University of Alberta

Patient-Provider Rapport in the Health Care of People Who Inject Drugs

by

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Abstract

Background: Injection drug users (IDUs) underutilize health services despite significant need. The goals of the research were to (1) explore how provider-patient rapport relates to IDUs' care experiences and care-seeking behaviour, (2) explore influences on the development of provider-IDU rapport, (3) compare formal health services to informal points of care in Edmonton's IDU community, and (4) test the hypothesis that perceived autonomy supportiveness of a primary care provider is associated with positive patterns of IDU service utilization.

Design: Data sources included focus groups, cross-sectional rapport and utilization data, and follow-up qualitative interviews. Descriptive statistics, correlations, and multivariate regressions were calculated for quantitative data. Paraphrasing and coding techniques were used for qualitative analysis.

Findings: Rapport is influenced by drugs and addiction, drug use disclosure, provider expertise, patient-centered care, and discrimination. Rapport influences compliance, criminal activity, and timing of care. Autonomy supportiveness predicts patient satisfaction.

Conclusion: IDU-provider rapport has several determinants and influences health outcomes.

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Chapter 1: Introduction

People who inject drugs suffer a disproportionate burden of illness relative to their non-drug-using counterparts (Cherubin & Sapira, 1993; Frischer, Goldberg, Rahman, & Berney, 1997; McKim & Kashluba, 2003). Despite their poorer health status, injection drug users (IDUs) underutilize primary health care services, as evidenced by delayed and more severe presentations, and presentations to hospital emergency departments as opposed to out-of-hospital settings (Chitwood, McBride, French, & Comerford, 1999; McGarry, Stein, Clarke, & Friedmann, 2002; Chan, Palepu, Guh, Sun, & Schechter, 2004; French, McGeary, Chitwood, & McCoy, 2000). IDUs face multiple obstacles when seeking and receiving health care; the focus of the following research is on interpersonal relationships between IDUs and their care providers, and how this might relate to health care utilization.

IDU: Prevalence, Mortality, and Morbidity

Approximately 75 000 to 125 000 Canadians are thought to actively engage in injection drug use (IDU), which is a similar per capita rate to estimates in the United States (Wiebe & Single, 2000). A telephone survey found that approximately 1.7 million Canadians have engaged in past or present IDU (Poulin, 1997). True lifetime or past-year prevalence is likely to be higher, given that many IDUs cannot be reached by phone or other traditional survey methods (Wild, Prakash, O'Connor, Taylor, Edwards, & Predy, 2003b). Although most IDUs reside in Toronto, Montreal, or Vancouver (Wiebe & Single, 2000), a significant IDU community exists in Alberta as well. Over 2000 IDUs are assessed by the Alberta Alcohol and Drug Abuse Commission (AADAC) on an annual basis (Wild et al., 2003b). Other estimates put past or present IDU numbers over 4000 within the Capital Health region alone (McKim & Kashluba, 2003). Street-involved youth, convicts, sex trade workers, and Aboriginals are disproportionately represented among Canadian IDUs (Health Canada, 2001, Wiebe & Single, 2000). The mean age of first IDU tends to be in the late teenage years, and IDU is often preceded by the much more common practice of non-injection drug use (Wild et al., 2003b). Data collected from a multi-site Canadian cohort identified cocaine and opiates as the local injected substances of choice, although methamphetamine is increasing in popularity (Wild, Curtis, &

Pazderka-Robinson, 2003a; Noël, Fischer, Tyndall, Bradet, Rehm, Brissette, Brochu, et al., 2006). Prescription opiates such as Talwin (pentazocine) and MS Contin (morphine) are more frequently used than the less accessible heroin. Frequency of injection varies, but is higher for those who use cocaine primarily, due to its rapid onset and equally abrupt withdrawal, with the subsequent tendency in users to go on cocaine runs of multiple (hourly or more often) injections lasting days to weeks (Wild et al., 2003b). Frequency of injection is reflected in the approximately 1.5 million needles exchanged through recognized needle exchange programs in Alberta annually; Edmonton's Streetworks needle exchange program alone exchanges over 800 000 needles every year (McKim & Kashluba, 2003).

The circumstances surrounding the injection of a drug of abuse predispose IDUs to a myriad of preventable health problems. Drug, set, and setting, that is, the psychopharmacological and toxic effects of the substance, the mental state and behaviour of the user, along with the environment in which IDU occurs, can all contribute to the development of disease (Zinberg, 1984). Reuse and sharing of injection equipment, acknowledged by over half of IDUs though probably more prevalent (Alcabes, Beniowski, & Grund, 1999; Fischer, Rehm, Brissette, Brochu, Bruneau, El-Guebaly, & Noël, 2005), is a major risk factor for infectious disease transmission. However, within the context of the sharing of drugs, the sharing of needles and drug paraphernalia are only a few ways that users engage in high-risk injection practice (Grund, Friedman, Stern, Jose, Neaigus, Curtis, & Des Jarlais, 1996). Drug purity and form, the drug used, along with tolerance and withdrawal may influence the care taken to inject properly (Grund et al., 1996). Repeated use of one vein, lack of filter use, and poor hygiene including use of saliva in the injection process can all produce medical complications (Grund at al., 1996). The secretive nature of drug access and purchase, coupled with often unstable housing, may lead to injection in unsafe and unfamiliar environments (Grund et al., 1996), and public IDU is associated with greater risk of disease transmission (Weeks, Clair, Singer, Radda, Schensul, Wilson, Martinez, et al., 2001). Socially marginalized IDU subsets—sex trade workers, street youth, Aboriginals, and inmates—are at particular risk of infection due to higher risk injection practices (Health Canada, 2001). Despite agreeing with safer IDU in principle, it is not possible in practice for many IDUs to inject more safely (Grund et al., 1996).

As a result of these risk contexts, the annual all-cause mortality rate of IDUs exceeds that of the general population several-fold; this mortality is often premature in timing and preventable in nature (Gossop, Stewart, Treacy, & Marsden, 2002; Frischer et al., 1997; AADAC, 2003). Canadian data from 2002 suggest that 0.8% of deaths are a direct consequence of illicit drug use; 62 110 potential years of life are lost based on the same figures (Rehm, Baliunas, Brochu, Fischer, Gnam, Patra, Popova, et al., 2006). Common causes of death include trauma, suicide, overdoses, hepatitis C, and AIDS (Gossop et al., 2002, Rehm et al., 2006).

People who inject drugs also carry a high burden of morbidity over and above the aforementioned high mortality risks. For example, HIV/AIDS and hepatitis B and C are blood-borne illnesses which can be transmitted via unsafe injection practices, and recent statistics indicate that one third to one half of new HIV cases and two thirds of new hepatitis C cases in the Capital Health Region and elsewhere in Canada have IDU as an antecedent factor (Wild et al., 2003a; Wiebe & Single, 2000; Health Canada, 2001). Estimated rates of HIV among other Canadian IDU cohorts are at least 25%, and over 75% for hepatitis C (Wild et al., 2003a; Strathdee, Patrick, Currie, Cornelisse, Reckart, Montaner, Schechter et al., 1997). Overall Canadian prevalence of hepatitis C likely approaches 240 000 people (Wiebe & Single, 2000). Worldwide hepatitis C prevalence rates among IDUs range from 50% to 100%, and approximately 170 million people are carriers (Wiebe & Single, 2000); worldwide HIV prevalence rates among IDUs range from 5% to 80% (Hagan & Des Jarlais, 2000). The HIV positive status, low socioeconomic position, and unstable housing which are frequently experienced by IDUs are associated with lung infections such as pneumonia and tuberculosis (Estrada, 2002; Bonin, Brehove, Kline, Misgen, Post, Strehlow, & Yungman, 2004). Risky injection practices can also increase the risk of skin abscesses, lung talcosis, bacterial endocarditis, cotton fever, trauma, overdose, and hospital admission (Cherubin & Sapira, 1993; Kerr, Wood, Grafstein, Ishida, Montaner, & Tyndall, 2004). Mental health and pain conditions are common among IDUs (Wild, el-Guebaly, Fischer, Brissette, Brochu, Bruneau, Noel, et al., 2005; Wild et al., 2003b) and may be under-treated or inappropriately treated for various reasons (Wild et al., 2003b; Noël et al., 2006; Weiss, McCoy, Kluger, & Finkelstein, 2004).

In addition to these health problems, the socioeconomic impact of IDU on both users and the community at large is enormous. Intravenous administration of a substance potently and rapidly increases its addictive potential. Occupational and social functioning may become compromised to the extent that income, and in turn shelter, food, and drug supply, are threatened (Wild et al., 2003b). Lower levels of education, employment, and stable housing associated with such dysfunction strain both IDUs' health status and their community's social and health services (Wiebe & Single, 2000; Fischer, Brissette, Brochu, Bruneau, el-Guebaly, Noël, Rehm, et al., 2004). IDUs may feel forced to obtain money via criminal means such as trafficking, work in the sex trade, and property theft; these activities and the higher risk context of IDU during incarceration expose IDUs and the larger community to infectious diseases and possible violence (Wild et al., 2003b, Fischer, Medved, Kirst, Rehm, & Gliksman, 2001; Health Canada, 2001). Sexual partners and offspring of IDUs in particular are at increased risk for HIV infection (Del Rio & Curran, 2005; Health Canada, 2001). Economically, estimated annual costs of health care, lost productivity, law enforcement, and property crime for which illicit drug use is a factor exceeds 8 billion dollars nationally and 300 million dollars provincially (Rehm et al., 2006). Treatment of HIV/AIDS over an infected individual's expected duration of survival costs at least $400 000 (Schackman, Gebo, Walensky, Losina, Muccio, Sax, Weinstein, et al., 2006), and costs of treatment for hepatitis C are anticipated to be even higher (Health Canada, 2001).

Benefits of IDU primary care

Primary care is provided by members of an interdisciplinary team, including but not limited to family physicians, general practitioners, nurse practitioners, and registered nurses. Ideally, it is characterized by comprehensiveness, continuity, coordination, community mindedness, advocacy, and attention to psychosocial issues (Smith, 1991, CFPC, 2004). These attributes are especially important when addressing the complex health needs of IDUs.

One of the principal aims of primary health care is to address illness, either prior to its occurrence, or early enough in its natural history to prevent additional harm to the patient. Screening, counselling, immunization, and treatment early in the course of disease are some of the means by which primary care providers can improve downstream health outcomes (Oleckno, 2002). For example, in the case of IDU, primary care providers might choose to screen for HIV, immunize against hepatitis B, or engage opiate-dependent patients in a discussion about initiation of methadone maintenance therapy, with the common goal of reducing transmission of blood-borne viral illnesses. Although provision of primary care is clearly not the only determinant of IDU health, it plays a pivotal role in disease prevention.

Primary care can also play a beneficial role in treatment strategies, since it can serve as a point of entry to complementary services such as formal treatment programs, specialty care, and methadone maintenance. In addition, initiatives such as treatment programs, methadone maintenance therapy, needle exchange programs, and supervised injection sites are more likely to reduce IDU-related harm when they include primary care services on an onsite or referral basis (Strathdee et al., 1997).

Health care utilization by IDUs

Despite a heavier burden of illness, and the potentially beneficial role of early preventive and primary health care, the IDU population appears to underutilize out-of-hospital primary care services. The majority of IDUs do not identify a regular site for primary care; when health services are used, multiple access points are common (McGarry et al., 2002; Weiss et al., 2004; Kerr et al., 2004). A significant portion of community physician visits do not involve preventive care, but rather are restricted to obtaining prescriptions (Leaver, Elford, Morris, & Cohen, 1992). Preventive services are inconsistently used and often uncoordinated, leading to under-testing of IDU communities for sexually transmitted diseases and blood-borne viruses and low pneumococcal and hepatitis vaccination rates (McGarry et al., 2002; Heinzerling, Kral, Flynn, Anderson, Scott, Gilbert, Asch, et al., 2006; Chitwood, Sanchez, Comerford, & McCoy, 2001; Chitwood, Comerford, & McCoy, 2002). Missed appointments are also common (Leaver et al., 1992).

Instead, IDUs disproportionately present to emergency departments, require hospital admission more frequently, and stay in hospital longer than other populations, suggesting higher disease severity, delayed presentation, and a relative lack of effective treatment earlier on in the course of a disease process (Chitwood et al., 1999; McKim & Kashluba, 2003; French et al., 2000). In 2002, illicit drug use accounted for 352 121 hospital inpatient days across Canada (Rehm et al., 2006). Locally, although they represent under 1% of the population in the Capital Health region, IDUs use approximately 6% of the regional health care budget (McKim & Kashluba, 2003). Concerns have been raised that IDUs are not as likely as other patients to comply with proposed treatment plans (Gebo, Keruly, & Moore, 2003; Pach, Cerbone, & Gerstein 2003; Bogart, Katz, Kelly, & Benotsch, 2001). IDUs are at greater risk of leaving hospital against medical advice compared to non-drug users (Chan et al., 2004).

A significant proportion of IDUs may not use any physician services at all (Marsh, 1980); a sample of 305 Edmonton inner city residents, of which 40% admitted to past or present IDU, reported high rates of no physician use (30%) and walk-in physician use only (21%; Owens, McKim, Doering, & Hanrahan, 2005). Studies of overdose among opiate users suggest that upwards of 25% of victims received no medical attention even for such an urgent incident (Fischer et al., 2004).

Barriers to health care

Members of the inner city IDU subculture face many oppressive social obstacles in seeking and receiving health care, which may not be experienced by mainstream urban Canadian populations. For example, IDUs often spend a large amount of their daily routine procuring shelter and food (Wild et al., 2003b; Downing, Knight, Reiss, Vernon, Mulia, Ferreboeuf, Carroll, et al., 2001). Income is frequently illegal and therefore unstable; incarceration rates, often as a direct result of drug trafficking, prostitution, and petty theft committed to generate a basic income (Wild et al., 2003b), are significantly higher compared to non-IDU rates (Fischer et al., 2001). The nature of addiction is such that procuring and using drugs holds a high priority for affected individuals (Chan et al., 2004; Wild et al., 2003b; Drumm, McBride, Metsch, Page, Dickerson, & Jones, 2003; Downing et al., 2001). As a result, there is a higher threshold for the perception of health care need; active users may delay seeking or not comply with what the general public considers to be needed care until health problems are numerous enough or a disease process is severe enough to warrant emergency care and/or hospital admission (Noël et al., 2006; Marsh, 1980; Chan et al., 2004). Many IDUs hold a low socioeconomic position; the associated illiteracy, innumeracy, and lack of enabling resources such as child care, a working telephone, stable shelter, and transportation pose further barriers to receiving quality health care (Reilly, Schiff, & Conway, 1998; Palepu, Strathdee, Hogg, Anis, Rae, Cornelisse, Patrick, et al., 1999; Drumm et al., 2003; Appel, Ellison, Jansky, & Oldak, 2004). Help-seeking behaviour also varies according to gender, age, and ethnicity, owing perhaps to differences in personal resources, expectations, and experiences of health care (Marsh, 1980, Chan et al., 2004, Palepu et al., 1999; Chitwood et al., 2001). Health care utilization is associated with availability of services as well (Noël et al., 2006); increased time and patient complexity, poor integration of services, and decreased financial remuneration have discouraged health care professionals from practicing in the inner city setting (Clarke, 1993; Deehan, Taylor, & Strang, 1997). A Florida study (Chitwood et al., 2002) found that IDUs were less satisfied with access to health care compared to non-users, after controlling for health status, actual utilization, and ability to pay. In addition to these direct barriers, failure to fully address social determinants of health among IDUs may undermine the effectiveness of health care manoeuvres (Lalonde, 1974; Berkman & Kawachi, 2000).

Although interpersonal barriers to care have been investigated in the IDU literature, they have not been explored to the extent that structural barriers have. The literature review presented in the following chapter describes what is currently known about this important aspect of IDU care.

Chapter 2: Interpersonal Considerations in IDU Health Care

Interpersonal determinants of IDU health care utilization

It is within the context described in the previous chapter that people who inject drugs often experience further health care disadvantage as a result of poor rapport with health care providers. A literature review was conducted in order to explore the interpersonal barriers to health care of IDUs, to explore the influences on development of rapport between IDUs and care providers, and to identify alternate points of health care access for IDUs.

Medline, Cinahl, Embase, Sociological Abstracts, Web of Science, and PsychInfo were searched for scholarly articles which addressed one of these rapport-related search objectives. Search terms included “Substance Abuse, Intravenous”, “Substance-Related Disorders”, “substance abuse”, “Injections, Intravenous”, “inject$”, “intravenous drug abuse$ or intravenous drug user$ or intravenous drug addict$ or iv drug user$ or iv drug addict$ or iv drug abuse$”, “parenteral drug abuse$ or parenteral drug addict$ or parenteral drug user$”, “heroin user$ or heroin addict$ or heroin depend$”, “Health Behavior”, “Professional-Patient Relations”, "Patient Acceptance of Health Care", “seek$ adj (health or care or healthcare)”, "Health Status", “Health Services Accessibility”, "Attitude of Health Personnel", “Attitude to Health”, “Interpersonal Relations”, “Communication”, “Physician-Patient Interaction”, “Nurse-Patient Interaction”, “rapport”, and “interpersonal”.

Articles were included if they described intervention and/or treatment studies designed to affect health care seeking by IDUs or health care reception by IDUs, described determinants of / barriers to health care seeking by IDUs or health care reception by IDUs, described determinants of IDU satisfaction with care, described determinants of / barriers to treatment adherence by IDUs, examined street-based social strategies applied within the health care setting, examined any point of health care, or examined any type of health-related, formal or informal help-seeking. Articles were excluded if they described studies conducted outside North America / Europe / Australia / New Zealand, were non-English publications, were nonempirical, opinion pieces, were practice guideline or policy pieces, were economic and/or cost-benefit studies, focused on the relationship between IDU and non-health care agencies / professionals, focused on public perception of IDU, reviewed determinants of disease or mortality in IDUs unless specifically dealing with health care access or compliance, were descriptive epidemiologic studies related to IDU utilization of health care, reviewed determinants of non-health care-related IDU behaviour, focused on willingness to participate in research, focused on access to injection equipment as opposed to the associated care providers, focused on drug interventions designed to improve medication compliance, or focused on a non-IDU population.

The results of this literature review indicate that patient-provider rapport is often not well described among the IDU population, since most research on interpersonal aspects of care focuses on disease-specific as opposed to IDU-specific populations (e.g. those living with HIV/AIDS as opposed to IDUs per se). Nevertheless, there are multiple accounts of the influence of IDU-provider rapport on IDU care-seeking, care-reception, treatment compliance, and satisfaction with care. System, provider, user, and encounter variables have all been identified. Several interventions have been proposed to improve IDU-provider interactions, and alternatives to formal points of care have also been described.

