrich, empower, embrace and care for our women and our community. We are fighting against poverty, abuse and discrimination for all women. We do this through user-based peer support, education and affirming the right to belong.

– VANDU Women’s Group Mission Statement

The VANDU Women’s Clinic Action Research for Empowerment Project (hereafter referred to as VANDU Women CARE) was a qualitative Participatory Action Research (PAR) project aimed at understanding and improving the primary health care experiences of women who use illicit drugs in the DTES. The research partnership was created specifically to address concerns raised by the VANDU Women’s Group about women’s experiences of primary health care in a context of multiple emerging policy and service reforms. The project brought together members of the Vancouver Area Network of Drug Users (VANDU) Women’s Group, and academic researchers from the British Columbia Centre of Excellence for Women’s Health, the Women’s Health Research Institute, and the University of British Columbia School of Nursing, to form the research team².

Research Design and Process

Although women who use drugs in the DTES have been the objects of a considerable amount of research during the past decade, they have rarely been supported to conduct their own studies of their health needs. **The leadership of women who use drugs was essential to the rigour, quality and relevance of this study.** Participatory Action Research (PAR) methods

² Throughout the report, we use the terms “research team” and “researchers” to include academic researchers, research assistants, the project’s Community Research Facilitator, VANDU leadership, and VANDU members who work together on the project.

Key goals of the VANDU Women CARE study were to inspire and foster dialogue between health care providers and women who use illicit drugs and to identify opportunities to enhance women’s health and continuity of care.

supported this approach to our research. PAR strategies focus on the development of knowledge through partnership and empowerment:

- individuals or groups most affected by the topic of study play an active role in setting the research agenda and the questions asked
- participants are often involved in the data collection and analysis
- participants have a voice in guiding the research process and determining the use of the research results (Tandon, 1988)³.

³ PAR methodologies have been successfully employed in a wide variety of health services and policy research for example in exploring pathways to care (Thomas et al., 2005), determinants of health (Groft, Hagen, Miller, Cooper, & Brown, 2005), community health development (Huang & Wang, 2005), the development of community-based health interventions (Kelly, 2005), community-based health services evaluation (Taylor, Braveman, & Hammel, 2004) and primary health services and policy reform (Cawston & Barbour, 2003; Thomas et al., 2005).

Throughout VANDU Women CARE, 32 women worked together to build an inclusive research design. Once the design was in place, eleven VANDU Women's Group members were trained and compensated to serve as peer interviewers during the data collection phase of the study⁴. **50 women's experiences of primary health care were documented in individual interviews between May and July 2007.** Women interviewed for this study were between 20-70 years old, and 62% were Aboriginal. Women who were interviewed for this study were included because they self-identified as women who use drugs in the DTES and had used DTES primary health care services in the 12 months preceding interview. Both qualitative and quantitative data were gathered in an effort to give a rounded and thorough description of women's experiences⁵.

Purpose and overview of this report

This report is a summary of the most relevant findings of this community-driven research project for health care providers treating women who use drugs in the DTES. A draft of this report was prepared and circulated as a background document to inform a Dialogue Day held on October 17, 2008, which brought together members of the research team, healthcare providers and policy makers involved in healthcare in the DTES. At this event, the research team received very useful feedback from participants which further illuminated the service provision and policy contexts that

shape the experiences reported by women in the study. This feedback has been incorporated into this version of the report. The research team's intentions for disseminating the project's findings and recommendations is to inspire conversation among diverse individuals, groups, and levels of government in order to identify opportunities for change and ongoing collaboration with respect to the issues raised.

The report is organized into two main sections:

Part 1: Women's Experience and Use of Primary Care

Part 2: Going the Extra Mile: Working Together to Improve Primary Care for Women who use Drugs in the Downtown Eastside

For the purposes of this report we concentrate on findings that are specific to the delivery of *non-urgent primary care services at DTES clinics*. While our intention was to distinguish between emergency care and primary care in terms of locations that care is provided, this was difficult to do based on our data, which indicates that primary health care is being provided in hospital Emergency Rooms, at clinics run by the Health Authority, at clinics run by for-profit and non-profit organizations, by street nurses, and by a wide range of other providers and agencies. The implications these findings have for health care providers and policy makers are explored in more depth in Part 2 of this report. This report also contains "quick fact" boxes that summarize key findings from the VANDU Women CARE data about the health and well-being of women who use drugs that are important for understanding women's health care experiences described in this report.

4 Peer interviewers received training in the use of all research instruments and equipment, University Research Ethics Boards' requirements for ethical research conduct, informed consent, qualitative interviewing techniques, communication skills, body language and conflict resolution.

5 Individual quotes by women are referred to using the pseudonyms that women chose when they were interviewed. Quotes included in this report are recorded in the women's own words, but in some case they have been slightly altered for readability.

Part 1: Women’s Experience and Use of Primary Care

Women interviewed for this study identified 29 different clinics or services from which they access healthcare services. Of these 29, 12 are

Quick Fact: Drug Use and Health

In academic health literature, women who use drugs in the DTES are often lumped together or treated as a homogeneous group. Although all of the women who took part in this study had to self-identify as having used street drugs in the past year, the women we talked to were diverse in many respects, including their level of substance use. We interviewed women who had not used drugs for nearly a year, and women who identified as using “as often as possible”:

- 83.7% of the women we spoke to smoked crack
- 85% of women who reported that they inject drugs also reported smoking crack
- 95% of women interviewed were on some form of income assistance. Among those women, many identified welfare cheque issue day (or week) as the time they use drugs the most.

Women interviewed for the VANDU Women CARE study reported many reasons for using drugs. These included:

- Emotional pain and trauma, such as depression, violence, loss, stress
- Physical pain, such as pain from injuries
- Pleasure
- To cope with difficult life circumstances
- For harm reduction or health purposes

Women had concerns about how drug use impacted their health; six women identified drug use or addiction as one of their major health concerns. They made reference to the impact of drugs on their dental health, on particular health conditions such as epilepsy, fear of HIV and Hepatitis C from sharing needles, and the impact of drugs during pregnancy. Fear of accidental overdose was also apparent, with 17% of women reporting an overdose in the past year.

located inside the geographic boundaries of the DTES and 17 are located outside of the DTES. Women did not tend to draw distinctions between the Community Health Clinics run by the Vancouver Coastal Health Authority and other clinics or services, such as methadone clinics or pharmacists. This report includes women’s comments about this full range of services, but focuses mainly on experiences women reported having at clinics in the DTES.

What Women Liked About their Primary Health Care Experiences

All of the clinics in the DTES received both positive and negative evaluations from women describing their experiences accessing care. There were no clinics that received unconditional praise, and none that received unconditional condemnation. In interviews conducted with the women who participated in this study, viewed “good” primary health care in many different ways. For some women, primary health care was considered “good” when it was conveniently located, when the provider offered additional supports (such as a free meal), or when it was efficiently organized in terms of patient waiting and flow. Sometimes women assessed the quality of their health care by the outcome: if they got better, their care was good.

A “good doctor” was described by women we interviewed as someone who is: caring, compassionate, kind, efficient, non-judgmental, flexible, and as someone who takes time and makes a person feel comfortable. **“Having a doctor that will listen to you” was centrally important for creating positive care experiences.** For example, women stated:

“It was a beautiful visit with her, and I had everything taken care of that I went there for” (Margaret).