System-level barriers. Several studies have addressed certain system-based barriers to IDU health care which may represent patient-provider rapport barriers on an aggregate level. People who inject drugs cite suspicion of or aversion to treatments offered by institutions as a reason for under-using them (Drumm et al., 2003; Appel et al., 2004; Pach et al., 2003). Facilities are commonly avoided due to concerns over personnel, confidentiality, wait times, and overall atmosphere (Drumm et al., 2003; Regen, Murphy, & Murphy, 2002; Downing et al., 2001). Some services are perceived as out of touch and unrealistic with expectations (VanderWaal, Washington, Drumm, Terry, McBride, & Finley-Gordon, 2001; Porter, 1999). Bureaucratic obstacles such as hospital policies requiring potential patients to hold valid insurance and identification documents can also prevent access to health services (Drumm et al., 2003; McCoy, Metsch, Chitwood, & Miles, 2001; Porter, 1999). Past experiences with the health care system deter potential patients from subsequently seeking needed medical care (Drumm et al., 2003).

Provider barriers. Nursing and physician attitudes towards IDUs have been extensively researched, and to a lesser extent, personal barriers to care provision for IDUs have also been examined. Unfortunately, much of this literature dates back to the early 1990's and focuses on HIV-positive patients as opposed to IDUs specifically. Nonetheless, a significant proportion of professionals and professional students hold negative attitudes toward IDUs in the available literature on this topic (Yedidia & Berry, 1999; McGrory, McDowell, & Muskin, 1989; Jemmott, Freleicher, & Jemmott, 1992; Hayward & Weissfeld, 1993; Deehan et al., 1997; Gerbert, Maguire, Bleecker, Coates, & McPhee, 1991). Moral conflicts, expectations of manipulative or dangerous patient behaviour, provider beliefs about the priority of abstinence-based care, and fear of contagion are prominent attitudinal themes identified in these studies (Clarke, 1993; Caplehorn, Irwig, & Saunders, 1996; Ross & Darke, 1992). Provider concerns about the capacity of IDU populations to demonstrate adherence to therapeutic regimens (e.g. antiretroviral medication) is translated into physicians being more reluctant to prescribe these medications when a patient has a history of IDU (Bogart et al., 2001). Also, concerns about addiction and lack of knowledge limit provider willingness to focus on pain management in the IDU population (Breitbart, Kaim, & Rosenfeld, 1999). Such attitudes appear to have an impact on IDU satisfaction with care; Bradley et al. (1994) found that drug-using HIV patients were afraid of their physician's response to IDU and more likely to report poor support from their physician than non-users.

Few determinants of such attitudes and related care providing behaviour have been studied. Jim Carroll's findings among nursing professionals (1993; 1995a; 1995b) suggest that lack of experience, patient HIV status and unfamiliarity with HIV, and occupational socialization by work area all have an impact on attitudes. Training experiences also appear to have a sustained effect on these attitudes (Yedidia & Berry, 1999; McGrory et al., 1989). Negative attitudes are compounded by the perceived futility of intervention by the same professionals (Carroll, 1995b; Deehan et al., 1997).

User barriers. People who inject drugs are often subject to certain personal resource and belief constraints which in turn limit their use of health care services.

Relative to other treatment-seeking populations, fewer or non-supportive social relationships dissuade many IDUs from establishing health care connections (Drumm et al., 2003; Porter, 1999; Lloyd, Ricketts, Strathdee, Cornelius, Bishai, Huettner, Havens, et al., 2005; Gourlay, Ricciardelli, & Ridge, 2005; Knowlton, Hua, & Latkin, 2005). Misinformation or lack of information about medications may undermine adherence to treatment (Pach et al., 2003). Negative self-concept or low perceived self-efficacy fail to provide enough empowerment for affected users to procure services (Porter, 1999; Gourlay et al., 2005; Kerr, Marshall, Walsh, Palepu, Tyndall, Montaner, Hogg, et al., 2005). Procrastination and lack of motivation are other barriers to quality health care commonly cited by IDUs (McCoy et al., 2001; Porter, 1999). Normalization of the risks inherent to IDU, and perceived lack of illness severity or need for treatment, may also predispose IDUs to underutilize or delay utilization of health care services as defined by non-users (Morrison, Elliott, & Gruer, 1997; Neff & Zule, 2000).

Research conducted in Edmonton has explored some of the ways that interactions among IDUs can facilitate or prevent risk. The street-based social strategies employed by Edmonton inner city IDUs have recently been described by Wild and colleagues (2003b) and are consistent with IDU peer interactions observed elsewhere (Grund et al., 1996). Although the resulting Model of Social Dynamics of IDU is not specific to help-seeking behaviour outside a person's street context, it nevertheless provides insight into culturally appropriate IDU codes of behaviour. In this model, responses to perceived threats to the IDU (e.g. loss of street credibility, drug supply, or safety) include a quick-thinking, fast-talking attitude known as bravado, which is used as a protective technique. A successful demonstration of bravado leads to a safe exit from the situation; conversely, if unsuccessful, bravado may lead to further confrontation and shame. Saving face, a second-line form of posturing, may then be used to attempt a safe exit and avoid personal harm or shame. Unfortunately, these street-appropriate negotiation tactics likely do not facilitate the development of rapport with health care providers, and this lack of efficacy of familiar strategies may deter people who inject drugs from using health services.

Encounter variables. Rather than exploring the attributes that providers and users respectively bring to the health care encounter, as has been discussed in the aforementioned studies, a number of studies have investigated perceptions of the patient-provider interaction itself. Positive IDU experiences with care are characterized by provider empathy, listening skills, relationship building, and ample allotment of time, whereas negative experiences occur when providers change behaviour upon disclosure of drug use, shame or stigmatize users, attribute all presenting symptoms to drugs or withdrawal, demonstrate incompetence or a lack of understanding of the medical nature of addiction, and withhold or inconsistently provide pain medication and other treatments as a result (Weiss et al., 2004; Drumm et al., 2003; Regen et al., 2002). Both utilization of services and disclosure of IDU to providers are less common when faced with the potential for such punitive encounters (Weiss et al., 2004; Regen et al., 2002). In fact, perceived discrimination by health care providers on the basis of drug use may have a greater impact on care than that based on race, gender, or incarceration status (Minior, Galea, Stuber, Ahern, & Ompad, 2003).

Wild and colleagues (2003b) undertook a multi-method study with the aim to better understand the previously under-documented experience of Edmonton inner city IDUs from the users' perspective. Qualitative interview findings included negative experiences with health care services. IDUs felt that health care providers had a poor understanding of chronic pain and tended to under-treat pain in users. Inflexibility, indifference, and judgment, along with past negative experiences, were seen as major barriers to care. Participants would avoid providers in order to avoid stigmatization, and tended to rely on themselves, health information from the Streetworks program, or peers—known as Natural Helpers—for their medical needs. Although rapport was not the primary focus of this research project, one of its key recommendations was to further study patterns of care-seeking and access to health services, as well as determinants of those access patterns.

Interventions to reduce interpersonal barriers

Provider-focused interventions. Reduction of one system-level barrier—health services occurring in unfamiliar, potentially hostile environments—via recruitment of primary care nursing and medical staff to inner city locations, treatment facilities, and harm reduction sites may be associated with high uptake of out-of-hospital primary care services and acceptability by IDUs (Selwyn, Budner, Wasserman, & Arno, 1993; Grau, Arevalo, Catchpool, & Heimer, 2002; Pollack, Khoshnood, Blankenship, & Altice, 2002). These linkages may also improve prescription rates for needed treatments such as HIV-related antiretroviral therapy (Selwyn et al., 1993). Employment of peer outreach workers and case managers also improve rates of preventive care delivery such as HIV testing (Tobin, Tang, Gilbert, & Latkin, 2004).

In Edmonton, enhancement of Streetworks staff to include more nurses increased immunizations by 520%, physical assessment by 201%, and nursing advice by 755% (McKim & Kashluba, 2003). Formal linkages between Streetworks and community physicians decreased hospital admissions by 50% and also reduced EMS dispatches and length of inpatient stays (McKim & Kashluba, 2003). The creation of the Inner City Public Health Project, staffed by a case manager, nurses, and a peer Community Health Representative, and operated out of the Boyle McCauley Health Centre (BMHC) and mobile outreach clinics, provided sexually transmitted disease (STD) and blood borne virus testing and immunizations to its clients, 40% of whom were IDUs and 30% of whom received no other formal care services (Owens et al., 2005). Although IDU reasons for increased service use were not elicited any further in these studies, recipient agencies of the latter project's mobile outreach services indicated that these services addressed their clients' crisis-based approach to help-seeking and discomfort with traditional health care setting; trust and relationship-building between clients and staff, in particular the Community Health Representative, was seen as key to the program's success (Owens et al., 2005).

<u>User-focused interventions.</u> Peer outreach workers, lay health providers, IDU advocacy groups, self-care, and social networks or street families are examples of informal points of health care commonly accessed by IDUs (Regen et al., 2002; Drumm, McBride, Metsch, Neufeld, & Sawatsky, 2005). As stand-alone points of care, they are more acceptable to many IDUs than formal health care services (Regen et al., 2002); in conjunction with formal attempts to improve health services, i.e.

inclusion of peer outreach workers on staff (see previous section), they appear to improve acceptance of formal services. Lay consultation occurs prior to, after, and instead of formal health care usage; it plays an important role in symptom recognition and attribution and subsequent management (Regen et al., 2002). Peer-driven interventions, wherein IDU patients themselves are assigned to work as health advocates for other IDU patients, appear to improve HIV medication adherence (Broadhead, Heckathorn, Altice, van Hulst, Carbone, Friedland, O'Connor, et al., 2002). Finally, IDUs commonly describe the use of proactive self-care strategies such as physical activity, nutrition, and regulation of substance use (Drumm et al., 2005).

Staff at Edmonton's Boyle Street Community Services were aware of people in the injection drug using community with a natural tendency to help their peers in need; the term Natural Helpers was employed to recognize their contribution (Taylor & Jasperson, 2001). The Natural Helpers and nurse facilitators were formally brought together as a group to exchange ideas on how to enhance the Natural Helper role; outputs of the project have included safer injecting and other health care booklets using street-appropriate language, the acquisition of first aid skills by participants, increased advocacy of members on behalf of their peers, and new insight for Streetworks staff into the lives of IDUs. Although health status and utilization outcomes have not been assessed, the formal recognition of this alternative point of care has clearly had some positive effects.

Rapport: A key interpersonal determinant of service utilization

Rapport refers to a "conscious feeling of harmonious accord, trust, empathy, and mutual responsiveness between two or more persons... that fosters the therapeutic process" (On-line Medical Dictionary, 2000). So defined, rapport is an integral part of any provider-patient interaction. Communication of diagnostic and prognostic information fulfils patient expectations and subjectively improves health outcomes better than a physical exam or a prescription (Jackson & Kroenke, 2001; Little, Everitt, Williamson, Warner, Moore, Gould, Ferrier, et al., 2001; Cegala, 1997; Beck, Daughtridge, & Sloane, 2002; Rao, Weinberger, & Kroenke, 2000). In general, patients prefer participating in a long term, health promoting partnership in which care and concern are conveyed (Little et al., 2001; Nutting, Goodwin, Flocke, Zyzanski, & Stange, 2003; Cegala, 1997). Physician behaviours that appear to improve rapport include empathy, reassurance, tension release, receptivity, and ample allotment of time (Beck et al., 2002). Canadian family medicine residency programs accordingly train residents in patient-centered clinical methods, whereby common ground between the physician's biomedical agenda and the patient's illness experience is actively sought (McWhinney, 1988). Regrettably, the available literature focused on provider-patient rapport contains scant information on its function among marginalized patient groups and IDUs in particular. Consequently, it is difficult to extrapolate the values of the average patient voiced in the above literature to the realities faced by people who inject drugs.

Cultural influences on rapport. Rapport is especially crucial in a cross-cultural setting, yet more complicated to develop. Although discussions of the role of culture in health have characteristically focused on ethnicity, religion, and language, *culture* can be also be understood from the perspective of socially acquired patterns of beliefs and attitudes, and as such delineates groups according to shared personal history and socioeconomic status (Rothschild, 1998). In keeping with this comprehensive definition of culture, two groups who may not differ considerably in terms of ethnicity and religion—health care providers and IDUs—nevertheless can be identified as two distinct subcultures. As with any cross-cultural interaction, the power and prestige associated with one cultural group—in this case, health care providers—tends to reinforce the medical acculturation of the other group, with little reciprocal acculturation. The subordinate group may adapt via adjustment, reaction, or withdrawal (Berry, 1986). Not all health care providers have developed the cultural competence necessary to fully understand this relationship, including biomedical cultural biases they often bring to the patient encounter (Rothschild, 1998).

Cultures vary in their explanatory models of health and illness; interpretation of symptoms and care-seeking behaviour differ from group to group (Rothschild, 1998). In the context of addiction and IDU in particular, the biomedical model upon which conventional health care delivery is based is at odds with many principles of harm reduction embraced by IDUs and the many agencies who serve them (Heller, McCoy, & Cunningham, 2004). Harm reduction is a grassroots philosophy developed as a pragmatic response to the reality that not all drug use can be prevented, nor are addicts always biologically or socially amenable to cure or remission at any given point in time. It seeks to minimize the inherent harms of IDU, with support on the user's terms and with user involvement, and adapts to the changing context in which it operates. Examples of harm reduction strategies include condom and sterile syringe provision, methadone maintenance therapy, and education and outreach activities. In contrast, the biomedical model accords most decision-making capacity to the provider, and recipients of care are expected to comply with evidence-based recommendations, which often include complete abstinence from illicit drug use. Deviance from these recommendations is not easily addressed by the latter cultural model.

Rapport and motivation for seeking services. Several models have been developed to explain factors that influence help-seeking and other health behaviours. Intrapersonal models of behaviour, such as the Health Belief Model and Transtheorethical Model, incorporate a concept known as self-efficacy, defined as the conviction that one can successfully execute the behaviour required to produce the outcomes (Bandura, 1977). Lack of perceived self-efficacy may partially explain why some people who inject drugs choose not to seek out formal health care or follow recommendations. However, the development of self-efficacy is not a focus of these models. In addition, models which focus exclusively on the patient do little to explain how rapport is facilitated during patient-provider interactions (Roter & Hall, 2002).

In contrast, Self Determination Theory (SDT) provides a useful perspective with which to understand how rapport might facilitate IDUs' motivation for seeking health services. In particular, this theory addresses how social events are perceived and how those perceptions affect motivational processes (Wild & Enzle, 2002). SDT characterizes motivation to engage in activities on a continuum, ranging from activities that are completely initiated and controlled by external social forces, to activities that are fully self-determined. On this theory, all people (e.g. service providers, IDUs) have fundamental psychological needs for autonomy, relatedness, and competence. Social contexts that support these elements of self-determination promote interested engagement in activities and personal growth. Conversely, when social contexts promote perceptions of being controlled or coerced, intrinsic motivation (i.e., interest and engagement in activities) is undermined (Deci & Ryan, 2002). These general predictions have been supported in an extensive empirical literature, and across a variety of health behaviours (e.g., smoking cessation, weight control, adherence to medication; Westmaas, Wild, & Ferrence, 2002; Williams, Gagné, Ryan, & Deci, 2002).

With respect to interpersonal aspects of IDU primary health care, SDT implies that autonomy support – not unlike the concept of patient-centeredness reviewed earlier – may be an important element of rapport between IDUs and health care providers. Autonomy supportive health care providers demonstrate empathy, disclose information and rationale for health decisions, and offer patients choice (Deci, Eghrari, Patrick, & Leone, 1994; Williams, Freedman, & Deci, 1998). Although SDT suggests that autonomy supportiveness of health care contexts can influence patients' motivation for complying with recommended interventions, this theory has not been applied in many marginalized or cross-cultural settings, nor has it been investigated in the context of IDU. The following research addresses these limitations.

Research objectives and hypothesis

Although the literature reviewed in this chapter confirms that the relationship between people who inject drugs and their health care providers influences care sought or received, very little research has described the nature of this relationship. In particular, we know relatively little about issues including: (1) how patient-provider rapport influences the health care experience of injection drug users; (2) how rapport between injection drug users and their health care providers develops; (3) under what interpersonal circumstances are formal points of health care accessed or not accessed; and (4) what alternate, informal points of health care exist in Edmonton's injection drug using community.

The multi-method study presented in the following chapters was designed to address these gaps in existing knowledge. Specifically, the research study's objectives were:

1. To explore how provider-patient rapport relates to IDUs' experiences of health care and subsequent care-seeking behaviour,
2. To explore factors that facilitate or prevent the development of rapport between users and their health care providers,
3. To describe and compare formal health care services to informal, peer-based points of health care in Edmonton's injection drug using community, and
4. To test the hypothesis, derived from SDT, that perceived autonomy supportiveness of a primary health care provider would be positively associated with service utilization among IDUs.

The first 3 research objectives are exploratory and descriptive in nature, and were addressed using qualitative methods. The 4th research objective's hypothesis was tested using quantitative methods.

Overview of Methods

Given the different ways that the culture of health care providers and IDUs can affect the development of rapport, divergent views of the care experience were expected. Thus, both potential patients and their health care providers were included as participants in the proposed studies. In addition, both quantitative and qualitative data were collected and analyzed to better understand the phenomenon of rapport. Specifically, the following studies were conducted: (1) IDU and health care provider focus group interviews, (2) a cross-sectional study examining the potential association of IDU-provider rapport and health care utilization, and (3) qualitative interviews with a purposive subset of study (2)'s sample IDU population. The focus group sessions were intended as a preliminary exploration of the development of IDU-health care provider rapport and the influence of rapport on health care utilization. The cross-sectional study was designed to test the hypothesis outlined in the fourth research objective, i.e. whether perceived autonomy supportiveness by providers is associated with IDU health care utilization. Findings from the first two studies were used to refine the third study's qualitative interview questions. These follow-up qualitative interviews examined the development and influences of rapport in greater detail, and also explored informal points of health care in Edmonton's IDU community.

These studies were made possible through a pre-existing partnership between the University of Alberta's Addiction and Mental Health Research Laboratory (AMHRL) and the Streetworks needle exchange and street outreach program based out of Edmonton's Boyle Street Community Services (Wild et al., 2003b). Determinants of this successful partnership include long-term research sustainability, research relevance to the agency, and extensive field involvement of research staff. Accordingly, both the primary researcher and other researchers involved in the field work outlined in subsequent sections have either provided primary care or assisted with the day-to-day harm reduction activities at Streetworks. The relevance and acceptability of this project have also been reviewed by both agency staff and clients as various stages throughout the research to maximize uptake of the findings.

Chapter 3: IDU and Health Care Provider Focus Groups (Study 1)

Methods

Overview. Two focus groups, one with injection drug users and another with inner city health care providers, were conducted to address the first two research objectives, namely: (1) to explore how provider-patient rapport relates to IDUs' experiences of health care and subsequent care-seeking behaviour, and (2) to explore factors that facilitate or prevent the development of rapport between users and their health care providers. Provider and IDU sessions were conducted separately to avoid any conflicts of interest between health care and drug user roles and to minimize the influence that the power imbalance inherent in the provider-patient relationship had over participant responses. General patient and provider experiences of IDU health care were solicited, with special attention given to the expectations of users and their health care providers and the interpersonal dynamics between these groups.

Sample. A purposive sample of actively injecting drug users known to have experience with the health care system were recruited to take part in the IDU focus group session. Potential informants were identified by both their peers and Streetworks staff, using word-of-mouth as a primary means of recruitment. Eligible participants were 18 years or older, able to speak English, actively injecting drugs within the past 30 days, out of residential drug treatment within the past 30 days, Edmonton residents, and not currently suffering from severe intoxication or a psychiatric emergency. Interested individuals who gave permission to Streetworks staff to be contacted by the research team were brought to the attention of a research assistant; this assistant further described the study, provided a written letter of information, and coordinated a mutually convenient interview time. Two senior Streetworks outreach workers with many years of personal and outreach experience in Edmonton's inner city community were also invited to participate in the focus group. Because the aim of qualitative research is not representativeness but rather thematic richness (Kuzel, 1999), the size of the focus group was limited to no more than ten participants. Appendix A provides the information and consent materials provided to eligible IDU focus group participants.

People who inject drugs seek health care from a variety of sources in a pattern distinct from that of the general population. As a result, for the provider focus group, the researcher recruited health care providers who have experience treating IDUs but who practice within a wide range of venues and levels of acuity. Physicians, nurses, and nurse practitioners who primarily work in the Royal Alexandra Hospital (RAH), the Boyle McCauley Health Centre (BMHC), the downtown STD clinic, the Eastwood public health centre, AADAC, Streetworks, or private practices with T5H postal codes (Streetworks and many inner city neighbourhoods share these postal codes) were identified by Streetworks and the research team and approached by the primary researcher to participate. Social and psychological services may serve as indirect points of access to the health care system; they also influence IDU health status and health care utilization. For these reasons, the input of a social worker, an addictions counsellor, and a mental health counsellor were also sought. A letter of information was provided in advance of the session. As with the IDU focus group, projected recruitment was limited to ten participants. Appendix B provides the information and consent materials provided to eligible health care provider participants.

Procedures. A $20 stipend was offered to all IDU focus group participants in order to offset transportation, child care, and other expenses incurred as a result of participation. Refreshments were provided to both groups. The focus group sessions were moderated by at least two researchers familiar with focus group interviewing technique. The IDU session took place on a weekday afternoon in the field research office in Boyle Street Community Services. The provider session was held in the BMHC's boardroom on a weekday evening. A moderator explained the study, provided a written letter of information, and obtained consent and baseline demographic information from all participants prior to proceeding with each session. One researcher moderated each session while the other maintained field notes and assisted in clarifying themes where necessary.

During these sessions, consent was sought to re-contact participants at a later date to obtain their feedback on the analysis ensuing from the focus group sessions. Those IDUs and outreach workers who provided this consent were asked to attend a second, more informal session, similar in time and venue to the focus group session, in order to review emerging IDU themes and provide feedback. A $20 stipend and refreshments were once again provided. Field notes were kept and considered in the analysis of the first session. Health care providers who agreed to re-contact were given a copy of emerging provider themes via fax or e-mail to limit the time commitment involved. They were asked to return brief written feedback, and their comments were considered in the analysis of the provider focus group session.

The primary researcher is also a medical professional actively involved in the delivery of primary health care to the Edmonton IDU population. To encourage uncensored participation by all focus group members, she was not present at the IDU focus group session or follow-up feedback session, was blinded from any identifying information for IDU focus group participants, and restricted her IDU session involvement to transcript analysis.

Measures. Semi-structured interview protocols were used for both focus group sessions. IDU session questions and probes (see Appendix C) were prepared to explore IDU expectations of health care services, interpersonal determinants of help-seeking among IDUs, and influences on patient-provider rapport. Similarly, health care provider questions and related probes (see Appendix D) were developed which initially explored the participants' personal experiences and expectations of IDU patient encounters and finished with the perceived importance of and influences on rapport. Probe questions and other reflective strategies were used during the interview sessions in an attempt to clarify responses as much as possible. The focus group sessions were audio-taped and transcribed verbatim and supplemented with field notes; the transcripts were also compared with the audio recording to ensure accuracy. The sessions lasted approximately two hours in duration.

IDU and provider feedback was sought in a less structured way. Emerging themes were provided to participants for review, confirmation, and/or elaboration. Attempts were made to clarify responses where necessary. In keeping with the verifying intent of this feedback step, although notes were taken of responses and the IDU feedback session was audiotaped, the content of responses was only used to clarify results from the analyses of the initial focus group sessions.

Analysis. The transcripts and field notes from the IDU and provider focus group sessions were read in their entirety before extracting prominent themes using a combination of paraphrasing techniques and thematic analysis (Wozniak, Prakash, Taylor, & Wild, 2007; Boyatzis, 1998). Line by line, then paragraph by paragraph, transcripts were examined for content addressing the semi-structured interview guide and initial impressions of themes were recorded. These relevant participant responses were paraphrased in order to capture the essence of the idea voiced by the participant without losing its inherent meaning. Thematically similar paraphrases were grouped together into common paraphrases or meaning units (underlined in this document), and a definition and raw data example were assigned to each meaning unit. Meaning units were not created for those themes alluded to by only one focus group participant unless clear nonverbal agreement by at least one other participant was observed. Finally, meaning units were categorized into overarching themes (**bold** in this document, with subthemes in *italics*).

Although variability of responses according to general demographic information (e.g. type of health care professional, length of time engaged in IDU) was explored where appropriate, no attempt was made to link identifying information to specific responses. The transcripts and field notes were reread completely after this analysis to ensure that the developed themes were consistent with the content of the interviews. Outreach research assistants involved with both focus groups also reviewed both the transcripts and the resulting themes to ensure interrater consistency. Focus group participants were also invited to review and provide opinions on the interpretations; a second in-person session was held for IDU participants, and feedback was solicited electronically from provider participants. In addition to this general review, an attempt was made during the follow-up IDU focus group session to specifically clarify the negotiation strategies they used in health care encounters, as these appeared to be central to the encounter but less well defined than other variables. Unfortunately, the focus group format was not as conducive to more in-depth discussion of these strategies as was hoped. Basic IDU negotiation themes are presented in the following section and were examined in greater detail in follow-up interviews.

Figure 1. Example of Process Used to Analyze Focus Group Sessions[1]

Example: Paraphrasing and Meaning Unit Development

Quote 1a: Xxxx1: Ya for sure, I don't want nobody to know I'm a junkie. (417)
Paraphrase 1a: I don't want anyone to know I'm a junkie.

Quote 1b: Xxxx6: Ya sometimes ya. But ya like I just like I don't like people knowing what I do and stuff. (135)
Paraphrase 1b: I don't like people knowing about my drug use.

Quote 1c: Xxxx2: They want you to talk about the most personal stuff in groups, which is, I don't believe in that. If I do get counselling, I like to do that on a one on one basis. (511)
Paraphrase 1c: I don't want to talk about myself unless it is with only one person.

Meaning unit: <u>I don't want anyone to know about my drug use.</u>

Example: Organization into Subthemes

Meaning unit 1: <u>I don't want anyone to know about my drug use.</u>

Meaning unit 2: <u>Health care providers sometimes talk about someone's drug use in front of others without that person's consent.</u>

Meaning unit 3: <u>Doctors sometimes record and look up drug use status on the electronic medical record without the patient's knowledge.</u>

Subtheme: *Confidentiality*

Example: Organization into Themes

Subthemes:
Confidentiality
Discrimination and trivialization
Patient-centered care
Honesty
Doctor as drug supply
Rules
Negotiation strategies

Theme: **Within-encounter variables**

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[1] For transcribed quotes, Xxxx# denotes IDU participant and (#) denotes within-transcript line number.

Results

The IDU focus group took place on September 22, 2006. Two moderators, both outreach research assistants at AMHRL, were present, as were 9 IDUs and one Streetworks outreach worker and former IDU. IDU participants ranged from 30 to 60 years of age, reported 5 to 35 years' IDU experience, and had 0 to 150 days elapse since their last IDU episode. All participants rated their health as good or fair. Most participants had completed some high school. All but 2 participants were male. Preferred points of care included family physicians (most commonly cited), hospital physicians, and other community physicians. Though they were not specifically asked for this information, participants related health care experiences during the session which suggested that they accessed care for multiple reasons, including drug-related issues, respiratory and skin infections, mental health, strokes, various sources of pain, and overdoses. No participants spontaneously cited HIV, hepatitis C, or disease prevention as reasons for which they have accessed care.

The provider focus group took place on September 25, 2006. Three moderators were present, including the writer and two outreach-research assistants, as were 7 health care providers. Participants ranged from 32 to 56 years of age, had 9 to 30 years' health care experience, and reported 5 to 100 IDU encounters a week. Two participants were male, and 5 were female. Two participants worked in a hospital emergency setting; the others worked in the community. Four RNs, 2 MDs, and a mental health counsellor were present.

In similar fashion to the available body of literature of IDU-provider rapport, discussion among members of both IDU and provider focus groups centered around four key determinants of IDU-provider rapport: (1) patient variables, (2) provider variables, (3) within-encounter variables, and (4) external context.

Patient variables. IDU participants acknowledged that they contributed to the development of patient-provider rapport. *The nature of drug addiction and withdrawal* is such that it exerts an inescapable influence on the IDU's behaviour during health care encounters.

Addiction is not a choice; it can take over your life. Participants stressed that addiction is an illness with potentially severe interpersonal and other consequences, over which its victims had little control:

> Xxxx4: Cause I mean, its I think a big part of the world, I mean, it doesn't seem like, especially like opiate addiction and stuff like that like where it's a physical addiction, it's not a choice. I mean it's like you had a choice at one point but that line's been crossed a long time ago. I mean, you can have like 50 doctors say no. It doesn't change the fact that you have to like you have to do what's required. I mean like you rob a drug store, rob another store or person or something to buy drugs with. And when you look at the severity of your problem and I mean you look at your entire life at something you destroyed, what you've lost. (177)[2]

Doctors often won't treat withdrawal. Withdrawal, or being "dopesick", was perceived as a legitimate illness within the context of addiction, yet it is not always recognized as such by providers:

> M1: And you're just sitting and sitting and sitting. And why did you go in?
> Xxxx3: Cause I was sick.
> M1: Dopesick? I'm trying to get a sense...[interrupted].
> Xxxx3: Ya, mostly dopesick.
> M1: Ya? Mostly dopesick?
> Xxxx3: You get run down and your body will only take so much eh?
> M1: Of course, ya
> Xxxx3: And all of a sudden boom. And suddenly you go there and they say "No we can't give you nothing". (299)

Care avoidance was another barrier to effective patient-provider rapport for many participants, and was usually attributed to past experiences with health care.

People will put off medical care because of how they're treated. IDUs related several past episodes of poor treatment by health care providers. These experiences led to delayed care seeking and care refusal, further compromising the establishment of good rapport with providers.

> Xxxx4: You almost like they almost feel like you pried (a prescription) out of 'em. And it gets to the point where a lot of people don't go to the hospital. I mean ammonias [assuming pneumonias] everything like that you'll see people sittin' on the street and an ambulance come and them refusing it. (72)

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[2] For transcribed quotes, M# denotes session moderator; Xxxx# denotes IDU participant; # denotes provider participant; and (#) denotes within-transcript line number.

People will get medical care only as a last resort. Health care did not take priority for participants unless an illness was severe enough that they had no choice but to get treatment.

> Xxxx4: Usually it's the very end result. It hits the point where like you're in such agony you have to go to the hospital or like somebody takes you to the hospital. (95)

People will put off medical care because they don't want to lose their prescription. Drugs and addiction play a central role in the lives of IDUs. Participants were particularly wary of medical care for drug-related illnesses because of the potential threat to their prescribed source of drugs.

> Xxxx4: I mean you're talking like, it's like 4 inch round like holes in their like skin and they won't they won't go to doctors and like they'll get pulled off the curb. You know it's that serious that people protect their prescriptions more than their own children. (404)

I will leave the hospital prematurely if I am treated poorly. Poor treatment by health care providers led not only to delayed care seeking but also premature termination of health care encounters by participants.

> Xxxx8: I take stuff off and I leave.... Well if somebody that you know isn't supposed to do that and they're doing it wrong and you know, I won't sit there and let somebody do that to me. (285)

Adding to this crisis-oriented care-seeking pattern, *perceived abandonment* of the IDU by a physician also influenced the way participants interacted with their physician.

It is hard when your doctor cuts you off, because s/he may be the closest thing to family you have left. Some participants indicated that their relationship with a doctor was the last potentially supportive relationship they had, and they approached the relationship accordingly. To have this relationship threatened was devastating.

> Xxxx4: I mean, like if you can't, by the point you're getting doctors usually you've already destroyed your friends, your family, with your addictions, they don't want to hear anything from you. I mean, if you can't talk to your doctor and you're hopeless in a situation like that, that's where a lot of people go like on your next like they're on the street, they don't want to give a shit about anything. (429)

Provider participants were equally mindful of the challenging context within which IDUs seek health care. They too recognized that IDU *patient needs* were unlike those of the general population due to the far-reaching impact of addiction. IDUs present with a wide range of drug-related medical conditions. Providers stated that IDUs commonly showed up with drug-related illnesses, whereas visits for unrelated illnesses and preventive care were uncommon.

> 2: They usually ya. Usually it's pretty extreme whatever it is. So they are usually clearly intoxicated or they have a really bad infection, a huge abscess or I think sometimes they don't have anywhere they think they can go. I know emerg is, you're scraping the bottom by the time you make it there. (119)

IDUs are often suffering from withdrawal or in crisis by the time they can be seen. Focus group participants were keenly aware that typical health care wait times for those patients dealing with drug withdrawal and street life were unrealistic, and were prepared for crisis presentations as a result.

> 6: People can't wait 3 or 4 hours. Or they'll come in the morning and by the afternoon, something, things will have completely fallen apart, that sort of thing. It really frustrates me to see people come in - in crisis. (847)

Many IDUs present with socioeconomic concerns. IDU presentations to health care providers were often fundamentally social as opposed to medical in nature.

> 5: And we do often see people that just need someplace to stay for the night. Like during triage so much. There are a lot of people that will just stay for several hours in the waiting room that don't necessarily have a chief complaint other than not being able to find some place to stay for that night.
> 2: Just cold and hungry. (130)

The complexity of these patients' problems can be overwhelming. Participants acknowledged that, given the nature of drug addiction, caring for IDUs is not a straightforward task.

> 4: I mean there's no question that some of my hardest interactions are with someone where it is mental health and addictions the complexity sometimes can feel overwhelming. And certainly I'm no master of any of it. So I feel at a loss sometimes of what to do, or how to help. (416)

Providers also expected hostile *patient behaviour* from IDUs exposed to drug effects, life on the streets, and poor past experiences with health care.

IDUs sometimes present in an agitated state. Though overt patient violence was rare, participants observed at least initial patient agitation during many of their IDU encounters.

> 1: I can do it all nicely and say "poor guy" right? That's right. He didn't have a hope from the beginning, all of that stuff. But the specifics of what he did really started to get personal with all of us. Started to be threatening. Was it inappropriate? Yes. We sort of had maybe worked too long being a bit too nice, thinking that would change it and then maybe we all felt a little bit abused, took it too personally? I don't know. But it was specific threats against all of us. Coming in intoxicated again and again and again. And I started feeling like it didn't matter what we did. (437)

IDUs tend to demonstrate initial resistance. Participants expected some IDU opposition to suggested care.

> 5: So if people are there for help that would be the same as [Participant 2], that sometimes especially depending on the circumstances of how they were brought in, sometimes there's some initial resistance but you hope for something both people can be a little bit reasonable. (88)

Thus, both IDU and provider focus group participants recognized the undeniable influence of drug addiction on any IDU accessing health services, including its physiologic, socioeconomic, and behavioural effects. Often low on the IDU's list of priorities, care-seeking tended to occur while in crisis if at all. Both IDUs and providers agreed that it was crucial to IDU-provider rapport to be mindful of the patient's circumstances when an IDU presented for care.

Provider variables. Provider focus group participants emphasized that their pre-encounter attitudes, experience, and position relative to IDUs had major impacts on the rapport achieved during IDU-provider encounters. All participants recounted experiences suggestive of well-developed *empathy* towards their IDU patients. With time you come to understand that people become agitated and fearful when they are expecting to be judged. Providers expected patient hostility but accepted that it had a legitimate, partially remediable cause.

> 5: I think sometimes people just come in feeling judged from the minute they get there and probably with great justification. And they come in and have been judged before and they're kinda scared to tell you anything or openly hostile when they first come in. (280)

With time you come to understand that patient attitude is protective. Participants became more comfortable with IDU patients when they recognized that most hostile IDU behaviours occurred for self-preservation reasons.

> 6: But it's those situations when you're trying to help and all you're getting is attitude in return. And there's a lot of that and still, I get it all the time. When you see enough of it and you get used to it and the more you realize what's behind it. So that's a very common thing where people....you have to learn that often with...you know, IDUs but lots of other people in this population as well. That's how they react. They can't show gratitude that easily, it's too exposing. And so you look for the thanks in amongst the other things they are saying, in how they behave, the fact that they come back to see you again, even if they've thrown a telephone book at you and stomped away and then come back a few days later and pretending that nothing had happened. That's actually quite a rewarding sort of thing. (453)

Experience with IDUs and with life in general, both during and subsequent to one's professional training period, also influenced a provider's ability to establish good rapport.

Experience brings with it a mature, realistic perspective. Some participants felt that older health care providers had been prepared by life experience to be more flexible and less judgmental than their younger peers.

> 1: To add to that, I hear what you are saying and I sometimes wonder if it's just age. Because I often find there is a certain maturity that comes with having dealt with people a lot. And sometimes young people that like...to me it depends on what their background is or something, what their beliefs are, I don't know. [In my workplace] there are certainly a number of new staff what come in with definite strong feelings about what's right or wrong. And I think that sometimes is what's hard. I agree with you, if you've done the same thing for 100 years it's hard to change you but there's a wisdom that comes with dealing with people. (555)

With time you acquire the skills to effectively deal with this population. Providers felt that any amount of field experience could assist in the development of an appropriate skill set for IDU patient care.