“She was very, vary caring towards me and very concerned about my health and wellbeing.”

(Margaret).

“She sat me down and spent a couple of hours with me to talk to me one-to-one about my HIV. I felt good inside, I felt safe again, I felt cared for again, I felt happy again. I felt I had hope again cause I had been unhappy ... She came along at the right time in my life, then I felt better again. I got trust in people again (FD)”.

One woman described a positive experience as follows:

“She’s wanting me to go see a doctor for my knees, for my arthritis, something I hadn’t done. Set up an appointment for me... She wants me to get better”.

Interviewer: How did it make you feel?

“Important. She made me feel like a somebody” (ECT).

For many women, **a positive relationship with a health care provider is one in which a woman feels she can be honest about herself, her drug use, and her health care issues**, as Blue Eyes comments:

“It’s nice because I don’t feel like I have to withhold or hold back on approaching him with anything, or about being open about my drug using. I don’t have any problems letting him know what I do or don’t do. I want to make sure it doesn’t counteract with anything I might get prescribed in general. It helps him keep me at my best health possible, knowing what I do and don’t do. It’s a smart thing to do”.

Women appreciated practical help they received with their health concerns, such as when providers gave them information, took time to explain things, went out of their

way to check out things they didn’t know, or gave advice on places go (or avoid) to obtain additional types of care. Having the health care provider write things down, or charting what women said, was also regarded as helpful. Nurses, in particular, were singled out as being helpful in this way. Again, flexibility was viewed by women as an important aspect of good care. Brandy Rose described street nurses in this way:

“They’re kind and gentle, they’re understanding, they’re compassionate. They give us knowledge... they take their time on letting us know where to go and how to get there. Instead of being just pushed aside like these people do”.

Relationships with health care providers were also viewed by women as having an important impact on their ability to maintain or improve their health. Among women who spoke of the importance of having an ongoing relationship with a provider they liked, a clear link was evident between *relationship and efficiency*. For example, having a long term relationship with a care provider ensured that women would not have to repeat their “story”, or argue for their needs. Where such relationships exist and are supportive, women placed a high value on their role in maintaining their wellbeing. Women also appreciated services which offered a more holistic approach to addressing complex health problems, where *“they take care of you, everything, like every part of your life”* (Anna).

Quick Fact: Women Doctors

25 women stated that they prefer too see a woman doctor. One woman said her biggest health concern was male doctors, others said they refuse to see a male doctor: “Yeah, if I can’t see a woman, I don’t see the doctor” (CM).

What Women Found Difficult in Their Primary Health Care Experiences

As was found in women's assessments of positive health care experiences, negative evaluations of health care providers were also diverse. Many negative descriptions of primary health care experiences included experiences with providers that were considered to be: disrespectful, dismissive, punishing, judgmental, lacking concern, stereotyping, condescending and too busy. Feeling that they were being "psychoanalyzed" was also very problematic for women. Some women complained about the difficulty they have getting regular and timely access to their provider, as Star 360 explains:

"...she won't make appointments and she's only there what, three or four hours once a week maybe, sometimes twice a week. You don't know and she doesn't have anything that's a regular schedule".

Providers that did not recognize that women had expertise regarding their own health conditions were a significant source of frustration, as underscored by FD:

And the nurses get upset with me because the bottom line is they know better and they're right. They always know better and they always know that they are right. And that's not the right thing. I've been dealing with this for years. I know what I am talking about and it's always a big chore to get that point across. It's a textbook knowing, it's not experience for them. They read it in a book and they learned it from the UBC. Me, I'm living it, I've experienced it".

It is important to note that when bad things happen in health care interactions, this can have a lasting and substantial impact on a woman. **Negative past experiences profoundly shape women's willingness to access care in the**

future, as well as their expectations of the health care they can or will receive.

The importance of respect

Many women talked about the importance of respect in creating positive health care interactions. **Women described feeling respected in health care settings as experiences of feeling safe, not being treated as a drug addict or "junkie", being seen as someone with valuable things to say, or as a "normal" or whole person.** For the women we interviewed, being respected meant being listened to, having one's history known, and being treated in a courteous and caring manner. Asked how she knew her physician was treating her respectfully, Nancy said:

"He listens, he asks questions, he gets to the root of the problem. And he sees that if you don't have this test done, he makes sure you get it done".

Women also said that it was important that clinic staff, including receptionists, security guards and physicians, treat them respectfully. Some women acknowledged that if they were not treated with respect themselves, they were unlikely to act respectfully toward the clinic staff. For them, respect fosters respect.

Despite the high value women place on respect, most of the women interviewed reported that they were treated in ways that felt disrespectful. Not being respected was evidenced by the time spent waiting⁶, not being listened to, or being spoken to in a discourteous manner.

The dilemma of "being known"

Findings from the VANDU Women CARE study suggest that "being known" is a core feature of some women's positive relationships with health care providers. There are many different ways women talked about being known. Sometimes

6 For further discussion on waiting, please see page 14.

being known meant having a provider who is empathetic, and respectful. Sometimes it meant having a provider who is knowledgeable about a woman's individual circumstances and health needs, and who is prepared to work with them to manage their conditions. For some women, being known gives them a sense of security and alleviates stigma, as CM describes:

"I know them and they know me. They know my case and my paperwork and don't have to go somewhere else for the information, so I feel comfortable".

Being known seems, in some circumstances, to facilitate a quicker and more flexible response to women accessing services. For example, being known can mean that a woman will be taken seriously when she comes in complaining of pain, because her drug use patterns are understood and recognized. This point is emphasized by Wonder Woman:

"I was in pain but they took care of it right away. 'Cause they know me, I'm not a frequent flyer there, so they threw some morphine at me immediately".

However, being known is not always a good thing. Women also described being known as increasing the stigma and discrimination associated with being a drug user, and the likelihood of refusal of services. Women therefore spoke about using different strategies to manage disclosures about drug use and the stigma which can accompany such disclosures. **Some women did not tell their providers about their drug use, believing it would compromise their care.** Women also spoke about a further danger: telling a physician about their drug use could result in all their health problems being interpreted through the lens of drug use. This was viewed as undermining women's efforts to get comprehensive care and be seen as a whole person. Otter agreed it was better not to tell:

"I have to lie to them. (...). Because if they knew about it, they'd freak and they'd give

me a whole lot of bullshit and problems and they'd deny me ... oh God, no. So, no, they don't know about my drug use, no".

To try to get better care from their providers, some women described strategies such as finding and developing a relationship with a doctor, or educating and keeping a doctor who they know and trust (and who they feel trusts them). About one third of the women stated that they brought professional or volunteer advocates with them for a medical visit. Women felt this improved the quality of care they received, reduced wait times, provided emotional support and made waiting easier. However, one woman reported that her relationship with her doctor "fell apart" because she brought an advocate.

Quick Fact: Health Problems and Care Needs

Almost all of the women interviewed had significant acute or chronic health issues:

- 43.2% had 3 or more chronic health problems
- 23.6% had 4 or more chronic health problems
- 56% had Hepatitis C
- 40% had dental problems
- 32.7% reported mental health problems
- 30% had lung problems
- 16% were HIV positive
- 14% were diabetic

In the year prior to interview 45.8% women needed emergency care and 44.9% needed an ambulance.

During the 24 months of the project three women involved with the project died and four members of the larger women's group (of about 150 women) have died. Women died from suicide, overdose, untreated acute health conditions, and violence.