> 6: Me, my personality, and male and a physician. It's just a horrible combination for self-righteous indignation. And it took me 2 or 3 years before I really had to learn to control my emotions. And it takes, I can't remember the time I actually got angry. I get angry all the time, but I am better at managing it. (450)

It takes a variable amount of time to be effective with this population, but it won't happen without the right attitude. Participants felt that the time frame required to develop these skills well was highly individual. Despite the perceived benefits of experience, participants cautioned that its positive effects were easily negated by the wrong provider attitude towards IDUs.

> 2: I think you can work 30 years in emerg and never get good at this. Unless you make an effort. (519)

Exposure to harm reduction early in training can positively influence a provider's attitudes towards IDUs. Though negative attitudes had a strong influence, early training experiences were felt to partially offset a health care provider's preconceptions about IDUs.

> 6: Whereas health science students who are now having that early exposure, they see it in a more realistic kind of non-judgmental and they already have a context for when they encounter those people who are in the emergency or come to some doctor's clinic they are shadowing for they day and they see these. And they understand. They even engage if that physician has a very negative reaction in a bit of a more open-minded discussion. (645)

Recognizing their role in establishing healthy IDU-provider relationships, provider participants exercised *self-evaluation* after their IDU encounters.

If an encounter doesn't work, I look back to figure out how it could have gone better. Participants understood the importance of reflecting on their health care experiences in order to build and maintain rapport.

> 4: And that's what touches on, for me, it's not that I'm with someone and they die or they live or they live well or they get clean, or they do whatever. It's if I don't have that connection - they don't come back? Then there was something wrong and I often sort of try to figure out what the heck happened here and what did I do wrong. Because those are the ones that bug me as opposed to the ones that.... (246)

It is easy to place the burden of failed rapport on the patient, when in fact the provider's behaviour may be responsible. Participants were also willing to accept responsibility for their crucial role in the development of rapport.

> 4: The idea, if that window slams shut? That was, you did it probably. It's a way to justify if they didn't come back then oh well they didn't take that window that I opened. And in fact maybe the provider didn't, was doing all the things wrong or you know. From a, I hate to say, from an enlightened

> perspective that wasn't welcoming, wasn't non-judgemental, that wasn't caring, that wasn't all of those, honest. All those sorts of things. I think it justifies a lot of bad behaviour to say people only have one window and "oh that's not going to happen". (786)

Providers not only assumed responsibility for their actions, but also recognized that they occupied a position of *authority* which could be harnessed in positive ways. Some participants used a parenting metaphor to help describe their role.

By setting consistent limits, a provider assumes a role similar to that of a father figure. Being an authority figure permitted providers to use discipline constructively while counselling their IDU patients.

> 6: I have a very paternalistic approach. I freely recognize it, I use it to my advantage and I use it to the patient's advantage and that's why I do it. But I learn a lot from my patients. And it's not that I'm telling them what to do. It's sort of my general approach. You know, I'm a bit disciplinarian, or, I'm the consistent, reliable but sometimes strict, oh this is turning out bad.... That sort of thing. The one who sets the limits and that sort of thing. And there are lots of people who don't respond very well to that. And there are lots of people who respond very well to that. So I think the term paternalistic needs to be used with caution. Because it can be a very constructive thing in the form of, the sense of, like a father figure. I mean that's literally right? The disciplinarian father figure is an entirely different thing. (365)

By supporting and caring for clients, a provider assumes a role similar to that of a mother figure. Authority allowed providers to advocate for and nurture their patients' health as well.

> 4: I think what we would find for example some of the people that (6) and us would share. If he takes on the paternalistic role, (we) tend to take the mothering type of role in a different type of way. We've got our team members that are you know...
> M: They get you to the appointments on time ...
> 4: Ya, ya. And hopefully not enabling, trying not to be. But sometimes people need that hug or they need that whatever so. (377)

Provider *values* regarding IDU were felt to mediate the effects of provider experience and authority on rapport development.

It can be difficult to change deeply entrenched negative attitudes about IDUs. Strong pre-existing value systems around IDU were seen as a major barrier to rapport-related skill acquisition.

> 4: I think it makes a big difference too when I have say new staff that start there and they're fresh out of school as opposed to someone whose entrenched in certain beliefs and it takes a long time to change those. (544)

New health care providers may have unrealistic beliefs about IDUs. Pre-existing attitudes did not need to be negative to present a learning challenge. Participants felt that impractical provider expectations of IDU health care had the potential to lead to provider disappointment and burnout.

> 6: But I think the interesting thing about the young and very keen they tend to be, besides being naive, they tend to blind themselves a little bit to reality. Not exactly the same way but the exact opposite way that the hard-nosed sort of cynical "I know right from wrong, this is the way it's always been." will not open his eyes to the reality and just deal with how things are. (623)

I had to deal with my own beliefs about addiction before I could be effective. Providers felt that inflexible values needed to be accounted for before any rapport-related progress could be made.

> 3: That was my original way of looking at people who presented as a drug addict. "I'm a mental health therapist, I'm not an addictions councillor, go up to Streetworks or somewhere." And that's really common in the mental health field. It's only now that, I mean it took me quite a few years to move past that and it's taken the mental health field even more years. But I have the luxury of being in (the community) where I see it everyday and it still took me a few years to get through that. It was more my issue rather than the clients' issue. If you're genuine, almost any personality type can work, I think, with people who are addicted or are marginalized. As long as you are genuine, as long as you can work through your own issues around that stuff. 'Cause in my case, the thing that interfered with me working with this population was my own issues rather than theirs and mine were pretty big.

In addition to provider values, provider *personality* influenced how rapport was achieved, and made it difficult for providers to prescribe any one approach to rapport.

You need to find an approach that works with your personality. Providers suggested that no one interpersonal style is appropriate for all health care workers, and that rapport was best developed in accordance with a provider's personality.

> 3: No. Your personality and what works for you is not going to work for the next person. Necessarily. Parts of it might. It's like I say to the students. Don't try copying everything I do because it's very me. You need to use your own approach which may use little bits of what I do but you need to do something that works with your personality. (514)

Though IDU participants did not allude to the above provider characteristics in any significant way, they put forth *provider knowledge and skills* as being very important in their dealings with health care providers. The areas in which they felt provider competence was essential may not be included in standard nursing and medical school curricula.

<u>Doctors undertreat pain when they're not used to treating addicted individuals.</u> IDUs felt that provider understanding of pain management and drug tolerance in the context of IDU was often inadequate.

> Xxxx4: I mean I have gone in for abscesses that have been like a pool ball under your skin like they are so infected that and they give ya 5 or 10 milligrams of morphine if you're really lucky. I mean when you're prescribed from a doctor 4-600 milligrams a day, I mean like people they don't realize that I mean just because you're on morphine like its happened like in prisons everywhere, they look at your dose like you're on 200 or 300 milligrams of let's say MS100's there's no need for any pain medication. You're already on enough. I mean, there's a hell of a need. I mean if your if your body, if you can do 3 or 400 milligrams and sit there and chill without anybody noticing, what's 10 milligrams like in your hip? (64)

<u>Providers may not know as much as a user about finding a vein, and won't always acknowledge this.</u> Participants also remarked that providers were usually not as skilled with intravenous procedures as their IDU patients were, yet appeared to be uncomfortable with their patients' expertise.

> Xxxx8: Ya. They let other people take care of you that aren't even supposed to be working in that. Like putting on your, to take your blood work, they don't even strap you right. You know how it's supposed to be done because you've been there so many times. They don't even do it right. (276)

<u>You get support from and open up in a regular, long-term relationship with a doctor.</u> Provider continuity was associated with better provider understanding of the IDU as a person.

> Xxxx2: My doctor, she just moved.... She was great. Like I'd go in once or twice a month and we would just sit down and have a rap session just like

> what we're doing right now. We established a really good healthy relationship so like, what she got to know what I was like. She didn't see me just like as a number a little bit more money in her pocket that I mean. (522)

It helps when a provider understands drug addiction and is familiar with the inner city. Familiarity with the area and users in general was seen as a great asset to good patient care.

> Xxxx8: I think they're um, better at the clinic too because they are more used to having drug users around and they're used to seeing the same people and pretty well know how their habits are. Who's the whiners and who's really in pain. (376)

To summarize, IDU and provider responses differed in that IDUs emphasized the importance of provider knowledge and skills in the area of addiction and injection, whereas providers emphasized global IDU experience and attitudes. However, both health care providers and IDU patients interviewed agreed that providers carry a significant responsibility for the development of rapport, and that their success depends largely on the application of pre-existing knowledge, skills, and attitudes.

Within-encounter variables. Though the aforementioned pre-existing patient and provider characteristics were seen to strongly influence rapport, participants in both focus groups devoted most of their discussion of rapport to the content and quality of the IDU-provider interaction itself. Both positive and negative encounter-based determinants of rapport were described.

IDU participants described several health care encounters and emphasized a few key behaviours which influence rapport. *Discrimination* against IDUs and associated *trivialization* of IDU concerns was a rapport-damaging experience common to all participants in this focus group.

People who inject drugs are often treated poorly compared to others. Participants felt that the care they received was substandard relative to non-IDUs with a similar problem.

> Xxxx9: They wouldn't take the pill popping alcoholic from (the suburbs) and treat them people like they treat you like they would down here. And I see that time and again. (704)

People who inject drugs wait longer to see a doctor. Participants suspected that the triage process, to which patients are subjected when accessing health care, discriminated against IDUs, and that they were made to wait longer than usual in the emergency room.

> Xxxx4: You watch people if like in the evening time in the winter I mean like if you're sick, you go in there they let you sit in the waiting room until 6 in the morning and then at 6 in the morning come say ok its time for you guys to leave now. And not even see you just assuming you're there for a place to sleep in the night. (85)

Many doctors assume all an IDU wants is drugs. Once participants were seen by a physician, they were often dismissed as drug seekers without real medical problems.

> Xxxx4: You automatically have HIV, you automatically have Hep C, you're automatically there for a prescription, and if you get a prescription it's automatically going to be sold or abused. (690)

Many doctors trivialize legitimate user problems. Not only did participants feel they were labelled as drug seekers, but they also felt that their medical illnesses and the associated suffering were largely ignored.

> Xxxx1: I think the doctors there think you're coming in there for drugs, even if it's a legitimate reason. Like if you have an abscess or something like that. They'll let you wait still. "Oh you're an IV user. You can wait a while, you left it this long, it's not a big thing" .... Ya yup you're the last stick on the totem pole. (383)

Good doctors treat a user like a normal person and do not judge. The absence of discrimination, or treatment of an IDU patient with respect and in the same manner as other patients, was central to a good IDU-provider relationship.

> Xxxx4: ...it's just all in all you don't feel like you're being looked down at your not like some piece of shit junkie trying to get something. Even if you're going in there for your triplicate prescription you like, generally, like you can talk to the doctors and the nurses and its not gonna be like looked down at even if it is like a drug injury type thing. (399)

While discrimination and trivialization were an unfortunate reality, all participants nevertheless pointed out positive health care encounters during which rapport was strengthened with *patient-centered care*.

A good provider is caring and friendly. Positive rapport was achieved when health care providers took the time, over and above basic medical treatment, to develop the patient-provider relationship.

> Xxxx2: I don't know about [methadone program A] but I'm on methadone.
>
> M1: On [methadone program B]? Through [methadone program B]? And how is it there?
>
> Xxxx2: It's alright. They're nice there.
>
> M1: What make them nice?
>
> Xxxx2: They're just friendly, they ask how you're doing and they generally care (249)

A good provider listens. Respected health care providers were willing to listen to their patients' story and consider their requests.

> Xxxx6: All doctors are not, aren't the same. There's good and bad in everybody. There're some good doctors and there's some bad ones. If you happen to get a good one, they'll listen to you straight out. I mean, if you seen a doctor for long enough and you're trying to quit or something like that. That could be part of your support thing too. But there are like I say, good and bad doctors, and if they, there are some that are willing to listen to you, and some that aren't. They'll just shun you off 'Ok, what do you want?!". If you're here for T3's or T4's or whatever. Forget it, they'll give you the alternative the little green ones. (475)

A good provider is supportive. Participants also appreciated it when their health care providers were concerned about addressing their patients' social circumstances in addition to their medical illnesses.

> Xxxx9: You know they need to start looking at the person as a whole. Do they have a place to sleep tonight. You know do they have a job to get enough money to live. (624)

In addition to patient-centered care, *confidentiality*, in particular about drug use, was of paramount importance to strong patient-provider rapport, though it was unfortunately not always present.

I don't want anyone to know about my drug use. Aware of the potential health care stigma associated with IDU, participants wished to disclose their drug use status to as few people as possible.

> Xxxx1: Ya for sure, I don't want nobody to know I'm a junkie. (417)

Health care providers sometimes talk about someone's drug use in front of others without that person's consent. Participants related several incidents where their drug use history was discussed openly and without an apparent medical justification for doing so.

> Xxxx9: when you talk about that one particular time when you overdosed here in the co-op and the paramedics started rattling off your whole history of drug usage and there were other people here and they were told to stop and they said "Oh these people wouldn't understand anyhow what we are talking about." (43)

Doctors sometimes record and look up drug use status on the electronic medical record without the patient's knowledge. With the advent of region-wide electronic medical records, participants felt that they no longer had any assurance of confidentiality.

> Xxxx9: Since they've got this net care in the last year or so like people can access medical files. The doctors subscribe to that. They put stuff about you on there whether you're [trail off], they have access to files at the hospital and everything. So I didn't know that. Ya so I mean... (169)

For these and other reasons, patient *honesty*, though it was acknowledged as an important influence on rapport, had both benefits and drawbacks.

If you tell a doctor about your drug use, he might not give you drugs; if you don't, he will. Within the context of the focus group, participants stated that they seldom tried to obtain a controlled drug prescription from a doctor unless they were truly ill from withdrawal or pain. Though they perceived their condition to be a legitimate medical issue, they understood that disclosure of their IDU status would jeopardize their likelihood of obtaining what they wanted for their condition.

> Xxxx2: It's just, if you tell the truth and then they just say "well go to [the detox] and they don't want to give you anything, prescribe nothing for you.
>
> M1: And what happens if you don't tell the truth?
>
> Xxxx6: Usually get a prescription. (123)

I sometimes have to lie about my drug use in order to get help for my other health problems. Disclosure of IDU even threatened some participants' ability to obtain health care services unrelated to a prescription.

> Xxxx4: I mean my problem is I have lie to a psychiatrist. Like thing is every single thing wrong with me to them is from drug use. I mean like every hallucination, every illness in my body is simply because you're an IV drug user this and that. So I have to sit there and kiss ass and lie to them and if I am having trouble I can't tell them that. (332)

Honesty is needed to develop a relationship with a doctor. Although honesty did not seem to help IDUs during initial or episodic encounters, participants recognized that it helped a great deal in building longer term rapport.

> Xxxx4: like I say before it's ah, like you see a doctor long enough, that you use that as a support system. 'Cause they know your background, they know you're telling the truth, they know you're trying to clean up.
>
> M1: Right. And you guys were saying that it takes two people and you bring something to the table. Can you explain a bit more about what you think you bring to developing that good relationship?
>
> Xxxx4: Honesty. (528)

In all health care encounters, a negotiation process between the patient and the health care provider occurs wherein both parties advance a health-related agenda and conclude the encounter having successfully addressed their agenda to varying degrees (McWhinney 1988). In general, a power differential exists in favour of the provider of care (Rothschild 1998). The negotiation process and its outcome have an impact on rapport and subsequent care-seeking behaviour. Where the recipient of care is an IDU, however, the nature of the negotiation appears to have additional unique characteristics. This is particularly the case in encounters where the patient agenda involves obtaining a prescription, in which case the role of the *doctor as drug supply* significantly alters the interaction.

A doctor will eventually cut you off. Participants acted from the outset of a prescription-based relationship with the knowledge that the eventual loss of one's prescription was inevitable.

> Xxxx4: Like when you have a prescription, it's not a matter of if you're gonna lose it it's when. (232)

If a doctor won't give you the drug you want, you will get it through doctor shopping or criminal means. Where IDUs' prescription needs were not met by their physician, many users felt justified resolving this agenda via less socially acceptable avenues.

> Xxxx6: Ya, they'll give you something different eh? And then it's another thing about tying up the medical system. "Oh I didn't get it here? Oh I'll go there. I'll go there." You know, and that's just one person. I mean it's...and if you get a bunch of people like that doing the same thing. It's tying up the medical the medical profession kinda thing eh? And that's why there's congestion in the hospitals, the everywhere. (484)

A caring doctor will give you drugs. Participants felt that physicians who truly cared about their IDU patients demonstrated so by being more willing to prescribe controlled drugs for their patients' suffering.

> Xxxx4: I don't know if anybody else has had this I mean like, when you get a doctor that's somewhat caring, and they'll do things like write Percocets for you or something like that. You're looking at a triplicate prescription. (214)

This physician role was accompanied by several provider-driven prescription *rules* which were perceived by IDUs as significant obstacles to negotiating effective health care.

Limited carries can screw up a user's life. Some participants resented the lack of freedom associated with tight provider controls on the amount of medication dispensed at a time.

> Xxxx2: Like also like at the end of this month I'm supposed to take a trip out of town. And those they won't give me a carry to go out of town. I [stutter] My-my father law had passed away, I wanted to go to the funeral you know my kids wanted me there and that. And I couldn't get a carry. I couldn't go to the funeral.... There's a lot of bullshit of having to get your pills every day. I've been getting them every day for the last year now. And it just I find like if I could get it even like every twice a week. Once a week. Shit. I would be a lot better off. I could take off for a few days. Go out of town, I could go up [north], see my kids. The way it is now, I have to be at the pharmacy. (599)

Sometimes users feel coerced into treatment. Participants occasionally felt that the choice to undergo residential treatment or opiate substitution programs as an alternative to their usual drug use pattern was made by health care providers for them.

> Xxxx9: With a lot of our moms that I've worked with, it's you tell your doctor you're an addict you're red flagged at the hospital they're gonna do tests on the baby and he's born and the baby's going to go on child welfare. You know they say "Go on methadone, you can keep your baby". (625)

<u>Prescriptions come with intrusive tests.</u> The lack of provider trust suggested by targeted physical examinations and urine drug screens was frustrating to many participants.

> Xxxx2: You know I go into the doctor's office, I go and see [my doctor], and first thing he is he says "roll up your sleeves I want to check for tracks". What the fuck you know like? Ya it's "When's the last time you had a fix" well look it you know I had a fix about 3 or 4 days ago. "Let's see your arms" you know. (652)

<u>Some doctors red flag and refuse to even consider prescribing certain drugs.</u> Participants stated that some physicians declined to participate in an encounter as a supplier of controlled drugs, regardless of the legitimacy of the request, because of the potential for illegitimate use. Any negotiation attempts by the IDU were rendered futile in this situation.

> Xxxx4: I mean, you walk into any doctor's office and mention any, like when they ask, even if you're legitimately on a prescription, and when you tell them the prescriptions you're on, the red light goes on when morphine comes up. And they'll sit back and say "I'll prescribe everything but that". (577)

<u>It's good when a provider is consistent in their treatment of patients.</u> Given the challenges associated with drug-related patient-provider negotiation, consistency in a provider's application of rules was reassuring to participants.

> Xxxx4: The clinic, the best thing about the clinic is the consistency. Like with the hospital[...] sure there's times I've gone in there and I've scored the right doctor and he's really helpful and he's given me two blister packs of like M-Eslon or something and I'll be on my way. But like with the [clinic] it's consistent. I mean, even though sometimes you might not like the answer you get, I mean, the staff treats you. It's like, basically equals respect type thing. Like as long as you're like honest and like, fair with the staff, they're helpful. (389)

Aware of the barriers they faced in satisfying their health care needs, IDUs developed *personal negotiation strategies* to improve their chances of success.

<u>It takes a lot of work to maintain good relations with a doctor and his staff.</u> Participants recognized that health care providers work in teams and that rapport building was a constant task which needed to include every member of that team.

> Xxxx4: And you have to take all of those things that just happened and prove to every single person along the way. 'Cause it's not just the doctor, it's the

> nurses at the triage centre, it's the ladies at the registration. Then it's like the nurse that comes to see you when you're in the examination room. You have to sit back and explain "no I'm on MS". And the next person comes and says "Why are you on that?" For Christ sakes, why am I talking to a receptionist about a health matter? It's just until you put these little hoops and stuff and on top of it you are usually the 50th person to be seen. (691)

<u>You have to come up with an elaborate story in order to get anywhere with a doctor.</u> IDUs felt that they often had to prepare a detailed, defensible narrative to legitimize their health care requests.

> Xxxx4: But to go to like a doctor in the west end, you have to totally choreograph the whole thing, you have to lie your ass off.... You learn from your other friends which doctor to go to what to say. (777)

<u>Even with a good story, you often have to settle for less than what you wanted.</u> Participants frequently compromised in order to partially fulfill their needs.

> Xxxx4: And then even by like giving you the 10 milligrams it's almost like "There." You almost like they almost feel like you pried it out of 'em. (72)

<u>You know right away whether or not you'll get what you want.</u> Participants alluded to a highly developed sense of intuition about health care encounters and their likelihood of successfully meeting their health care needs.

> Xxxx3: I try to walk in there with an open mind. Normally you get an idea of what they're like on your first visit. And so any assumptions that you had... you'll find out on that first visit with the doctor. (760)

<u>You are treated better if you have someone else there to advocate for you.</u> IDUs were also aware that their health care experience improved when a support person was present.

> Xxxx4: Like I've gone like with people in this room to the hospital and stuff. And I mean I'm glad, like it's almost as if you have to as a pair so somebody can actually watch what's going. Like...[trails off] Well, you're by yourself, I mean like I found like you gets treated like crap I mean like I say, [bkgrd cough, cough] I've gone up to the staff at [the needle exchange program] and the treatment you get is even better and it's not because it's a [needle exchange program] staff member it's somebody else witnessing the fact that it's [trails off]. (78)

Providers, like IDUs, described having developed a "bag of tricks" or set of negotiation strategies for IDU-provider encounters, though their approach was quite different. They echoed the importance of *patient-centeredness* in their dealings with this group as with any other.

<u>The patient and the provider both help to define what problems will be addressed and how.</u> Mindful of their IDU patients' general experiences with health care, providers took the time to find common ground with their patients and share control of the encounter where possible.

> 2: I guess I expect at times sometimes a little bit of initial resistance but then I expect at the end that we will have a plan that I think will work for both parties. To help keep that person healthy and safe at least in the short term from an emerg perspective. (65)

<u>Patients are a major source of practical information.</u> Participants appreciated that they not only gave information and services to their patients but also received wisdom from them.

> 6: Some of the new stuff, if I hear it. One of my tricks is if someone says something that I don't understand, I'll say, "Hang on, what's that, what does that mean?" And that's a very powerful way of creating a rapport. Even the guy I was telling you about, used some term I wasn't familiar with, I can't remember I was "What's that?" (333)

<u>A provider's communication skills adapt over time to the community in which they work.</u> Providers described undergoing a degree of street acculturation as a natural consequence of interacting with IDUs. This acculturation usually improved rapport.

> 4: I think though too when you work in the community for a long time and [my colleague] often says that you take on the characteristics of the community that you work with. And I think that's very true in terms of reading people and little bit of street smarts and a little bit of what can you get away with and what can't you. I think you pick that up as well when you are in the community for a long stretch of time. And so that just plays in your favour usually. (355)

While being responsive to one's patients was essential, *authenticity* was equally important.

<u>You have to avoid trying too hard and just be yourself.</u> Participants felt that an overly formal persona hindered rapport-building efforts. Rather, "being real", or engaging oneself in the encounter, was much more effective.

> 1: I almost respond to that by saying it's almost by not using any tricks. I don't know, I sort of think of myself when I started and I tried too hard and

> really I think, the best thing that I ever started to do was you know, just being me, the same as I am with anybody and everybody. And hopefully that is non-judgmental but it's gotta be real. (296)

<u>If you are genuine, almost any personality type can work with this population.</u> "Being real" was seen as a key rapport builder which could be used by any kind of provider.

> 3: If you're genuine, almost any personality type can work, I think, with people who are addicted or are marginalized. As long as you are genuine, as long as you can work through your own issues around that stuff. (573)

Connection with one's patients on some level was more important than the health-related content of the interview because it created the potential for longer term patient-provider relationships. Though patient-centeredness and authenticity were important for connection, providers discussed other ways to make connections as well.

<u>I expect little more initially than to make some sort of connection.</u> Participants recognized that attempts to address more than the basic health services requested by IDUs before a provider-patient connection was made were likely to result in failure.

> 4: …I suppose my expectation is that we make some sort of connection. Just sort of an eye contact, I'm ok, you're ok, at least a starting into that. I never expect that much, except two steps back sometimes from one step forward. I just mostly at that point just want us to be able to talk to each other whether it's about the weather or something more serious. (76)

<u>Harm reduction programming gives me the chance to connect with patients.</u> Some providers felt that the harm reduction services available in their workplace provided the opportunity to connect with IDUs with whom they might not otherwise have come into contact.

> 4: I'm the luckiest because they come for our needles. That's our first hook, that's what gets people in the door. And so that's great. Mostly, the needles aren't the main thing, the needle exchange, it's the connection. But that's what gets people in the door. (139)

<u>Humour can help to make a connection.</u> Many providers found that humour relieved patient-provider tension, and found ways to laugh even with their most severely ill patients.

> 5: I know I had asked one girl with talc lung who was almost intubatable. I was trying to get her into a room and I said, "Have you talked to doctors before about whether or not you want a breathing tube put in or not?" She was like, "I know, *[pant, pant]*," because she couldn't breathe, "I'm trying to quit I'm trying". I'm like, "Oh my god, no no no no no, that's not what I'm asking you, I don't care if you're still using, I just want to know if you talked to them like if you have a personal directive and stuff." She laughed too, "You don't care if I still use?" Like "I care, but not like that. Not at this exact moment of time that's not my concern" and she did kinda laugh. And I thought, "That's good you can still laugh when you can only do one to two word sentences". (312)

I start with neutral topics and wait to get into drug use until later. "Safe", relatively value-free discussion topics unrelated to drug use were used initially; drug use, harm reduction, and treatment topics were deferred until a connection was made.

> 4: For me it's always too about just not just getting straight into the safe injection practices immediately. It's backing off waiting many many times, sometimes talking about the weather, the Oilers, "Hey you look great I love that shirt, where did you get it. Nice tattoo". I mean there's all kinds of little opening lines where even sometimes you get a quick eye contact but then they come back the next time and it's a little bit more and a little bit more. (322)

I feel incompetent and disheartened when I am unable to connect with someone. Participants took personal responsibility for establishing IDU-provider connections, and were therefore disappointed when their attempts were unsuccessful.

> 6: I think though by that same token, not too long ago, within the last two weeks I saw some fellow who had scabs all over him stuff like that. Who wasn't really tweaked out or anything but he...it was a really bad encounter from my point of view because I made absolutely no connection. I tried all my little tricks, all my ways of trying to engage him. It wasn't that he was intoxicated or jonesing. Anything. Simply I was unable to connect with him. All he wanted was a straightforward answer and solution to his problems. I felt quite incompetent. It's disheartening. (227)

Timing was crucial when bringing up sensitive topics such as drug use. If you initially focus on building a connection with someone, they will come back more willing to talk about addiction. Early encounters with an IDU had a very different character from later encounters. Relationship-building and minimal focus on drug use were central to early visits, and once connections were made, the focus of return visits could turn more to drug use.

> 3: Once you start, it's a slippery slope you just do more and more. My thing is more the mental health. I tell them I don't care that much if they are using. At least initially. The idea is, "Why are you using, what are you using?". More a conversation rather. And if they are using so much they are picking the sawdust off my table saw, then we have a discussion about how much they're using and perhaps they need to take a little bit of a break. But I'm more interested in the mental health status, how they're doing, how they're going to survive. Are they having visitors, friends or whatever. So my initial concern is not even the drug use, it's more the mental health, what's going on. (267)

Every visit is an opportunity to further engage the patient. Rapport-building was an ongoing process, with each new encounter providing an opportunity to both further connect and gently explore drug-related issues.

> 7: The fifth time I've seen her in the last two weeks was today. She's been mad at me every time but she keeps coming to see us so there you go. And finally today I said "You know, you gotta take a rest from this, don't you think we should try something cause this is..." Because today she could hardly do anything but cry in between. And "no". I said "well you have to give this some thought cause you really do have to take a rest from this, you need some time out here". So we just walked together and she left but. I don't know. Sort of maybe gradually a little bit. Maybe she will come back tomorrow and we will see. (536)

Demonstrated *openness* during IDU encounters significantly helped rapport-building with a patient population accustomed to differential treatment by health care workers.

You have to be comfortable with the patient. Providers were aware that their patients reacted negatively when health care workers were uncomfortable around IDUs. It was important for providers to show IDUs that they felt secure during the encounter.

> 2: I think too showing you have some understanding of where they're coming from. So like for me it's sitting at the bedside, talking the talk. Saying like, "What are you using", making it more everyday like, "we see this all the time". (305)

Sometimes people just need a little support. Aware that the balance of IDU encounters with health care was negative, participants looked for ways to affirm and nurture their IDU patients.

> 5: For people that haven't been told that they haven't done a very good job at anything probably very much in their whole life sometimes being that mama

> thing. Or just saying "good job" at something. Even if you really have to dig. (390)

<u>I expect myself to be approachable.</u> Participants felt that informal contact with patients, like saying hello and talking to patients in the hallway, humanized the IDU-provider relationship.

> 6: Where and I think we all here, all the staff is really good to try to take, even if it's to walk across the clinic to fax something or something, I will stop and spend 30 seconds, that sort of thing. Which is, that's a big part of rapport building it's not, it's being available. It's being open at all times. Rather than, "Here's your 15 minutes where we're going to work on developing our rapport".. It's like you'll run into them on the back step and they're telling you about their little problem. You spend 30 seconds on your way home right? That is also recognizing their reality and dealing. This is when they realize—this is when they want to talk about an issue. (849)

<u>Trust has to come before anything else.</u> Providers and IDUs needed to trust each other's intentions before moving forward in an effective fashion. Providers also felt that they needed to trust their own intentions.

> 1: I think there has to be trust. I don't know if that's the answer but you have to trust if you are going to make a mistake it's going to be for the right reason. (769)

<u>I expect mutual honesty.</u> Though disclosure and its consequences was not as central to encounters for providers as it was for IDUs, some providers mentioned that honesty of intentions significantly improved both parties' ability to trust and connect with each other.

> 6: I expect, *[pause]* I expect as much honesty as they are capable of giving in the context. So that I can help them and they can...My other expectation when dealing with IV users, of myself. I expect myself to be as open and as approachable as I can be. So expectations of openness on both parts I guess to summarize. Try to be as open as you can but in the actual situation. (99)

<u>After you get to know someone, you can tell them candidly how worried you are about them.</u> Once rapport was better established, participants felt better placed to openly express their concern for someone. Demonstrations of concern helped some participants to further cement their rapport with a patient.

> 3: A few times in the hospital when I visit somebody I just tell them, "I don't know what to say. This is just stupid." And that seems to work really well

> sometimes. “You look like a bag of crap. You’re wearing a mask, you have double pneumonia or whatever the hell is going on now. For what? What a waste of everybody’s life, especially yours!” That works really well sometimes. It’s like, but I mean they’re kind of on the end of their ropes, so there’s nowhere to go but hopefully improvement. So some of the best stuff has come out of that sort of thing but you’re going, “Oh my god this is not good”. So some of the best work comes out of that but you have to have the relationship before you go in and have that kind of conversation. (403)

Like IDUs, providers acknowledged that IDU-provider rapport required a significant amount of *effort*. However, it was important that these efforts were applied constructively.

<u>You get into trouble when you try to do too much for someone else.</u> Though providers were conscientious about establishing rapport, they cautioned against assuming responsibility for fulfilling all a patient’s needs, an approach which was often more damaging than helpful.

> 3: Once you start, it’s a slippery slope you just do more and more. (267)

<u>Rapport takes a lot of work but it is also very fragile.</u> Providers worked hard at building rapport, but damage was easily done, and rebuilding and repairing rapport required just as much work.

> 6: What’s worse is you work like hell and then you screw it up yourself. (817)

Provider participants, unlike IDU participants, also described the *emotion-laden* nature of IDU encounters as well as their strategies for dealing with these emotions.

<u>Strong reactions to a patient can interfere with one’s ability to help that patient.</u> Some providers acknowledged that when IDUs presented with strong emotions, they as recipients naturally experienced strong reciprocal emotions which got in the way of patient care.

> 1: I will stick my neck out and say I can think of one client as my worst encounter. It was really, was it the client? Well you know, I didn’t enjoy his, what he presented with over a year’s period. What made it worse was I actually got angry. He got under my skin. I really could not—I could go on and on about what he said, I’m sure everyone has had that situation. But the problem wasn’t what he was doing, it was I was actually angry and could no longer give any help in the situation. Whatsoever. And our whole team was

> angry. So that we actually couldn't help him even. I don't know if you want the details of the situation but the problem was really we had let a situation, let ourselves get angry, get caught up. (425)

Staying calm and not reacting can calm down an agitated patient. Participants had also come to understand that IDUs reacted to provider emotions as well. When participants remained calm, their patients usually responded in the same way.

> 6: I know it sounds a bit odd but you tell yourself that you're comfortable and you're casual and that actually you see people, the other person calms down. That's speaking slowly and softly. Great trick for calming down in a situation like that 'cause people are often not necessarily hostile but still agitated, worried, you know. (338)

If you show you understand the patient's context, you can usually calm them down. IDUs responded positively when participants demonstrated empathy.

> 4: You'd walk in sometimes and the unit would totally be in an uproar and you just knew it was that room that it was coming from but what exactly was the problem. And to have someone that had a foot in both worlds who could do that sort of helpful to all sides calming thing down sort of a thing. (673)

Explaining your actions can calm someone down. Sometimes accounting for one's decisions was all that was necessary to reassure an agitated patient.

> 7: Most of the time I'm saying no to people. They want something and they come for something. "I won't give you a bottle of Nix to pour in your eyes because I know you don't have lice in there." It's, so they don't like it. They came for it, they want it. So you get called all kinds of things and they're screaming and going down the hall. And when I first was here and putting up with that regularly a couple times a day, then it didn't, it wasn't good. It upset me. Now I just go "No, it'll hurt you." Somebody says "You just said I was nuts". "Gosh, I never said you were nuts, I don't think you are. I'm telling you I'm not going to give you the Nix. But I'll help you out here. Let's go upstairs..." And so you just stay calm and do what you can. (528)

Rapport, then, is determined by a multitude of within-encounter variables which are approached differently by IDUs and health care providers. IDUs not surprisingly described significant discriminatory behaviour during their health care encounters, to which providers alluded in their awareness of the influence of pre-existing attitudes towards IDU. Patient-centered care—the finding of common ground, approachability, and supportiveness—was another important determinant of rapport for respondents from both focus groups. However, the impact of disclosure of drug use was perceived differently by each group, with IDUs stressing its potentially disastrous consequences on fulfilling their medical needs, and providers emphasizing its crucial role in the development of a trusting, longer term relationship. The "bag of tricks" each group used to negotiate the encounter, and the perception one group had of the other's negotiation strategies, were also unique. Whereas providers discussed strategies to manage emotion and engage the IDU patient, IDUs were instead preoccupied with navigating provider-centric rules of negotiation and creating a "legitimate" argument for their health care requests. Finally, physician participants perceived their roles to be quite different from the drug supplier role identified by IDU participants.

External context. Participants in both groups alluded to certain system-level rapport builders and breakers. IDU respondents acknowledged that wait times, prescription-related rules, and location of care all influenced rapport, and these variables are determined in no small part by forces beyond the control of the patient or provider. However, when asked to clarify how these variables contributed to rapport, IDU participants emphasized the provider's differential treatment of IDUs within this context as opposed to the context itself. The influence of location in particular did not meet with unanimous agreement during the follow-up focus group session, and it became clear that the health care staff within a facility were viewed as a more important determinant of rapport than the location of the facility. For this reason, these contextual issues were analyzed at an interpersonal or within-encounter level for the IDU session. Location of care was not included in the focus group findings but was examined in follow-up interviews.

Unlike IDU participants accessing the *health care system*, provider participants working within this system readily discussed its influence on their work. <u>The system isn't set up to address marginalized patients' needs.</u> Participants were frequently frustrated in their attempts to comprehensively address substance use and social issues by the health care system's time, space, and resource constraints.