How Women Use Primary Care Services

Networks of Care

For women in the DTES, it seems that clinics are not “islands” but rather integral parts of networks of care. Women described what they saw as a continuum of care with primary care and acute care, methadone clinics, the NAOMI Project⁷, InSite⁸, street nurses, pharmacists and other specialist health resources, as part of this continuum. It seems as though **the distinction that health systems make between emergency care, primary care, pharmacy, and outreach, for example, do not reflect the care seeking patterns of the women we spoke to.**

Women who were interviewed in advanced stages of illness spoke about their transition from primary to palliative care. For some women, their experiences of system avoidance and bad care “tipped over” into receiving what they perceived to be “good care” when they were nearing the end of their lives. These findings point to a possible improvement in women’s relationships with health care providers once they move into specialist and tertiary health systems for palliation.

Use of multiple providers: challenging the integrated care ideal

Vancouver Coastal Health Authority (VCH) has undertaken a redesign of primary care services, in which some Community Health Centres are beginning to operate according to a “One Stop Shop” model. The intention of the VCH primary

care redesign was to improve integration of health services, and to avoid vulnerable and marginalized people getting “lost in the system”. Within this model of care, multidisciplinary teams of health care providers are housed under one roof. While “One Stop Shop” models are intended to increase continuity of care and foster relationship building between patients and providers, this model was not received positively by many of the women we talked to. **An unintended consequence of this policy seems to be that some women feel “pushed away” from health care settings.** Interviews revealed that this model of integrated care can support practices in which some women are refused service and sent to “their clinic” if they attempt to access services elsewhere. Blaze Storm explained how she felt when this happened:

Interviewer: How did you feel when you were there?

“Like I was pushed away. (...) I mean my needs weren’t met, she told me to choose which clinic and for me not to show up at [one clinic] since I’m going to [another clinic]. In order to be a permanent client at [the clinic] you’ve always got to consistently go there, you can’t go to another clinic ...”

From the interviews it was clear that women’s strategies around seeking healthcare are complex; sometimes being driven by practical concerns such as what service is closest to where they live, what clinic is open on the day a woman is sick, or a desire to access care at places they are known best or least well (as explored above). In scenarios where a woman does not get along with their doctor, or perceives that her needs are not being met, a “one stop shop” model may therefore create rather than reduce barriers to care.

In many instances, women reported that they managed the challenge of getting their needs met by spreading their care across many

7 The North American Opiate Medication Initiative (NAOMI) is a clinical trial that tests whether heroin-assisted therapy benefits people suffering from chronic opiate addictions who have not benefited from other treatments (from www.naomistudy.ca).

8 InSite is a supervised injection facility where users can inject their own drugs off the streets and under the supervision of nurses (from www.communityinsite.ca).

different providers. Most women we spoke to received health care at more than one clinic. **Indeed, multiple provider use was a regular feature of the primary care experiences of the women we spoke to.** FD gave us an insight into the reasons why she attends more than one primary care clinic:

"I have to bounce around in order to get the help I need, 'cause some days he's not there and other days she's not there. So off I go to a different clinic, so I can find out if he's on or she's on and then I'll get the help I need".

Quick Fact: Transportation and Proximity

Approximately half of the women interviewed spoke about transportation as part of their health care experience and as part of the effort involved in accessing health care. Proximity was particularly important for women who were unable to walk or travel for long distances due to health-related mobility problems. Very few women we interviewed had bus passes or money to pay for the bus. For some women, and at some times of the day, walking is the only accessible mode of transportation, as Mary explains:

"It's hard for me from where I live. Like I walk from my place to [the clinic]. And then I hop the Skytrain and then I walk from [the station] to [the hospital]. That's a lot of walking, like, especially when my legs swell up so bad and my kidney's aren't functioning right. My kidneys are only functioning 14%, you know. That's hard on me, I get so tired. It's the transportation that I need".

Travelling, even if it meant walking, outside the Downtown Eastside was one of the more common strategies used by women to get the health care and/or medication they needed. A clinic's or health care provider's proximity was often a factor in choosing a particular healthcare facility or provider on a given day, and was often a reason cited by women for attending multiple clinics or seeing different providers.

The effort required to coordinate their own care across multiple providers is increased for some groups of women, such as women on methadone or women with chronic physical and mental health needs.

Although some women accessed health care in a variety of settings, many women who did so commented that the best way to get good care is to have a primary care provider "who knows you" and who can "take care of everything that is needed". As was noted in women's descriptions of positive health care experiences (described above), this was seen as valuable if the provider was perceived by women to be interested in them, supportive, respectful, and accepting of them as drug users with complex lives and health challenges.

Understanding multiple provider use as a strategy for seeking safety and care

Many women we spoke to go from clinic to clinic, or between primary, secondary and tertiary care, as a strategy to build networks that allow them to get the healthcare they need, when they need it. What is clear is that a 'fragmentation of care' is occurring: one in which women participate in while trying to get their needs met and compensating for system limitations. "Doctor-shopping" is one of the pejorative ways that multiple service use is described by providers and policy makers. Our findings offer an opportunity to revisit this negative way of understanding women's multiple provider use by looking at the wider rationale and broader benefits for women and for women's health that this provides.

Implications for service delivery: Rethinking concepts of care

For women who use drugs in the DTES, the formal service distinctions drawn by policy makers between different parts of the system (such as primary care, emergency care, street outreach, or tertiary care) do not seem to be evident in the course of their primary care experiences. This has important implications for how we think about the delivery of care. For example, getting care in a number of places can result in a greater number of partial histories, which can in turn compromise continuity of care or interfere with coordination of medications, leading to fragmentation of service and

increased potential for medical complications. Also, when women are getting care in many places and from different individuals and at different sites, opportunities (both positive and negative) for communication between providers and clinics need to be considered. The idea of *'networks of care'*, or a *'continuum of care'*, upsets the notion of primary care nested in a single site where a person sees one doctor who meets all their needs. These insights into when, why, and how women access multiple providers can help to re-define what primary health care means and looks like, based on the concerns and relevancies of women who use drugs in the DTES.

Quick Fact: Housing, Homelessness and Health

The challenges of maintaining health in poor housing conditions was a strong and recurring theme in our study. 61.2% of women reported having health problems related to their housing situation, and 44.9% of women reported that their housing was unsafe. Eight women (16%) were homeless at the time of interview. 23 (46.9%) women were living in a Single Room Occupancy (SRO) hotel, 10 women were living in apartments or houses and 8 women had other unspecified housing arrangements. 3 women who were HIV positive reported being homeless. The most often mentioned housing-related health concerns were:

- ventilation issues (mold, mildew, asbestos)
- infestation (bedbugs, cockroaches, mice)
- lack of heating
- unusable bathrooms (unclean, backed up toilets, always needing repair, housing with no running toilets, not having a private bathroom), and
- security issues (disruptive neighbours, not having locks on doors, frequent break-ins).

One woman reported using homeless shelters when her SRO hotel felt particularly unsafe:

"There was no lock on the door, I couldn't lock my door when I was sleeping for six months" (Lo).