> 2: I think just speaking about the context in which we work. The biggest problem for me in emerg is the way the system is set up. Because it's not designed to help people who are marginalized. So there's a long, emerg is busy, you have to be triaged, takes 6 hours to get in, by the time you get in by

> the time you get in you know, we want to get things done quickly. The biggest problem for me is I see these people, I convince them to stay, and they leave AMA two days later. I had a girl who I saw last month who was very sick, huge arm cellulitis, bordering on septic shock, clearly needed to be in the hospital. Checked two days later and she's signed herself out and I get her positive HIV test and no one had, no one got back in time to tell her and now we can't find her because she's not staying in any particular place. That's what I find the most frustrating. The system isn't set up to take care of these people while they're in hospital and deal with the big picture. I'm sure she wasn't getting enough pain medicine or enough drugs in hospital and she just said, "Screw you guys, I feel better, I've got other needs" and we're not addressing those other needs. When we have them there, when we have the opportunity to do it. Not that we can fix everything but I think we have to at least make sure those things are addressed so they don't feel like they have no other options but to leave. (654)

My profession's governing body supports my work. When participants were asked whether medical and nursing associations imposed similar practice constraints, they instead indicated that their governing bodies understood their unique practice issues and supported their activities.

> 4: There's certain rules in nursing about how you're supposed to document or communicate which I would say we kind of skirt around the edges on that one. We can't demand all the information that they would probably expect us to. I think they know we are in a little different boat and they haven't said anything about it. (700)

In addition to larger system influences, the *health care teams* within which participants functioned influenced each individual's ability to forge rapport with an IDU patient.

The makeup of a health care team influences how a patient interacts with each member. A provider's role, as perceived by the patient, changed depending on what other health care disciplines were represented on the team. In particular, the presence of a physician on a team commonly led to a more peripheral perceived role for other team members.

> 1: And the person that you are seeing brings a certain amount of baggage and what they expect of you as whatever your profession is. What I used to find as a nurse working with a physician, what was requested of me when I was working beside that physician being entirely different than if I was by myself. Because, and I don't mean this to sound like I have a self-esteem problem, but there was less expected of me. There was a physician was there and more

> could be received from that physician than probably of me. And that worked negatively, obviously that was not always comfortable for the physician. (604)

A negative encounter with one team member can damage the rapport built by others. Sustained IDU-provider rapport depended not only on their interaction but also on IDU interactions with other health care personnel external to the encounter but associated with the provider.

> 5: Well we'll have people though that everything will being going well, everything's great, they're being admitted and all this stuff. And then all of a sudden the next thing you see them slamming at the door and they're angry. And they go through so many people, the nurses, the doctors, right down to the porters and one person they will have a really negative interaction with somebody where they feel judged. (794)

Other health professionals are not always comfortable with harm reduction. Provider-colleague interactions also influenced the atmosphere within which rapport was being built. Participants often worked alongside colleagues who had misgivings about their approach to IDU health care.

> 6: Harm reduction, talk to physicians about harm reduction and they are already suspicious. "What does that mean, what exactly are you doing, isn't that just sort of giving out needles and heroin to anyone who wants it?" Some actually think that. (726)

The *health care setting* in which an encounter occurred also exerted an influence on rapport.

Rapport is developed differently depending on the location in which health care is provided. Providers' approach to rapport-building reflected the venue in which care was provided, be it episodic and hospital-based, clinic-based, or in an outreach setting. Emergency room providers especially felt that the relative lack of provider continuity in their workplace led them to focus on finding common ground on shorter term issues and helping IDU patients feel welcome to return.

> 5: I think mine in the emergency is shorter. You don't see the same long term rapport. You don't develop the same long term rapport. But we do see the same people repeatedly and sometimes they recognize you and go, "You're the nice one or you're the mean one or you're the one I said I would come back and kill". *[laughter] (772)*

Patient expectations differ depending on the location in which health care is sought. Likewise, IDU patients approached health care providers differently depending on their work setting.

> 1: At [my workplace], we are an outreach site so we do see people who come in specifically for a needle exchange. But as a sideline because of where we are because we're called a health centre, we often have people walking in from off the street looking for a physician which we don't have. (175)

Thus, rapport also appears to be mediated, though to a lesser extent, by factors external to the encounter itself. Health care system, team structure, and location of care influence providers in particular in their ability to develop good rapport.

Study Limitations

As with all qualitative research, the content of these focus group sessions, though rich in detail about the nature of IDU-provider rapport among participants, is not necessarily representative of general IDU or provider populations. The provider sample in particular was selected to reflect the views of those with significant expertise in IDU health care as opposed to those of the average health care professional, and relatively favorable experiences with IDU patients are therefore expected. Similarly, the IDU sample was largely male and drawn from regular users of local harm reduction agencies; it has been historically much more challenging to involve women and other disadvantaged groups in research. It is also possible that many of the focus group findings would be no different from those of a general population sample exploring patient-provider rapport in the non-IDU setting. That the responses from both groups contain much common information, however, suggests that their rapport-related experiences are a reality shared by many of the participants' inner city Edmonton peers. Follow-up qualitative interviews with other IDUs explored these findings in further detail.

Rapport-related factors external to the actual encounter—patient and system characteristics, for example—were not as thoroughly explored during the sessions. This may be because participants had not previously given much thought to the context in which care takes place or to the role that the health care recipient assumes during a health care encounter. There may also have been a certain degree of reluctance by both groups to assign much responsibility for good rapport to the patient.

IDU participants focused overwhelmingly on their experiences with physicians and shared very little of their likely extensive experience with nurses. Given the priority of drugs in IDU patients' lives, that doctors have prescribing authority and nurses do not could explain the physician-focused responses. It may be that IDU participants' interactions with nurses differ significantly from their interactions with physicians.

Finally, it is also possible that the involvement of a medical doctor on the research team influenced IDU responses in particular. It is hoped that her remaining blinded to identifying information on IDU participants reduced the likelihood of such a response bias.

Summary

The IDU, the health care provider, the setting, and the interchange during the encounter itself can contribute both positively and negatively to the development of rapport. IDUs and their health care providers have complementary perspectives on rapport's development and its consequences.

Chapter 4: Cross-sectional Rapport-Utilization Study (Study 2)

Methods

Overview. A convenience sample of Edmonton inner city IDUs was recruited in order to quantitatively describe local health care seeking patterns by Edmonton IDUs and to identify potential socio-demographic and interpersonal correlates of these patterns. Of particular interest was the hypothesis, described in research objective four, that perceived autonomy supportiveness of a primary health care provider is positively associated with service utilization among IDUs.

This study was carried out as part of a larger research project examining the social dynamics of injection drug use. Specifically, data for this study were collected as part of a multi-method study intended to (1) elicit IDUs' accounts of social competence and the interpersonal dynamics associated with needle sharing, (2) assess psychometric characteristics of social construct self-report items developed from qualitative analyses of these accounts, and (3) explore cross-sectional relationships between these new measures of social context and IDU-related risk and protective behaviours (Wild, Salvalaggio, McKim, & Taylor, 2007). Thirty-one qualitative interviews were conducted, audiotaped and transcribed verbatim, and analyzed using a combination of numerically aided phenomenology, thematic analysis, and the constant comparative method. The resulting self-report items were collated into a preliminary version of the Assessment of Risk Contexts (ARC) instrument (see Appendix E). The ARC measure addresses the micro-social, macro-social, biological, psychological, substance, and spatial-temporal contexts of IDU. Feedback on the preliminary version of ARC was obtained from 11 clinical and research experts on IDU, after which ARC was pilot tested with three people who inject drugs. A revised version of ARC was then tested and its cross-sectional relationship to IDU-related risk and protective behaviours examined in a larger sample. The ARC instrument included several items assessing issues related to health care utilization and rapport, and as such, provided a quantitative data source for testing predictors associated with research objective 4.

Sample. The study sample was recruited through Streetworks as well as the BMHC. Due to the exploratory nature of this research and the difficulty in reaching the IDU population with traditional sampling means, a non-probability sampling strategy known as chain-referral sampling was used; this involves identification and recruitment of a small number of participants via word of mouth, who then provide contact information for other potential participants (Erickson, 1979). Eligibility criteria were identical to those for participation in the IDU focus group (Study 1).

Procedures. Appendix F provides the information and consent materials provided to eligible cross-sectional study participants. At the time of enrolment in the Social Dynamics study, a research assistant advised participants verbally and in writing of the rapport-utilization component of the project. All participants were also asked whether they gave permission to disclose their Alberta Health Care Unique Identifier (UI) in order to review participants' patterns of health service utilization during the previous year. Those individuals who did not remember or did not have documentation of their UI at the time of baseline data collection were given the opportunity to submit their UI to a research assistant at a later date, up to one month following the baseline interview. The research team did not contact other sources for this information. Baseline demographic, behavioural, interpersonal, and self-reported health status and health care utilization variables were then collected by the research assistant as part of the main ARC protocol; administrative data were obtained thereafter from Capital Health (CH). Remuneration in the form of two transit coupons, assistance with child care arrangements as needed, and $20 was given to all participants at the baseline collection session.

In order to prevent any undue influence on study participation or care-seeking behaviour as a result of the primary researcher's clinical role in the inner city, participants were assigned a numerical identifier, and names and UIs were kept separate from other collected data. However, at the baseline collection session, consent was sought from participants to contact them again for a follow-up qualitative interview; prior to agreeing to such contact, they were asked whether they had had clinical contact with the primary researcher and excluded from the follow-up qualitative study if such clinical contact had occurred. Those participants who agreed to contact for a follow-up interview, and who had not encountered the primary researcher clinically, were informed that the researcher would then have access to health care utilization data; even at this stage, the researcher did not have access to UIs or information on specific health care providers used by participants.

Data entry was performed by a research assistant; data on 10% of participants were selected at random and data entry verified for these participants by a second researcher.

Assessment of Risk Contexts interview. Baseline self-report measures of interest in this study were embedded within the ARC interview protocol developed for the aforementioned Social Dynamics of IDU study. The ARC protocol is comprised of three distinct sections and requires approximately 90 minutes to complete. Section 1 (About You) contains 56 self-report items assessing demographics, access to food, clean water, drugs, and clean needles, drug use, and health care and perceived health status. Embedded in the health care portion of Section 1 of the ARC interview is a validated 6-item questionnaire assessing perceived autonomy support by health care providers, the Health Care Climate Questionnaire (HCCQ, Williams, Freedman, & Deci, 1998). After completing this section, participants completed the Blood-borne Virus Transmission Risk Assessment Questionnaire (BBV-TRAQ, see Appendix G; Fry & Lintzeris, 2003), a 34-item standardized measure of injecting, sexual, and skin penetration practices that exhibits good reliability and validity (Cronbach's α = .87, test-retest correlation = .84 in Fry & Lintzeris sample). Section 2 of the ARC interview (Your beliefs) consists of 29 items assessing participants' beliefs about personal responsibilities in relation to IDU, as well as their perceptions of community rules and obligations with respect to drug use. Section 3 (Who you hang out with) consists of 2 parts. In Section 3.1, participants were asked to rate themselves in relation to other Edmonton IDUs and/or partners who they inject with on 10 dimensions of social comparison. In Section 3.2, participants were initially asked to identify *nominated network members*, i.e., individuals with whom they have used alcohol or illicit drugs with during the preceding 30 day period (these procedures were modified from Friedman, Curtis, Neaigus, Jose, & Des Jarlais, 1999). Each of these network members were identified by initials using a contact chart. Next, for each nominated network member, participants were asked a series of 18 questions designed to assess sex, relationship, age, gender, duration of relationship, frequency of contact over 30 days, drug supply, whether the nominee is an injector and for how long, whether they injected together, what drugs they use and inject together, shared fixing habits and social support measures.

Demographics. The following baseline demographic variables were obtained through the ARC structured interview: (1) age, (2) gender, (3) ethnicity, (4) education, (5) marital status, (6) parental status, (7) legal status, (8) housing stability, (9) income, and (10) employment status.

IDU and drug-related behaviours. High risk IDU behaviours may potentially be negatively correlated with both disclosure of health information to a health care provider (important in the development of rapport) as well as protective behaviours such as health care-seeking. As part of the Social Dynamics study, information was also collected on participants' injecting practices and other behaviour, including: (1) ease of access to drugs, (2) duration of use, (3) cessation attempts, (4) income source for drug acquisition, (5) drug-related expenses, (6) substances used, (7) overdose risk, (8) experience of withdrawal, and (9) the BBV-TRAQ.

Health status and health service utilization. Variables specific to health and health care were also collected through the ARC interview, including (1) addiction treatment history, (2) self-reported physical health status, (3) self-reported mental health status, (4) ability to identify a regular physician, (5) regular physician knowledge of drug use, (6) self-reported number of visits to regular and other physicians, (7) preferred point of health care access, (8) satisfaction with care, (9) perceived HCV risk, and (10) perceived HIV risk.

Rapport. The Health Care Climate Questionnaire (HCCQ) was used to assess patient-provider rapport. Derived from Self-Determination Theory, the short form of the HCCQ is a validated 6-item questionnaire assessing perceived autonomy support by physicians (e.g. "I feel that my doctor has provided me choices and options" and "My doctor listens to how I would like to do things"; University of Rochester, 2006; Deci, Eghrari, Patrick, & Leone, 1994; Williams, Freedman, & Deci, 1998). Participants were asked to answer the HCCQ according to their experience with their most commonly accessed physician; where no such physician was identified, participants were asked to answer the HCCQ according to their experience with physicians in general. Physicians were chosen as the object of the HCCQ questions to facilitate comparison to follow-up administrative data, which captures physician access comprehensively; nursing service utilization is less well documented. In the present sample internal consistency for the 6 item scale was excellent ($\alpha = .93$).

Secondary (service utilization) measures. All health care utilization measures were based on data for the period of November 2005 to November 2006 inclusive. Owing to sample size constraints, the a priori decision to approach Alberta Health and Wellness for more comprehensive data was abandoned in favour of more accessible Capital Health administrative data. As such, Alberta Health and Wellness statistics on the number of physician encounters and the number of physicians used were not available. However, Capital Health was able to supply the following information on each UI submitted: (1) Most responsible diagnosis, (2) Public health diagnosis, (3) Emergency department (ED) visits, (4) ED triage score[3], (5) ED visit date and time, (6) Length of ED stay, (7) Mode of transportation to ED, (8) Disposition (including instances of Left Without Being Seen (LWOBS) and Left Against Medical Advice (LAMA)), (9) Inpatient admissions, (10) Inpatient case mix group (CMG)[4], (11) Inpatient complexity[5], and (12) Actual and expected length of inpatient stays[6]. Aggregate CH data on the mode of transportation, disposition, and diagnosis for a comparable population not limited to people who inject drugs (i.e. the Boyle McCauley neighbourhood) were also provided to compare sample findings to that of the general population.

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[3] Triage codes are assigned by a registered nurse upon patient presentation to the ED in order to determine the relative urgency with which the patient should be assessed by a physician. The Canadian Emergency Department Triage and Acuity Scale (CTAS) ranges from 1 (resuscitation acuity requiring immediate attention) to 5 (non-urgent acuity requiring assessment in no more than 2 hours), and has been implemented in EDs across Canada (Manos et al, 2002).

[4] Case Mix Grouping was developed by the Canadian Institute for Health Information (CIHI) and classifies patients into similar clinical and resource usage groups according to diagnosis and procedure codes (CIHI, 2007).

[5] Complexity is an extension of Case Mix Grouping which takes into account the presence of other chronic conditions which may influence care (CIHI, 2007).

[6] Expected length of stay is calculated using national data for a typical case in each case mix group, complexity level, and age category. Typical cases are those in which treatment is completed successfully within a predetermined reasonable amount of time (CIHI, 2007). CH also provided typical / atypical status for each admission.

Analyses. The Intercooled Stata 9 statistical package was used to perform all data analyses. Initially, univariate descriptive statistics were examined for all quantitative measures (i.e., ARC items, BBV-TRAQ items, health status and utilization items). Distributions were checked to determine skew, kurtosis and outliers. Next, to determine which participants had the opportunity to establish rapport, bivariate analysis was conducted using the student-t test (for continuous measures) and chi-square measures of association (for categorical measures) to examine the association between each measure and the existence of an identifiable regular physician.

For those participants with an identifiable regular physician, correlations were calculated to determine the bivariate-level association between rapport (i.e. HCCQ) and three primary service utilization outcomes, namely: (1) disclosure of drug use to regular physician, (2) ED visits, and (3) satisfaction with care. Secondary correlations were also calculated for other available service utilization outcomes.

For all statistically significant rapport-utilization correlation coefficients, a hierarchical regression approach was used to predict each service utilization outcome. Specifically, Step 1 of the analysis predicted the outcome from demographic covariates (age, sex, living arrangements, education, income derived from the appropriate ARC interview items). Step 2 of the analysis added IDU-related risk behaviours (e.g. risky needle use, derived from the BBV-TRAQ items). Finally, Step 3 added perceived autonomy support (derived from the HCCQ items). This procedure determined whether rapport measures added to the prediction of service utilization, after taking into account demographic covariates and baseline IDU risk behaviours.

Results

A total of 91 individuals consented to participation within the study period, and of those, 42 individuals provided consent and their Alberta Health Care Unique Identifier (UI) to allow researchers to assess their administrative health records.

Who has the opportunity to establish rapport? Focus group findings suggested that the nature of rapport development differs according to the location and continuity of the relationship, with longer term doctor-patient relationships lending themselves better to rapport-building efforts. For this reason it is suspected that respondents with a regular family physician assigned values to the HCCQ differently than those respondents without a regular physician. Participants' sociodemographic, injection behaviour, and health status responses were therefore examined for their association with being able to identify a regular physician prior to examining any further rapport-related associations.

Sociodemographic characteristics (Table 1). Study participants averaged 40 years of age and were predominantly male (74%). Most respondents described their ethnicity as Caucasian (44%) or First Nations (33%). Most were single (70%) and had obtained less than a high school education (48%). Though most individuals had children (67%), few had custody of their children (13%). Self-reported housing stability was generally poor or very poor (69%) and most participants were unemployed (78%). A significant number of respondents were under some form of judicial restraint (46%). The majority of respondents reported a monthly income of less than $2000 and total assets of less than $100. Of these characteristics, mean age and legal status varied significantly according to physician status; individuals identifying a regular physician were older (41 vs. 36, $t_{87}=2.45$, $p<.05$) and less likely to be under judicial restraint (39% vs. 65%, $\chi^2(1)=4.61$, $p<.05$). Other sociodemographic characteristics did not vary according to physician status.

IDU characteristics (Table 2). Mean age and duration of IDU were 22 and 17 years respectively. In keeping with the cyclical nature of addiction, participants had attempted and succeeded in long-term injection cessation an average of 3.5 times. They reported generally easy access to drugs (71%) and $1370 in average monthly drug expenses. Multiple drug sources and polysubstance use were also evident. Within the past month, most respondents had used "beyond their normal limit" (80%), but fewer had experienced significant withdrawal (30%). Mean total BBV-TRAQ score was 35 out of a possible 215; this study's score distribution is similar to that of other IDU samples (positively skewed, with 35 corresponding to the third quartile in the original sample; Fry & Lintzeris, 2003). Those participants identifying a regular physician had been involved in IDU longer (19 vs. 13 years, $t_{87}=2.31$, $p<.05$), had attempted cessation more often (4 vs. 2 injection-free periods, $t_{81}=2.50$,

Table 1

Sociodemographic Characteristics of Sample, by Physician Status.