Substandard housing conditions impacted women's health by causing respiratory illnesses (asthma and lung infections) and skin conditions (bedbug bites). Unsafe or unsuitable housing also exacerbated women's already serious health conditions. Having to contend with serious housing and security concerns left women with little energy to think about their health or to follow their doctor's instructions:

"About a year ago or so I stopped not having a place to cook with food so that the pills would work properly, ...so I ended up moving out and then couldn't get to a place. ...I've been tired from not eating, not drinking properly and just don't have the patience, the time. You're just worn down, the stress. I give up too easy" (Marlene).

Indeed, VANDU Women CARE data strongly suggests that it is not always in women's interests to have health care services all in one place, or to mandate women to use a sole primary health care provider. At the same time, women who participated in this study also identified clear benefits associated with having an on-going relationship with a trusted, respectful care provider who understands and responds to their complex medical and social circumstances. Together, these findings present a challenge for health systems, providers, and community members to work together to create conditions in which comprehensive, respectful and welcoming primary health care services can be delivered safely and effectively to women whose experiences have discouraged them from seeking such care from a single provider.

Time and Waiting

Many women talked about the time and effort involved in trying to access health services. Women described this as being "shuffled around", or being given the "run around". This is a particularly onerous situation for women with complex needs and women on methadone, who require frequent visits to their doctor for assessment of chronic conditions or to renew prescriptions. Having accurate information about when and where their doctor was seeing patients on any given day was critical to women's ability to coordinate their care. Women talked about "*planning the day around the doctor*" and noted that these requirements to "*put a full day in*" regularly keep them from doing other important things in their life. Women also recognized that these difficulties were in part a function of physician's complex schedules, which sometimes include part-time hours or working in

Waiting was one of the most salient concerns raised by women we interviewed.

"...they could die waiting" (CM).

different places on different days.

Women's experiences of waiting for care

43 out of 50 women spoke about problems they encountered waiting to access care at community clinics. Our data indicate that waiting times at clinics may be an unintended consequence of policy: eliminating the ability to make appointments in favour of a "first come, first served" approach may be resulting in another bottleneck for patients (and providers).

Women wait outside at some clinics in order to register to be seen by a doctor. Women provided numerous accounts highlighting the risk of losing their place in the queue, which could result in an even longer wait or, potentially, the need to return again the following day to begin the process all over again. Women also reported being turned away after waiting, leaving because the wait is too long, and not seeking healthcare because of anticipating a long wait and/or being turned away.

Prolonged waiting was described as impacting negatively on women's experiences of care and on their health outcomes. For others, waiting was viewed as a normal part of accessing health services in the DTES. Women interviewed for this study also expressed concern that marginalized people are more likely to wait for health care, and those who wait longest also have the most difficulty doing so.

Waiting as punishment and control

Many women viewed waiting as a form of controlling, punishing, or rewarding women. Participants in this study spoke of clinic environments where no appointments can be

made, but in which it is still possible for women to be “late” for theirs: if the person waiting steps out for a cigarette, to get something to eat, to get fresh air, or to use a bathroom, they will miss their “turn” because they didn’t come promptly when called. **Waiting was regarded as a dehumanizing process which made women feel “like a number”, like an “outsider”, or like they were “not being heard”.** Women also spoke of long waits as evidence that their health care providers considered their lives to be of little value. When asked about what needs to change at the clinics with regard to waiting, Linda stated:

“They kind of keep you in that same spot. Pigeon-holed”.

Interviewer: Why would this change be important?

“Because you wouldn’t feel so frustrated, you’d feel heard.... You wouldn’t go out and use”.

It is important to note that clinic intake and reception staff who are responsible for managing waiting patients are typically also the lowest paid staff, and are likely to need better supports

“...everyone down here is surviving, you know, and they don’t need to hear a doctor being negative, or a lady on the desk, or anything” (Cher).

in their roles in order to meet women’s needs during long waiting periods.

Women also remarked on the poor physical conditions of the places they have to wait. Clinic waiting rooms were described by women interviewed as being “like a zoo” where people are “herded” or “treated like guinea pigs”.

Some physicians were described as being good at “taking time” when a woman actually got into the office or exam room, and this was highly valued by women when it occurred (as described

in the sections above). Other women stated that the imposition of waiting for a long time to see a doctor was more frustrating for the fact that that they were “rushed out” when they did finally get their turn, as Tamara states: *“they’re all just processing people through so there’s not enough time for patients”.*

Strategies women use to cope with waiting

Although many women reported leaving without being seen, they also employed a wide range of strategies to manage long waiting times. These included coming early, bringing a friend, being tenacious (just staying no matter what), and making and keeping appointments (where possible). Women also spoke about adopting behaviours that they felt would result in being seen by a doctor in a timely fashion. Most women agreed that non-confrontational, collaborative, and “sincere” approaches were their preference, noting that it is important that patients “don’t be a bother”, that “acting up will only keep you waiting longer”, and that it is important to “back off” when needed. Others noted that they would resort to “making a fuss” and “hollering” if they felt they were waiting longer than they were able, or when they needed to have the urgency of their concerns recognized. However, women who adopted more confrontational strategies noted that these can be prone to backfire, with significant consequences for themselves and for clinic staff. In particular, some women spoke of occasions

“It is too easy for doctors to pass you off, to get rid of you as a patient” (Star 360).

in which a healthcare provider mistook their expressions of frustration at waiting as evidence that they were drunk or high.

Dismissal and Denial of Services

Thirty-two women raised the issue of being dismissed or denied services when attempting to access primary care. A variety of different types of dismissive treatment were described in interviews. Women spoke about being turned away from health care settings when they had been injured, when they were having a mental health crisis, when they were suicidal, and when seeking HIV prophylaxis medication. Women also reported being treated dismissively through interactions with providers that they perceived to be cursory, condescending or rude, as Cher explains:

"...they don't have much feelings, you know, they snap at you. That's one reason why I didn't go there after that. And they

made you sit two or three hours just to renew your prescription ... when I go with my friends to the women's night and I just watch, I can hear, you know, how they talk to somebody like that... it's not good policy for me anyways".

Women expressed frustration with doctors who they perceived as doubting their complaints or who (in their view) dismiss their symptoms by attributing them to a psychological origin. Linda provides an example:

"He was too busy getting into the shrink side of things, and not listening to my physical aspects. I think he wanted to be more of a psychologist than [a] frickin' GP... So that was nightmarish, because... they're not listening and I'm getting sicker and sicker. And I'm still feeling the same symptoms today as I did then".

Women who reported these concerns often expressed that they felt particularly vulnerable to dismissive treatment because they are drug users. As Speedy notes:

"They think it's all in your head because we're addicts. That's the way they look at us. That's the way they look at me".

These experiences inspired a lack of confidence among women in the care they were receiving.

Some women also spoke of treatment they experienced as "rough" in terms of their interactions with health care providers and other clinic office staff. Aboriginal women in particular voiced concerns with providers not respecting their bodily boundaries, specifically with regards to what they felt to be unnecessary demands to remove their clothing or keep parts of their body uncovered. Others reported that a provider was "rough" when drawing blood or during a physical exam. For women whose lives are so profoundly shaped by violence, trauma, and dismissive treatment, perceiving that they are "roughly" treated has the potential to further exacerbate their anxieties about seeking healthcare.

Quick Fact: Violence and Health

79.2% of women reported experiencing violence that currently impacts their physical health and mental health. Women reported childhood sexual abuse, assault (by peers, for one's drugs), interpersonal relationship violence/woman abuse, and rape (including women working in the sex trade):

"Well, I've been sexually abused. And I've been physically, mentally, verbally and emotionally abused by my partners" (Wonder Woman).

21.7% of the women said they used drugs as a strategy to cope with violence or trauma. Some women talked about difficulties in accessing the support they needed to cope with violence and trauma. Sex workers reported not receiving help from healthcare providers when they experienced violence from clients. Project participants were interviewed with bruises, broken bones and scars from violence. Two women's group members died under violent circumstances during the period in which this project was undertaken.

Not getting enough information from one's healthcare provider about medication, health conditions, treatment options, or prescriptions was another way that women spoke about being dismissed or denied services. Women attributed this to a lack of time with one's healthcare provider, to a provider's lack of knowledge, and to assumptions on the part of medical staff that marginalized women who use drugs don't understand or are not interested in receiving health information. Women expressed anger, frustration, and concern that they received inadequate information to support them in managing their own health. As Blaze Storm

explains, *"I never really had the chance to ask questions because they pushed me away"*.

Contrary to many negative stereotypes about women who use drugs, women interviewed for this study also reported that they refuse to take prescriptions from doctors they do not trust.

Accessing Medications

90% of women talked about problems with access to prescription medications, primarily for pain complaints (such as analgesics, muscle relaxants, or anti-inflammatory medications). Women felt they were being denied treatment out of suspicion on the part of healthcare

Quick Fact: Women's Pain and Women's Health

- 28% of women reported chronic pain problems
- 45.7% of women reported use of drugs to cope with pain
- 39.6% reported trouble getting medication when needed and being denied pain medication when they requested it.

Experiences with pain, and attempts to seek treatment for pain, appear in more than half of the interviews. "Pain" includes both physical pain (i.e. related to injuries, dental problems and chronic health problems) and emotional pain (such as depression and trauma). Many women described their use of drugs to cope with pain, emphasizing that women use drugs for this reason, as Kika observes:

"I think that's one of the major things that a lot of people were getting frustrated 'cause they couldn't have access to any sort of pain killer. You know, so if they can't get that pain killer they go out and they start using the drugs to help deal with the pain"

This has important harm reduction implications, as it suggests that interventions which support women with pain issues may be an important way to reduce harms associated with illicit drug use. It is interesting to note that women talked about using non-opiate street drugs to cope with or relieve pain, such as crack, marijuana and amphetamines. Women described using prescription methadone to treat pain, and acknowledged that prescribing methadone to treat pain is common in the DTES. When women talked about using drugs in a context of pain, their responses emphasize that the drugs they take "numb", help them to "cope", "escape pain", "take my mind off it" or "get me through the day". As Brandy Rose observes: ***"...because it numbs my body, numbs my pain, doesn't make me think I'm unhappy. Takes me away from it all"***.

In this sense, women may be managing their pain, but it is not being treated nor are they recovering. No obvious pattern emerges from the data confirming whether drug use began as a way to cope with pain, or if familiarity with and availability of street drugs make drugs "easier" Or more accessible tools for coping with pain later in life. For FD, ***"...in the beginning it was recreational but I found that I got a lotta trauma in my life. I gotta face up to and deal with. So one of my excuses is trauma"***.

providers that they were “drug seeking”, as Lynn notes:

“...because you are a drug addict they treat you different. Don’t get good care, don’t get pain killers, don’t get treated same as others, are seen as after free drugs”.

Women’s reactions to being constructed as “drug seeking” (and as “addicts” more broadly) ranged from accepting (“*what would you expect?*”) to depressed and angry. In a number of instances, women talked about feeling discouraged from seeking care at a later time when they had a health concern, in anticipation of being accused of drug seeking.

Women spoke about feeling confused and frustrated when they are “cut off” medications for which they had long-standing prescriptions.

Women spoke about restricted access to medication as a form of “punishment” that health care providers use to manage women’s behaviour, as Brandy Rose describes:

“He always threatens to cut me off my pills if I don’t do this and I don’t do that. He said he’s gonna cut me off...I don’t know how much power he has over me. But he shouldn’t be allowed to do that, you know. But they do.”

Women were unanimous in stating that when they are “cut off” medications they buy what they feel they need on the street. Nancy described an interaction with her doctor that occurred when she was “cut off” her pain medications:

“He doesn’t care...I told him I’ve needed stronger drugs for my pain, for my feet,

Quick Fact: Mental Health Issues

32% of women interviewed identified mental health concerns as one of their chronic health issues. However, given the stigma and discrimination experienced by many people who have been given psychiatric labels, the extent of women’s mental health concerns may have been under-reported. 37% of women interviewed said they used drugs to cope with depression and suicidal feelings:

[Interviewer: Have you overdosed?] “On purpose, yes. I used heroin though...I shoot up heroin to go to heaven to go see my kids” (Brandy Rose).

“I was in mental strife and I felt suicidal, and I had done everything drug under the sun and knew it that it wasn’t my path. I went to [the hospital] and had this guy wearing Burberry little sockettes telling me that there was nothing wrong with me, and I felt it was due to my address. And I said, “look I got pills at home, man, and I’m going to do myself.” And he said. “Ah well, go on, go home.” And that just blew me away. Because I had tried 5 or 6 times before, unsuccessfully, but I didn’t tell people. I hoarded and I went for it ... and he just let me go” (Linda).

Of the 60 women involved, two women are believed to have died by suicide over the two years of the project. Homelessness, poverty, severe grief and loss, stress, violence, and drug use were all entwined in women’s conversations about their mental health or mental distress. A lot of the women we spoke to live on a day to day basis with mental health challenges in environments that do not promote good mental, physical, emotional or spiritual health. Their stories clearly described how the wider contexts of their lives shaped their mental, emotional and spiritual health, including their will to continue living.

Two women talked about the role of traditional Aboriginal culture in fostering positive mental health:

“I go to sweats and, you know, you...you pray for it: gratitude, and then the brothers, and then the sisters, and then for yourself ...sweats really helped me out mentally” (Melissa).

for other places... my lower back. And I'll buy them off the street. [He says] "Oh go ahead, waste your money"... But it's not a waste of money, I'm getting the medication that I need, that will help me sustain myself through the day".

While women would take medication they bought on the street, they voiced strong preferences to get medication by prescription from their doctors. This was primarily because prescription medications are covered by government funding and because taking medication by prescription assures them that they know what they are taking, and how much, and that they can rely on regular medical follow-up for the condition being treated. Women also reported that it is often easier to buy medications on the street than to get them by prescription, emphasizing that they make the effort to access prescription medications through their physicians because they are concerned with their health, not because it is an efficient way to get drugs. These views stand in contrast to prevailing stereotypes of drug users as people who have no concern for their wellbeing, and who exploit health care providers to get drugs for illegitimate purposes.

Indeed, the data show that women are primarily interested in getting their health conditions properly diagnosed and treated, not in getting high or feeding an addiction. Many women viewed their communications as honest and open in this regard, and that such communication is important for ensuring good health care: *"I am very honest with doctors"* was a phrase that appeared in multiple interviews. **Women reported having a strong desire to work in partnership with their health care providers to improve their health.** Positive interactions with health care providers were described in which women perceived providers to have an equal interest in their health, rather than in dismissing their complaints or treating them like "junkies":

"If you're getting pills and that to mask the pain, and not to see what's causing the pain and how you can help it, you need to get to that problem to face it and make sure you're getting the right treatment, which Dr K does. He sits there and gets you on the right pain medication, or gets you on something. He makes sure you need this medication. If you don't need it, why prescribe it?" (Nancy).