Variable	Total Sample (n=89)	Regular Physician (n = 66)	No Regular Physician (n = 23)	Statistical test
Age (M, SD)[1]	40.1 (8.5)	41.4 (8.3)	36.4 (8.6)	t=2.45*
Sex				χ^2=1.22
Female	23 (25.8%)	19 (28.8%)	4 (17.4%)	
Male	66 (74.2%)	47 (71.2%)	19 (82.6%)	
Ethnicity				χ^2=0.70
Caucasian	39 (43.8%)	28 (42.4%)	11 (47.8%)	
First Nations	29 (32.6%)	21 (31.8%)	8 (34.8%)	
Metis	16 (18.0%)	13 (19.7%)	3 (13.0%)	
Other	5 (5.6%)	4 (6.1%)	1 (4.4%)	
Education				χ^2=0.26
Less than high school	42 (47.7%)	30 (46.2%)	12 (52.1%)	
High school	16 (18.1%)	12 (18.5%)	4 (17.4%)	
Any post-secondary	30 (34.1%)	23 (35.4%)	7 (30.4%)	
Marital Status				χ^2=0.17
Single	62 (69.7%)	46 (69.7%)	16 (69.8%)	
Married / Common-law	21 (23.6%)	15 (22.7%)	6 (26.0%)	
Same sex couple	1 (1.1%)	1 (1.5%)	0 (0.0%)	
Other	5 (5.6%)	4 (6.0%)	1 (4.35%)	
Parental Status				χ^2=0.61
No children	29 (32.6%)	23 (34.9%)	6 (26.1%)	
Children	60 (67.4%)	43 (65.2%)	17 (73.9%)	
Custody of Children				χ^2=0.75
Custody	7 (12.5%)	4 (10.0%)	3 (18.8%)	
No custody	49 (87.5%)	36 (90.0%)	13 (81.3%)	
Legal Status				χ^2=4.61*
Judicial restraint	41 (46.1%)	26 (39.4%)	15 (65.2%)	
No judicial restraint	48 (53.9%)	40 (60.6%)	8 (34.8%)	
Housing Stability				χ^2=3.07
Stable	28 (31.5%)	24(36.4%)	4 (17.4%)	
Not stable	61 (68.5%)	42 (63.6%)	19 (82.6%)	
Monthly Income				χ^2=3.54
$0-$500	9 (10.1%)	8 (12.1%)	1 (4.4%)	
$500-$1000	28 (31.5%)	23 (34.9%)	5 (21.7%)	
$1000-$2000	32 (36.0%)	21 (31.8%)	11 (47.8%)	
$2000+	20 (22.5%)	14 (21.2%)	6 (26.1%)	
Personal Assets				χ^2=0.29
$0-$100	49 (55.7%)	37 (56.9%)	12 (52.2%)	
$100-$500	16 (18.1%)	12 (18.5%)	4 (17.4%)	
$500+	23 (26.1%)	16 (24.6%)	7 (30.5%)	
Employment Status				χ^2=2.53
Legally employed	20 (22.5%)	12 (18.2%)	8 (34.8%)	
Unemployed	69 (77.5%)	54 (81.8%)	15 (65.2%)	

*p<0.05.

[1]M=mean, SD=standard deviation.

Table 2

IDU Characteristics of Sample, by Physician Status.

Variable	Total Sample (n=89)	Regular Physician (n = 66)	No Regular Physician (n = 23)	Statistical test
Age of first IDU (M, SD)	22.7 (7.2)	22.5 (6.8)	23.0 (8.4)	t=0.30
Duration of use (M, SD)	17.4 (10.1)	18.8 (10.5)	13.3 (7.6)	t=2.31*
Quit Attempts (M, SD)[1]	3.5 (3.9)	4.1 (4.3)	1.7 (1.7)	t=2.50*
Access to Drugs				χ^2=0.15
Not easy	26 (29.2%)	20 (30.3%)	6 (26.1%)	
Easy	63 (70.8%)	46 (69.7%)	17 (73.9%)	
Drug Expenses (M, SD)	$1370 (1652)	$1037 (1308)	$2312 (2137)	t=3.37**
Drug Acquisition				
Prescription	38 (42.7%)	31 (47.0%)	7 (30.4%)	χ^2=1.95
Drug exchange[2]	59 (66.3%)	40 (60.6%)	19 (82.6%)	χ^2=4.00*
Sex work	13 (14.6%)	10 (15.2%)	3 (13.0%)	χ^2=0.06
Criminal activity[3]	54 (60.7%)	35 (53.0%)	19 (82.6%)	χ^2=6.79**
Other[4]	86 (96.6%)	63 (95.5%)	23 (100.0%)	χ^2=0.00
Drugs used in past month				
Opiates	80 (89.9%)	60 (90.9%)	20 (87.0%)	χ^2=0.28
Stimulants[5]	79 (88.8%)	58 (87.9%)	21 (91.3%)	χ^2=0.21
Use "beyond normal limit"[6]				χ^2=0.76
Not frequently	69 (80.2%)	52 (82.5%)	17 (73.9%)	
Frequently	17 (19.8%)	11 (17.5%)	6 (26.1%)	
Withdrawal				χ^2=6.82**
Not frequently	60 (69.8%)	49 (77.8%)	11 (47.8%)	
Frequently	26 (30.2%)	14 (22.2%)	12 (52.2%)	
BBV-TRAQ (M, SD)[7]				
Injection practices	28.6 (29.8)	28.9 (29.1)	27.4 (32.4)	t=0.20
Sex practices	4.7 (8.0)	4.6 (7.8)	4.9 (8.7)	t=0.14
Other risk practices	2.2 (6.4)	1.5 (2.3)	4.1 (12.1)	t=1.63
Total	35.4 (37.7)	35.1 (34.1)	36.5 (47.8)	t=0.14

*p<0.05.
**p<0.01.

[1] Defined as number of periods where injection ceased for >6 months.

[2] Denotes trade of other drug, pills, or alcohol for drug of choice.

[3] Denotes drug dealing and theft.

[4] Includes sharing, bartering, contributing to group purchase, and nonspecific favours.

[5] Denotes cocaine or methamphetamine use.

[6] Frequency defined as occasional, frequent, or consistent injection beyond respondent's perceived personal dosage limit over the past year.

[7] The Blood-borne Virus Transmission Risk Assessment Questionnaire measures risk practices under the three domains of drug injection, sexual activity, and other skin penetration (e.g. tattooing, shaving, assault).

$p<.05$), spent less on drug acquisition (\$1037 vs. \$2312, $t_{86}=3.37$, $p<.01$), relied less heavily on peer-to-peer drug exchange (61% vs. 83%, $\chi^2(1)=4.00$, $p<.05$) or criminal activity (i.e. drug dealing or theft, 53% vs. 83%, $\chi^2(1)=6.79$, $p<.01$), and were less likely to have experienced withdrawal (22% vs. 53%, $\chi^2(1)=6.82$, $p<.01$).

Self-reported health and health care (Table 3). The study sample averaged fair to good physical and mental health (3.6 and 3.4 respectively on a 5-point scale). Mean perception of HIV risk was neutral (3.0 on a 6-point scale), with 20% of participants reporting HIV-positive status. In contrast, mean perception of hepatitis C risk was "very likely" (4.9 on a 6-point scale), with 73% of the sample reporting hepatitis C-positive status. The majority of respondents had received formal addiction treatment in the past (87%). Most individuals listed family physicians as their preferred point of health care (58%); however, this was the preference only among those with a regular physician (71% vs. 22%, $p=.0001$). Individuals without a regular physician preferred to see a nurse (26% vs. 5%, $p<.01$) or another community physician (32% vs. 10%, $p<.05$). Other self-reported health and health care parameters did not differ according to physician status.

Given the opportunity to establish rapport, what variables predict rapport quality? Prior to conducting a bivariate analysis of rapport and service utilization outcomes for those participants with an identifiable regular physician, univariate descriptive statistics for the HCCQ were examined. The distribution of HCCQ scores was found to be significantly negatively skewed (-0.77) with a median score of 23 and few scores below 10. Given the non-normal distribution, a new dichotomous HCCQ variable was created, with high rapport defined as a score greater than 23 and low rapport defined as a score equal to or less than 23. Correlation coefficients were calculated using both continuous and dichotomous HCCQ variables; because coefficients did not change in statistical significance using either approach, the dichotomous HCCQ variable is presented and log transformation of the continuous HCCQ variable was not undertaken.

Table 3

Self-Reported Health and Health Care, by Physician Status.

Variable	Total Sample (n=89)	Regular Physician (n = 66)	No Physician (n = 23)	Statistical test
Physical Health (M, SD)[1]	3.6 (1.1)	3.5 (1.1)	4.0 (1.0)	t=1.62
Mental Health (M, SD)[1]	3.4 (1.3)	3.4 (1.3)	3.3 (1.4)	t=0.32
Perceived HIV Risk (M, SD)[2]	3.0 (1.7)	3.2 (1.8)	2.4 (1.5)	t=1.79
Known HIV positive	17 (19.5%)	15 (23.4%)	2 (8.7%)	$\chi^2=2.66$
Perceived HCV Risk (M, SD)[2]	4.9 (0.2)	5.1 (1.8)	4.4 (2.1)	t=1.55
Known HCV positive	65 (73.0%)	51 (77.3%)	14 (60.9%)	$\chi^2=2.22$
Addiction Treatment				$\chi^2=2.21$
Past formal treatment	77 (86.5%)	59 (89.4%)	18 (78.3%)	
No past formal treatment	11 (12.34%)	6 (9.1%)	5 (21.7%)	
Preferred Point of Care				
Family physician	52 (58.4%)	47 (71.2%)	5 (21.7%)	p=0.0001*
Nurse	9 (10.2%)	3 (4.6%)	6 (26.1%)	p<0.01*
Peer	6 (6.7%)	4 (6.1%)	2 (8.7%)	p=0.65
Hospital physician	5 (5.6%)	3 (4.6%)	2 (8.7%)	p=0.60
Other physician	13 (15.3%)	6 (9.5%)	7 (31.8%)	p<0.05*

*Fischer's exact test used to calculate p values.

1Measured using 5 point scale, where 1=excellent and 5=poor.

2Measured using 6 point scale, where 1=very unlikely, 5=very likely, and 6=known positive. Statistical significance was not achieved by eliminating respondents with known positive viral status.

Table 4

Intercorrelations[1] among measures of rapport, health, and health care utilization: Self-report data and visits to ED.

Measure	1	2	3	4	5	6	7	8
1. Autonomy supportiveness[2]	--							
2. Drug use disclosure	0.20	--						
3. Physical health	0.11	0.20	--					
4. Mental health	0.10	-0.01	0.52**	--				
5. Visits to regular physician	0.14	0.03	-0.15	0.09	--			
6. Other physicians consulted	0.13	-0.23	-0.32*	-0.20	-0.02	--		
7. Satisfaction with care	0.58**	0.14	-0.00	-0.03	0.17	0.07	--	
8. Presentation to ED[3]	0.04	-0.36*	-0.13	-0.17	0.23	0.10	0.01	--

* $p < .05$, ** $p < .0001$

[1] Pearson correlation coefficients presented where both variables are continuous; point biserial correlation coefficients presented where one variable is dichotomous.

[2] Measured using Health Care Climate Questionnaire (HCCQ), used in this study as primary rapport measure. HCCQ score distribution was negatively skewed for the study sample. HCCQ scores were therefore dichotomized, with a high score being greater than the median of 23, and a low score being 23 or lower. Because continuous and dichotomous HCCQ correlations with other items did not change in significance, the dichotomous HCCQ coefficients are presented here and were used in further regression analysis.

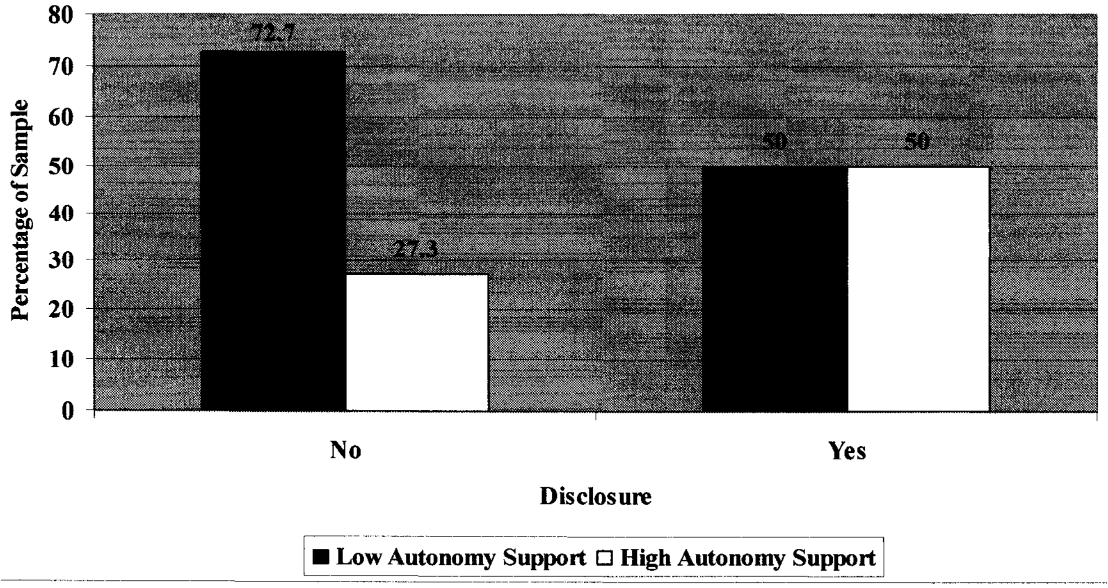
[3] Defined as any vs. no visits to ED. Statistical significance was not achieved using other cutoffs (e.g. >1 vs. ≤1 visit) or total number of visits.

Self-report data and presentation to ED (Table 4). Rapport-utilization correlation coefficients were calculated using the HCCQ as the primary independent variable and patient satisfaction with care, disclosure of drug use, and any vs. no visits to the ED as the primary dependent variables. High HCCQ score were strongly positively correlated with patient satisfaction with health care ($r=0.58$, $p<.0001$), but was not significantly correlated with either disclosure of drug use or ED presentation. Other dependent variables were also examined (perceived physical health, perceived mental health, reported number of visits to regular physician, reported number of other physicians consulted) but were also not found to be significantly correlated with rapport.

However, disclosure of drug use was negatively correlated with ED presentation ($rho=-0.36$, $p<.05$). Correlational analyses were supplemented with an examination of the bivariate relationships between the two measures of rapport (dichotomized HCCQ scores and whether or not respondents disclosed the extent of their drug use to their physician) using Chi-square tests of association. As shown in Figure 2, there was a marginal association between perceived autonomy supportiveness of the health provider and drug disclosure, such that those participants with high perceived autonomy supportiveness with a primary care provider were more likely to have disclosed their drug use to that individual (50% vs 27.3%, $\chi^2(1)=3.06$, $p<.08$). Finally, as shown in Figure 3, disclosure of drug use remained significantly negatively associated with ED presentation, such that non-disclosers attended the ED more often (92.9% vs 7.1%, $\chi^2(1)=4.86$, $p<.03$).

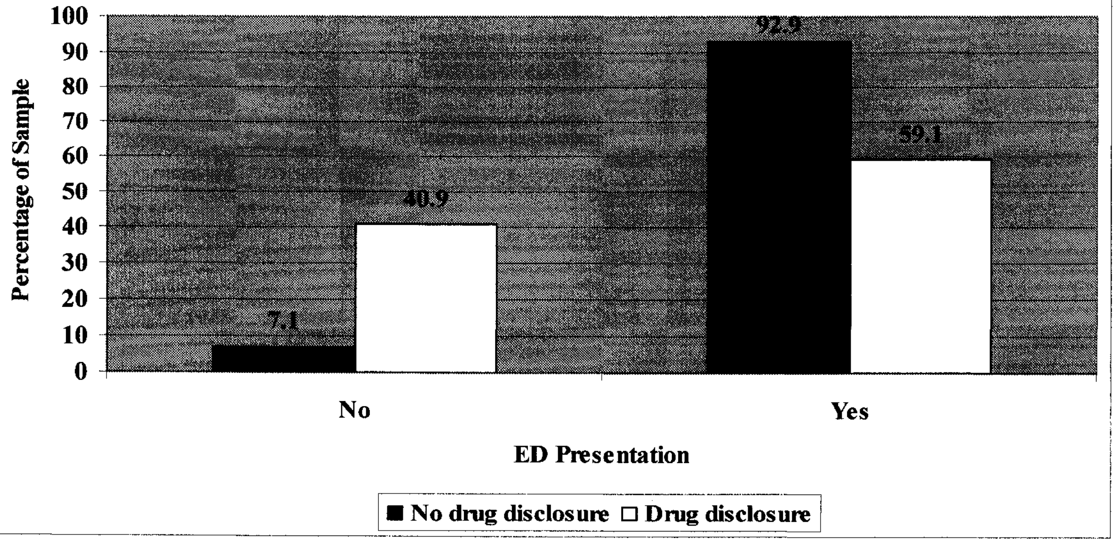
To determine whether the bivariate findings were robust after taking into account the impact of sociodemographic and drug use covariates, multivariate analysis of the relationship between high perceived autonomy supportiveness and patient satisfaction with care was carried out using a hierarchical linear regression approach (Table 5). Neither demographic (step 1) nor IDU behaviour (step 2) covariates significantly predicted patient satisfaction with care. After taking these covariates into account, autonomy supportiveness retained the ability to significantly predict patient satisfaction with health care ($\Delta F_{1,24}=25.4$, $p<.01$).

Figure 2. Drug Disclosure in Relation to Autonomy Supportiveness



$\chi^2(1)=3.06, p<.08$

Figure 3. ED Presentation in Relation to Drug Disclosure



$\chi^2(1)=4.86, p<.03$

Table 5

Predicting Residual Changes in Patient Satisfaction due to Rapport.