Going outside of the DTES was another strategy women mentioned frequently in terms of getting the medications they needed. Women who did this noted that they felt they were treated with greater respect, waited less, could make regular appointments, and were more likely to get certain types of prescriptions when they sought care from a provider outside the neighbourhood. Linda provides an illustration of the reasons some women go outside the DTES for care:

"So I don't have to wait, so I get treated normally (long pause) get the meds that I need. And I need that, I need to be treated individual, I need to go to the pharmacy once a month. And I need the swiftness of my appointments. And for the most part I remove myself from this area and the address".

Women believed that doctors could make a big difference to the quality of care women receive when the doctor was prepared to take their health concerns at face value, instead of attributing their complaints to drug seeking behaviour. Breezy explains:

"He was a nice doctor and he cared. He knew you were an addict but he didn't judge you. He didn't say "oh, well you're just tryin' to get drugs outta me". If it was legitimate he would write you a prescription. But he wasn't a pushover, he was just a sympathetic and caring person for the area".

Women's Experiences of Being on Methadone

Experiences related to being on methadone were frequently discussed in interviews; indeed, nineteen of the women interviewed talked about methadone issues. Some women were on methadone for opiate addiction and some were on methadone for pain. Despite differing reasons for being on methadone, women who were taking methadone for pain expressed concern that they are often “lumped together” with those who are on methadone to treat an addiction. Women described wanting to get onto the methadone program because they were “getting tired of hustling”. Despite its use as a medically supervised treatment, many people still see a person on methadone as a “drug user”, including other drug users.

The predominant comments from women who were either currently or formerly on methadone concerned the effort required to get on and stay on this medication. One of the most frequent complaints from women receiving methadone was the amount of time they had to spend waiting to see their doctors and get their prescription. As Breezy explains:

“People don't realize, especially if you're on weekly scrip⁹, we're talking every week you're putting a full day in. When you go in it usually takes a full hour to see them because there's a methadone nurse you have to see first, so that's like an hour to see her, then usually two to three hours

9 Script/scrip (used interchangeably): prescription. Methadone is a regulated medication requiring a prescription. Not all physicians are licensed to prescribe methadone. Methadone prescriptions are usually written on a weekly, bi-weekly or monthly basis, and renewals typically require a visit to the prescribing doctor. In most cases, people living in the DTES are dispensed a daily oral dose of methadone in a liquid solution at a pharmacy, and consumption of each dose must be witnessed by a pharmacist. Missing a dose of methadone results in withdrawal symptoms which can range in severity from uncomfortable to life-threatening.

after that. So that's like a whole day you're putting in just to get your methadone scrip. And that's every week, that's crazy. I mean how do they expect us... people have to have a life, too, other than going to get their methadone scripts?”

Another central theme for women on methadone was the way that “the methadone system” was able to control them in a number of different ways: through requiring personal information (“they know your life”) and placing restrictions on which pharmacies women had to use to fill prescriptions. Because of requirements to receive methadone through a daily witnessed dose, most women's ability to travel away from the DTES was very limited. This was another way that they saw being on methadone as controlling their lives. The amount of time that needed to be spent making special arrangements for carries¹⁰ for travel was considerable for women who had attempted it. Some women talked about feeling very vulnerable because of the need to refill their prescriptions frequently. They feared their pharmacist being closed when they went to collect their methadone, and what would happen to their access to methadone in the case of an emergency situation.

Some women talked about getting on the methadone program as a positive experience. Women with positive experiences described providers that were flexible in making sure that if a physician was not available when needed, an alternate physician would make a phone call to get a dose arranged for the day. Most women preferred having a methadone doctor who also acts as their family physician. Women also reported that they valued doctors who are knowledgeable in addictions and methadone, as Blue Eyes describes:

“I'm very comfortable with him; he's very knowledgeable in addictions, as well as with methadone. Just generally he's very

10 Carry/carries: take home dose/s of methadone.

wise about what goes on... He's been around the block and doesn't shock easily. It makes a big difference".

Conversely, some women reported being scared of their methadone doctor because of the power and control that they feel doctors wield. Some women stated that they feel physicians use methadone as a way to reward or control behaviour. From this perspective, the physician is perceived to be the exclusive supplier of the medicine they need to function daily, and patients have to be "good" to get this medication. These women described a desperate lack of power and control in interactions with their methadone-prescribing physicians. For women who are marginalized in multiple ways and who

Quick Fact: Dental Health Issues

Many women we interviewed talked about having dental problems. Some women shared that their dental problems are due to use of methadone and use of crack cocaine. Women described having dental problems even after only a few years on methadone. Women reported many problems getting satisfactory dental care including:

- getting access to dental care in the first place
- having to wait for dental care
- getting the care provided at the times booked (e.g. cancellations of appointments last minute)
- getting the care that was agreed to (one woman had her whole top set of teeth removed when she had only agreed to two teeth being extracted)
- being denied financial coverage for having dental treatment, such as caps:

"Yeah, well, I'm still trying to fight the welfare to get my teeth done, so that's something.... I'm always fighting for something that's mine"
(Cher).

have repeatedly experienced violence, trauma, and discrimination in many aspects of their lives, feeling a lack of power and control may substantially compromise their ability to build and sustain collaborative relationships with a primary care provider.

Pharmacies

Women described restricting patients to particular pharmacies as a practice that was problematic for them. Most women felt they should be able to go to the pharmacy of their choice. Some women described situations they felt were unethical, such as doctors recommending people go to pharmacies that they have a financial interest in, and writing "no carries, no deliveries" on prescriptions. Women also described being "forced" to do heroin to avoid going into withdrawal when pharmacies were not open or when they were unable to renew their script on time.

Women we spoke with drew attention to a number of suspect practices concerning pharmacies in the DTES. Some women felt that providing methadone was "big business" and described their shock at how much money pharmacies receive for each person they dispense methadone to. Some pharmacists were described as "money hungry" or "a bunch of crooks":

"You sell your script, they'll pay for it. They'll also give carries. They'll also deliver, that's how they make their money. It's unfortunate, but like everything, it's a money-making fiasco, right?" (Otter).

Pharmacy environments in the DTES were also seen by women to be very unappealing because of people falling asleep in them, or because "unpleasant and violent" people frequented them. Some pharmacies were reported as giving carries that had not been prescribed by doctors and watering down their methadone.

Some who were currently or formerly taking methadone voiced concerns about inequities in the methadone system, where some clinics charge fees to patients. One woman described having to leave a methadone program because she couldn't afford the charges. Women also gave accounts of problems with getting the money they pay for their methadone reimbursed from welfare, and experiences in which clinics withheld their methadone until payment had been received.

".. the attitudes down here leave a lot to be desired"
(Otter).

Stigma and Discrimination

70% of women interviewed described stigma as a regular aspect of their primary health care experience. Although some women initially said they had never experienced stigma or discrimination, they then went on to describe experiences that would qualify as such by most working definitions of the terms. The majority of women interviewed identified drug use as the primary reason they were stigmatized. Women describe being treated *"like garbage"*, *"like dirt"* and *"like you should die"*. However, women also said they experience stigma from healthcare providers based on having a Downtown Eastside address. When asked how clinic staff treated her, Blaze Storm described:

"Half of it's okay, but the other half they look at you as if you were dirty. Like with me, I have an apartment and everything, right? But sometimes they look down on you because they come from another part of town, and they've got to come into the Downtown Eastside. They look at the clients as if they're dirty. And prejudice,

there's a lot of people in there that really don't like even associating with us people down here".

In the interview data, *"being treated like a drug user"*, *"junkie"* or *"addict"* emerged as shorthand for poor treatment. Women described stigma and discrimination as being evident when they wait longer than other (non-*"junkie"*) patients, when care providers assume that problematic substance use is the main cause of their presenting symptoms, when care providers dismiss women's concerns or insights into their condition, when security guards are frequently called to remove them from the facility, and when they are denied care in serious situations such as mental health crises and sexual assaults. Women reported assumptions from some healthcare providers that women who use drugs are less intelligent than the rest of the population, and that it is acceptable to treat less intelligent people poorly. Five women talked about urine drug screens as a way of providing *"stereotypical"* or *"judgmental"* treatment of people who use drugs, particularly for those being treated with methadone.

Due to previous experiences of stigma and discrimination, some women reported avoiding the health care system entirely, or seeking care only in emergency situations. A small minority of women reported that they complained or followed up after treatment they felt to be discriminatory: the majority of women seemed to expect such treatment, evident with comments like: *"I just expect it all the time"* (Marlene).

Seven women talked about experiencing racism in interactions with health professionals and described how racism affected their health care. Brandy Rose describes a situation she witnessed at a clinic she attends:

"And I see how they treat the other Natives there. "Oh you can't come in, you drank too much. Oh you, you have the freshest

breath in town". Because some of these poor Natives down here drink Lysol... mouthwash. And they joke about the Natives. "Oh here comes the guy with the freshest mouth in town". So yeah it hurts me to see them being laughed at like that".

Women who do sex work or survival sex also reported increased stigma and discrimination. Women described keeping this information from health providers, a strategy that they acknowledge can increase their health risks.

Quick Fact: Women's Hospital Experiences

The focus of this report is women's experiences at clinics delivering primary health care services in the DTES, a neighbourhood in which there are no hospitals. However, the research team felt that it was important to make brief mention of women's hospital experiences due to the severity of many of the experiences women described. Overall, hospital experiences seemed to be harsher and more traumatising for women than were other health care experiences. For example, women described being discharged from hospital without explanation, being discharged before they were ready, and one woman reported that she was discharged who was actively suicidal. Some women felt that the care they received at hospitals was minimal. For others, this care was seen to be expected because of who they are and because of pressures on the system. For women living in the Downtown Eastside, safety while walking to and from hospitals in a vulnerable condition is an important concern. Blue Eyes described this experience:

"I was asked to leave the hospital after I was treated and seen by the doctor. I said, "...it's three in the morning, like there's no buses" ...I had no cab fare, I had to go all the way down to the Dominion from the hospital. I wasn't going to walk, 'cause I had a screwed up foot, I had an abscess on my foot that I had popped and they wouldn't give me a voucher to get down there. They told me that I couldn't just stay in the hospital 'and wait for the busses to start. I had to leave the hospital, so the security guard dragged me out of the hospital into the parking lot".

Part 2:

Going the “Extra Mile”: Working Together to Improve Primary Care for Women who Use Drugs in the Downtown Eastside

Findings from the VANDU Women CARE study have provided insights into the primary care *experiences* of women who use drugs in the DTES; the *organization and delivery* of primary care; and the role of *policy* in shaping how primary care is delivered and received. These findings also highlight opportunities for primary care providers, health care administrators, policy makers, community organizations, and women who use drugs to work together to create and sustain urgently needed change in each of these areas. This section of the report draws on the findings reported in Section 1 to identify key areas that could benefit from such collaborations, and result in meaningful improvements to the quality and relevance of primary care service for marginalized women who use drugs.

Improving Relationships between Primary Care Providers and Women who Use Drugs

1. When women have bad experiences with health services they can easily ‘fall out’ or feel “pushed out” of the health system. **Practice with the understanding that poor care for women in DTES clinics places women at additional risk for a range of serious health and social harms, such as: delaying seeking care for health**

“...really listen to the person is the only way you’re really going to get to the root of the problem” (Nancy).

concerns that can quickly escalate to major illness events, buying drugs they need on the street that they are unable to get in clinics, and feeling unable to seek care for serious health and illness issues. **Making small changes to the accessibility and quality of health care can create substantial changes in women’s lives.**

2. **Address the different reasons why women seek care from multiple providers.** Pejoratively labelling this strategy as “doctor shopping” eclipses the many reasons women have for going to more than one provider for health care. Women’s interviews spoke to their low expectations of care, and evidenced opinions that their care providers often had low expectations of them. Women chose to use multiple providers to get care that is being denied to them in their ‘assigned’ clinic or where they have had a particularly negative experience.

Improving Organization and Delivery of Services at Clinics

3. Women who use drugs in the DTES recognize that health care providers are working in a high stress environment, and that this should be considered when hiring and training health care and associated staff. **Workers whose values and social justice commitments are aligned with the needs of women for acceptance will be critical to the provision of responsive, respectful care.**

Health care administrators can support improved relations between patients and providers by ensuring that these attributes are considered as highly relevant to hiring and performance evaluations.

4. Give front line health care providers and clinic staff (including reception and security) **the support and supervision they need** to do their job well.
5. **Develop capacity to engage peer workers in collaboration with health care providers and administrators.** Advocacy organizations such as VANDU can be key resources to providers and administrators in supporting this work.
6. **Addressing the long waiting times for patients and improving the waiting experience is an important concern for women who use drugs and women who are receiving methadone treatment.**
 - a. Consider ways to humanize the waiting experience. **Waiting experiences, which will sometimes be inevitable due to demands on services, can be made more productive and comfortable for patients and staff.** This can involve thinking about the staff roles and staff attitudes that are needed to support people when they are waiting for prolonged periods of time. The place where the waiting is done is also crucial. Think about ways to make the waiting area in clinics more inviting and comfortable places to be. Make sure women feel safe in these environments. Could the space be looked at as an extension of the healthcare consultation, with opportunities for people waiting to interact with others

in a positive way, learn more about their health, their community, opportunities for harm reduction, etc?

- b. Consider putting **expedited processes in place for patients requiring regular prescription renewals.** This was a particular concern for women on methadone.
 - c. Some women wanted to be able to make appointments to reduce their waiting, other women were clear that a drop-in access point was ideal, but wanted to wait less time to see a doctor. **Consider making some bookable appointment time available for those patients that can manage these and want to access care in this way. Make sure this is still low threshold and does not penalize patients if they cannot make appointments.**
7. Triage processes were described as complicated, confusing, and frustrating for women. **Consider ways to ensure that people with urgent needs are seen first, through a triage process that is transparent to all who use the service.**

“Try not to judge, or seem like you’re judging. Just accept people and what they’re saying for what it is, and try not to question it... You may not agree with it, you may not even like it but it is the way it is and it’s from a personal perspective so... just take it for what it is” (Blue Eyes).

Improving Policy to Enhance Quality and Continuity of Primary Care for Women who Use Drugs

8. Consider ways to balance and integrate the need for continuity and flexibility in health care service access in the DTES. The main goal should be to ensure that women are engaged in low-threshold primary health care that meets their needs. How can women be supported to seek care at a time and place of their choosing, and how can health systems support service linkages needed to ensure continuity of care?
9. “One stop shops” can provide an effective and efficient model for organizing health service, and an environment that supports accessible, integrated, and continuous care. However, **the benefits of a “one stop shop” can only be achieved when women feel safe, comfortable, and empowered to work with a provider (or providers) of their choice.**

They looked at me and said “junkie” and didn’t want to deal with me, you know? I wasn’t important” (Melissa).

“...they got a lot of things for Hep C and for AIDS and whatever. but they gotta get some more things. Programs, like for the ones that smoke crack, classes and things that we can learn, treatment, and things for us. And more nutrition, food things, too. Like some of us, like me, don’t always eat” (CM).

10. Women want more women-only and women-centred services. Consider the **provision of more women-only primary health care services in the DTES.** A suggestion with support from a number of women was the provision of one women-only clinic day per week, with each of the clinics running this on a different day. This suggestion fits with women’s use of multiple providers and addresses women’s need and desire for safe places to receive care. There also needs to be more systemic support, for example more resources and policy recommendations, for the development of women-centred care in primary health care delivery.

Summary

Out of a community in crisis came a call to look at what was happening to women in their experiences with primary health care. In our research, we did not find one bad clinic, or one bad doctor. Instead, we found that women, some of whom were very sick, were accessing care in complex ways, enduring long waits, and dealing with discrimination. Compared with other groups, women who use drugs continue to have poor outcomes despite many creative interventions on the part of patients and providers to implement effective strategies and advocate for change.

Some experiences described in this report are not just happening in DTES, but are occurring in many Canadian communities facing under-resourced health care systems, scarcity of providers, and overwhelming demands on service use. The women who were interviewed for this research are a group of people who are not valued by wider society, and their health care concerns tend to emerge in debates on access and distribution of health care services as national *problems*, not national *priorities*.

The VANDU Women CARE project findings demonstrate that women who use drugs can make important contributions to collaborations with researchers, health care providers and administrators, community-based organizations, and policy makers at all levels of government, in identifying opportunities to advocate for and implement meaningful changes and improvements in quality of health care. Together, we can also identify what is currently working when it comes to delivering accessible, relevant, and high quality primary health care for women who use drugs in the DTES. We invite you to continue this dialogue, to examine how the findings of the VANDU Women CARE project can be of service in achieving these goals while supporting the health, wellbeing, and leadership of women who use drugs in our community.

References

- Anderson, R. T., Barbara, A., Weisman, C., Hudson Scholle, S., Binko, J., Schneider, T., et al. 2001. A Qualitative analysis of women's satisfaction with primary care from a panel of focus groups in the National Centers of Excellence in Women's Health [Electronic Version]. *Journal of Women's Health & Gender-Based Medicine*, 10, 637-647.
- BC Ministry of Health Services (2004). *Advancing the Health of Girls and Women Provincial Women's Health Strategy*. Victoria: BC Ministry of Health Services.
- Burgelhaus, M., & Stokl, M. 2005. Sheway: Supporting choice and self-determination [Electronic Version]. *Journal of Aboriginal Health*, 2, 54-62.
- Buxton, J. A., Rethon, D., Lem, M., Durigon, M. 2007, September. *Drug using behaviours of youth in custody in BC*. Oral presentation at the Canadian Public Health Association 98th Annual Conference, Ottawa, ON.
- Cawston, P. G., & Barbour, R. S. 2003. Clients or citizens? Some considerations for primary care organizations [Electronic Version]. *British Journal of General Practice*, 53, 716-722.
- Gijsbers Van Wijk et al (1996). Gender Perspectives and Quality of Care: Towards an Appropriate and Adequate Health Care for Women. *Social Science and Medicine* 43 (5): 707-720.
- Gonen, J.S. (1999). Quality in Women's Health: Taking the Measure of Managed Care. *Women's Health Issues* 9 (2 (Suppl. 1)):79S-88S.
- Groft, J. N., Hagen, B., Miller, N. K., Cooper, N., & Brown, S. 2005. Adolescent health: a rural communities approach. [Electronic Version]. *Rural and Remote Health*, 5, 366. Retrieved March 13, 2007.
- Huang, C. L., & Wang, H. H. 2005. Community health development: what is it? [Electronic Version]. *International Nursing Review* 52, 13-17.
- Hull, J. 2001. *Aboriginal single mothers in Canada, 1996: A statistical profile*. Winnipeg, MB: Department of Indian Affairs and Northern Development Research Directorate.
- Joseph, R. 1999. *Healing Ways: Aboriginal Health and Service Review*. Vancouver, BC: Vancouver/Richmond Health Board.
- Kelly, P. J. 2005. Practical suggestions for community interventions using participatory action research [Electronic Version]. *Public Health Nursing*, 22, 65-73.
- Pollard, T. M., and S.B. Hyatt (1999). Sex, Gender and Health: Integrating Biological and Social Perspectives. In *Sex, Gender and Health*, Eds. T. M. Pollard and S. B. Hyatt. Cambridge, UK: Cambridge University Press.
- Registered Nurses Association of BC. (2002). *Primary Health Care: Policy Statement*. Vancouver, BC: RNABC.
- Safer Crack Use, Outreach, Research and Education (SCORE). 2008. *Lessons Learned From the SCORE Project: A document to support outreach and education related to safer crack use*. NEXUS: Vancouver.
- Shah, B.R et al (2003). Markers of Access to and Quality of Primary care for Aboriginal People in Ontario, Canada. *American Journal of Public Health*, 93(5); 8-802.
- Smith, M A. et al (1997). Peer Review of the Quality of Care. *Journal of the American Medical Association* 278 (19):1573-1578.
- Spitall, P. M. 2006. Drastic Elevations in Mortality among Female Injection Drug Users in a Canadian Setting [Electronic Version]. *AIDS Care*, 18, 101-108.

Tandon, R. 1988. Social Transformation and Participatory Research [Electronic Version]. *Convergence*, 21, 5-18.

Taylor, R. R., Braveman, B., & Hammel, J. 2004. Developing and evaluating community-based services through participatory action research: two case examples [Electronic Version]. *American Journal of Occupational Therapy*, 58, 73-82.

Thomas, P., McDonnell, J., McCulloch, J., While, A., Bosanquet, N., & Ferlie, E. 2005. Increasing capacity for innovation in bureaucratic primary care organizations: a whole system participatory action research project [Electronic Version]. *Annals of Family Medicine*, 3, 312-317.

Weisman, C. S (2000). Measuring Quality in Women's Health Care: Issues and Recent Developments. *Quality Management in Health Care* 8 (4):14-20.

Wilde Larsson, B., G. Larsson, and B. Starrin (1999). Patients' Views on Quality of Care: A Comparison of Men and Women. *Journal of Nursing Management* 7:133-139.

Vancouver Area Network of Drug Users. 2005. *VANDU Women's Group Mission Statement*. Vancouver, BC: VANDU.

Vancouver Coastal Health Authority. 2005. *Community Health Area 2, Mid-East: A health and social profile*. Vancouver, BC: Author.

**For more information
about the VANDU Women CARE project, contact:**

Dr. Amy Salmon
c/o: Women's Health Research Institute
BC Women's Hospital and Health Centre
E202-4500 Oak Street
Vancouver, BC V6H 3N1

Phone: (604)875-2424 ext. 4880

Email: asalmon@cw.bc.ca