Set	Predictors entered	ΔF	B (95% CI)
1	Demographic covariates	0.74	
	Age		-0.001 (-0.043,0.040)
	Gender		0.753 (-0.127,1.632)
	Ethnicity		-0.119 (-0.492,0.254)
	Education		-0.059 (-0.461,0.343)
	Marital status		-0.007 (-0.289,0.267)
	Parental status		-0.263 (-1.026,0.500)
	Legal status		-0.411 (-1.110,0.289)
	Housing stability		0.159 (-0.561,0.879)
	Income		0.273 (-0.117,0.664)
	Assets		-0.128 (-0.559,0.303)
	Employment status		-0.588 (-1.021,6.972)
2	Injection covariates	1.1	
	Duration of IDU		-0.038 (-0.122,0.045)
	Quit attempts		-0.044 (-0.179,0.091)
	Drug expenditures		-0.000 (-0.000,0.000)
	Drug access		0.019 (-1.130,1.168)
	Use "beyond normal"		0.882 (-0.421,2.185)
	Withdrawal		1.256 (-0.087,2.600)
	Drug acquisition		
	Prescription		-0.489 (-1.660,0.683)
	Drug exchange		-0.613 (-1.666,0.441)
	Sex work		-0.050 (-1.552,1.452)
	Criminal activity		-0.059 (-1.147,1.029)
	Other		0.266 (-2.204,2.735)
	Drugs used		
	Opiates		1.195 (-2.060,4.451)
	Stimulants		0.161 (-1.477,1.798)
	BBV-TRAQ		
	Injection items		0.038 (-0.067,0.142)
	Other items		-0.014 (-0.241,0.213)
	Total		-0.042 (-0.128,0.044)
3	Main effects	25.4*	
	Rapport (HCCQ)		1.856 (1.084,2.628)

*p < .01.

Multivariate analysis of the relationship between disclosure of drug use and ED presentation was attempted. The first two regression steps, i.e. demographic followed by IDU behaviour covariates, did not significantly predict ED presentation. Unfortunately, a partial likelihood ratio test could not be calculated for step 3, i.e. addition of the disclosure variable, because nondisclosure correlates perfectly with ED presentation. However, disclosure of drug use is assumed to retain the ability to significantly predict ED presentation after taking covariates into account, given that these covariates do not predict the outcome.

Given the negative correlation between disclosure of drug use and ED presentation, the possibility that disclosure of drug use might complement perceived autonomy supportiveness in defining rapport in the IDU context was considered. Rapport-utilization correlation coefficients were therefore also calculated using disclosure of drug use as the independent variable instead of HCCQ score. Disclosure of drug use status did not correlate with any other self-reported or administrative health care outcomes.

Administrative data. Secondary bivariate analysis was carried out on CH administrative data to examine the relationship between rapport and available utilization variables. In this case the unit of analysis was the encounter as opposed to the participant, because several participants had presented to CH facilities on multiple occasions; a total of 100 ED encounters and 10 admissions were recorded over a one-year period for the 42 participants who provided UIs. Of these 42 participants, the majority identified a regular physician regardless of their ED utilization pattern (86% of ED attenders had a regular physician, vs. 77% of non-attenders, $p>.05$). Data for the sample were similar to those for a comparable Edmonton population not restricted to people who inject drugs, i.e. the Boyle McCauley neighbourhood (Table 6). Specifically, the sample did not significantly differ from the Boyle McCauley neighbourhood with respect to frequency of EMS transportation, public health diagnoses, or disposition patterns.

For ED encounters (Table 7), high HCCQ score was marginally negatively correlated with EMS transportation (rho=-0.21, $p=.056$) and significantly negatively correlated with night shift presentation (rho=-0.23, $p<.05$). HCCQ scores were not

Table 6

Health Service Utilization for IDU Sample, Compared to General Population.

Variable	IDU Sample	Boyle-McCauley neighbourhood	p
EMS transportation	28.6%	32.6%	ns
Diagnosis			
Injury	24.5%	22.4%	ns
Toxic ingestion	3.1%	2.6%	ns
Respiratory	16.3%	8.7%	ns
Dermatological	10.2%	5.1%	ns
Musculoskeletal	5.1%	5.5%	ns
Mental health	5.1%	9.1%	ns
Pain	16.3%	15.9%	ns
Disposition			
Discharged	70.4%	71.1%	ns
Left Against Medical Advice	15.3%	14.9%	ns
Admitted	8.2%	12.0%	ns

Table 7

Intercorrelations[1] among measures of rapport and health care utilization: ED encounter data.

Measure	1	2	3	4	5	6	7	8
1. Autonomy supportiveness[2]	--							
2. Triage assignment[3]	-0.02	--						
3. Length of stay[4]	-0.02	-0.35	--					
4. EMS transportation	-0.21*	-0.42***	0.43***	--				
5. Disposition[5]	-0.02	-0.28***	0.43***	0.28**	--			
6. Night shift presentation[6]	-0.23**	-0.06	0.17	0.27**	0.17	--		
7. Injury diagnosis	-0.19	0.15	0.00	0.01	-0.03	0.21	--	
8. Respiratory diagnosis	0.16	-0.27**	0.34***	0.14	0.25**	-0.15	-0.27	--

* .04 < p < .06, ** p < .05, ***p < 0.01

[1] Pearson correlation coefficients presented where both variables are continuous; point biserial correlation coefficients presented where one variable is dichotomous. Also, correlation coefficients calculated on a per-encounter basis given multiple ED presentations by several participants.

[2] HCCQ score distribution was negatively skewed for the study sample. HCCQ scores were therefore dichotomized, with a high score being greater than the median of 23, and a low score being 23 or lower. Because continuous and dichotomous HCCQ correlations with other items did not change in significance, the dichotomous HCCQ coefficients are presented here and were used in further regression analysis.

[3] Denotes Canadian Emergency Department Triage and Acuity Scale (CTAS) score out of 5.

[4] Defined as time in minutes from first assessment / registration to disposition.

[5] Denotes direction of patient discharge from ED, and includes Discharge, Left Against Medical Advice, Left Without Being Seen, Admission, and Transfer categories.

[6] Day shift 0700h-1500h; evening shift 1500h-2300h; night shift 2300h-0700h.

Table 8

Intercorrelations[1] among measures of rapport and health care utilization: Admission data.

Measure	1	2	3	4	5	6
1. Autonomy supportiveness[2]	--					
2. Complexity[3]	-0.14	--				
3. Actual length of stay[4]	-0.27	-0.08	--			
4. Typical / atypical status[3]	-0.53	0.08	-0.41	--		
5. Expected length of stay[3]	0.09	0.47	0.58	-0.14	--	
6. Disposition[4]	0.41	0.08	0.26	0.76*	0.26	--

* p < .05.

[1] Pearson correlation coefficients presented where both variables are continuous; point biserial correlation coefficients presented where one variable is dichotomous. Also, correlation coefficients calculated on a per-encounter basis given multiple admissions for some participants.

[2] HCCQ score distribution was negatively skewed for the study sample. HCCQ scores were therefore dichotomized, with a high score being greater than the median of 23, and a low score being 23 or lower. Because continuous and dichotomous HCCQ correlations with other items did not change in significance, the dichotomous HCCQ coefficients are presented here and were used in further regression analysis.

[3] Derived from Canadian Institute for Health Information Case Mix Grouping methodology.

[4] Defined as time in days from admission to disposition.

correlated with triage assignment, length of stay, or disposition. Exploratory data analysis visually suggested associations between high rapport and the two most common diagnostic categories (decrease in injury diagnosis and increase in respiratory diagnosis); however, high HCCQ score was not found to be significantly correlated with either diagnostic category.

For the few admissions recorded (Table 8), rapport was not significantly correlated with case complexity, actual or expected length of stay, assignment of atypical case status, or disposition.

Multivariate analyses of the relationships between HCCQ score and EMS transportation and between HCCQ score and night shift presentation were carried out using a hierarchical logistic regression approach. After taking demographic and IDU behaviour covariates into account, autonomy supportiveness did not significantly predict EMS transportation or night shift presentation.

Study Limitations

The sample described constitutes a small, non-random, convenience sample with connections to local harm reduction and health agencies or peers who use these services. As such, it may not be representative of other Edmontonians who inject drugs or other IDU populations. Health and health care utilization differences due to rapport may be more pronounced with the most marginalized and least poorly connected IDUs. Recruitment was constrained by the limits of the study period, and the resulting small sample size was underpowered to predict rapport-utilization associations such as disclosure of drug use. The study protocol also limited access to UIs and administrative data, in that, though most participants were willing to consent to UI release, few had valid UIs readily available at the time of the interview or returned to provide this number within the time frame allowed. The study was therefore underpowered to predict any differences in ED presentation or other administrative outcomes due to rapport. Nonetheless, this study was intended as exploratory research and provides pilot data for further work with larger samples. In addition, chain-referral is a well-established sampling approach for hidden populations.

Participant responses may have been affected by the structure and length of the interview. It is possible that individuals did not consider each interview item in equally detailed fashion given the number of ARC and BBV-TRAQ items presented, with the potential for inaccurate responses. The HCCQ itself was structured such that respondents with a regular physician answered based on their experience with that physician, whereas respondents without a regular physician answered based on their overall physician. Those with and without physicians can therefore not be easily compared with respect to rapport development because the nature of rapport relies at least partly on continuity of provider. In addition, the six HCCQ items and the item addressing patient satisfaction with care were grouped in the same stem; it is possible that this presentation contributed to their association since respondents may not have differentiated between autonomy supportiveness and patient satisfaction. For these reasons, differences in rapport by physician status and the relationship between rapport and satisfaction have been explored in greater detail in follow-up qualitative interviews.

There are limitations to administrative data apart from sample size constraints. These data rely heavily on physician contact and facility usage; measurement of rapport influences on patient encounters with other health care team members—nursing, reception, EMS, and security personnel—is difficult. Because rapport could potentially influence wait times, an attempt was made to obtain ED wait time data, but wait times were not available for pre-April 2006 encounters. Capital Health data also do not include information on visits with physicians external to their facilities. A chart review process or data requests to Alberta Health and Wellness might have captured some of this information but were beyond the scope of this study. Self-report and qualitative data were collected to augment rapport-utilization findings and address some of the sample size and other shortcomings of the administrative data.

As with other studies in this series, the research team included a medical professional. Participants may have duly guarded their responses. To address this potential for response bias, participant names and UIs were withheld from this researcher. Those who agreed to re-contact for a follow-up qualitative interview had their names but not UIs revealed to this researcher, and only if she had not provided any past medical care to the participant.

Summary

For people who inject drugs, having a regular physician is associated with older age, lack of judicial restraint, longer IDU involvement, more attempts at cessation, fewer drug expenditures, less withdrawal, and less reliance on peer-to-peer drug exchange or criminal activity for drug acquisition. For those IDUs with a regular physician, perceived autonomy supportiveness of a physician is strongly associated with satisfaction with care, marginally associated with disclosure of drug use, but not associated with presentation to the ED; however, non-disclosure of drug use is associated with presentation to the ED. Drug use disclosure may therefore be an IDU-specific indicator of rapport. Trends in EMS transportation and night shift presentations suggest that IDU-provider rapport may also be associated with the timing of IDU health care, in that care is accessed not at a last resort or emergency, but rather in the earlier, less severe stages of disease processes.

Chapter 5: IDU Qualitative Interviews (Study 3)

Methods

Overview. A subset of the cross-sectional sample from Study 2 was asked to participate in semi-structured qualitative interviews intended to explore the phenomenon of IDU-provider rapport in various settings in greater detail. Individual interviews were chosen over focus group interviews to preserve participant confidentiality in discussing potentially sensitive interview topics. In addition to deeper exploration of the first two research objectives, i.e. how rapport is developed and how it influences care-seeking and the experience of care, these interviews also explored the third research objective, i.e. to solicit IDU perspectives on the differences between formal health care services and informal, peer-based, non-professional care, and reasons for choosing one over the other.

Sample. In keeping with the non-representative, exploratory objectives of this qualitative study, a convenience sample of eight IDUs was recruited for participation. Interview participants were purposively selected from Study 2 participants who had consented to re-contact and for whom rapport and self-reported health data from the ARC interview and administrative data from Capital Health were available. Efforts were made to recruit participants who differed from each other with respect to rapport, satisfaction with care, identification of a family physician, and ED use in order to assist in the interpretation of data from earlier studies and provide a better understanding of rapport-related themes common to a broad spectrum of IDUs (Kuzel, 1999). IDUs identifying a pre-existing clinical relationship with the primary researcher were excluded from the sample.

Procedures. A $20 stipend, two transit tickets, and refreshments were offered to all interview subjects in order to offset transportation, child care, and other expenses incurred as a result of participation. Consent for follow-up contact to occur was obtained at the time of enrolment in the cross-sectional study. A Streetworks staff member contacted potential interview subjects and coordinated a mutually convenient interview time if an individual remained interested in participating after a brief description of the study. At the time of the scheduled interview, the primary researcher provided a more detailed description of the study and a written letter of information prior to obtaining consent and initiating the interview. Appendix H provides the information and consent materials provided to eligible IDU interview participants. All interviews took place in the main Streetworks office in Edmonton's Boyle Street Community Services.

Interviews were conducted by the primary researcher. Her clinical activities may have prompted some participants to withhold certain information; conversely, this same field experience assisted in the development of interview rapport with participants and informed the subsequent analysis. Because physician status was disclosed in advance, it was understood that interview subjects were comfortable with this arrangement. Past research collaborations with the Streetworks needle exchange program have indicated that researcher field experience facilitates the understanding of local culture and language and the development of trust within study communities (Wild et al., 2003b). In addition, none of the interview subjects had previous clinical encounters with the primary researcher.

<u>Measures.</u> A set of interview questions and related probes (see Appendix I) were used as a general guide for data collection. Findings from Studies 1 and 2 assisted with question development. Specifically, issues such as the locations of care, nurses as health providers, health care negotiation strategies, the central role of drugs, the impact of disclosure of drug use on quality of health service encounters, and the relationship between autonomy support and satisfaction with care were incorporated into the interview questions. The interview guide was then reviewed by Streetworks staff to ensure appropriateness. Because of the potentially sensitive nature of the relationship being examined, interviews began with an open-ended health history, wherein the user provided a narrative of his / her experiences with health care and controlled the disclosure of information. This life history or lifeline approach has previously been successfully applied among Edmonton's inner city IDU community (Wild et al., 2003b). When key health care experiences were related, more in-depth questions were used to further characterize the experience.

Basic demographic, injection, and health information was collected at the beginning of the interview for descriptive purposes; HCCQ scores, levels of satisfaction, and family physician and ER use status were also retrieved from Study 2 datasets for further sample characterization. All interview sessions were audiotaped and transcribed verbatim; field notes were compiled by the interviewer to supplement these transcripts. Two transcripts were selected at random and compared to the audiotape to confirm accuracy. Identifying information was omitted from the transcripts. Interviews lasted approximately one hour.

Within-Transcript Analysis. Interviews were subjected to multiple rounds of analysis, initially on the interview day, then upon receipt of transcripts, and subsequently as data from further sessions became available. Analysis was primarily manual but was augmented by NVivo7 qualitative software. A combination of two inductive analytic techniques, paraphrasing and coding, were used (Wozniak et al., 2007). Paraphrasing, derived from a phenomenological approach to qualitative analysis, involves line-by-line followed by section-based summaries of participant experience, taking care to preserve the unique perspectives and experiences of participants. Paraphrases for each participant were then compared to those of other participants in between-transcript analyses (described below). Coding, a technique used in grounded theory approaches to qualitative analysis, uses paraphrases to identify overarching codes or themes.

Field notes were created on the day of each interview to capture the essence of each session. Once the interview transcript was available, interviews were read from beginning to end twice—once to reacquaint the researcher with the interview content, and again to document initial impressions of thematic material. This second reading generated potential thematic categories on a line-by-line and quote-by-quote basis. A paraphrase capturing the key concept alluded to by the participant was created for each of these raw data excerpts to facilitate subsequent comparison between excerpts. The researcher then grouped together paraphrases which were similar in content and created a higher order paraphrase for each group. Thus, for each participant, a set of paraphrases was created. Finally, paraphrases were compared to transcripts and field notes to ensure that they accurately reflected interview content.

Between-Transcript Analysis. Paraphrases for each participant were compared with those of other participants for content similarity. Those paraphrases with equivalent meaning were rephrased to create a single meaning unit (underlined in this

Figure 4. Examples of within-transcript and between-transcript analysis

Example: Within-transcript Analysis

Excerpt 1: So that's another way to do it and in other words, I get along with him but then I was impatient I was hyper because I need my daily hoot hey. So I get all kind of mad and angry right?

Thematic category: behaviour

Paraphrase 1: Sometimes my addiction makes me angry and impatient.

Excerpt 2: I just get mad and angry because I wasn't getting what I wanted like now it don't work that way, I realize so.

Thematic category: behaviour

Paraphrase 2: When I'm actively using I get angry even though it doesn't help me get what I want.

Excerpt 3: Then the junkie's going to get really pissed off and all angry 'cause you cut him off now you cut off his other resources for his other dope.

Thematic category: behaviour

Paraphrase 3: An addict will get angry when he's cut off.

Summary Paraphrase for Participant A: My addiction can make me angry.

Example: Between-transcript Analysis

Paraphrase from Participant A: My addiction can make me angry.

Paraphrase from Participant B: I get angry when I'm dopesick.

Paraphrase from Participant C: Belligerence is a side effect of addiction.

Meaning Unit: Belligerence is a side effect of addiction.

document). A definition and sample quotes were prepared to describe each meaning unit in detail. Those meaning units which were shared by more than one participant were retained and grouped into thematic domains relevant to patient-provider rapport (**bold** in this document, with major subthemes ***bold and italicized***).

The aforementioned analysis was subjected to multiple tests of validity. Copies of data analysis and interpretation were given to another researcher for review; the same researcher also reviewed and coded two transcripts to ensure interrater agreement. Clarifying questions during each interview, as well as thematic probes in subsequent interviews, were used to explore early thematic impressions. New interview sessions continued until thematic saturation occurred, i.e. until little new thematic material was manifested in the latest interviews (Kuzel, 1999). An experienced Streetworks outreach worker also reviewed shared meaning units to ensure consistency with her observations of the local IDU community's experience.

Results

A total of eight interviews took place between October 2 and November 13, 2007. All but one participant were male as it proved very difficult to locate females who had agreed to re-contact. Participants ranged from 29 to 54 years in age and from one to 40 years of IDU experience. Most had completed high school. Cocaine and opiates were equally preferred. Most reported fair health status, and most had and preferred seeing a family physician for their care, though a couple of participants cited peers as their preferred point of care. With respect to participant characteristics gleaned from Study 2 data, there was limited ED use in general. Levels of perceived autonomy support were usually positively associated with levels of service satisfaction, though two participants reported high satisfaction despite low perceived autonomy support. Participants related their experience of patient-provider rapport in four thematic areas: (1) Determinants of rapport, (2) Negotiation strategies, (3) Outcomes of Rapport, and (4) Alternative Points of Care.

Determinants of Rapport. Interview participants confirmed many of the themes which surfaced during the earlier focus group sessions about the pre-existing patient and provider variables, the external context, and the encounter-based variables which contributed to IDU-provider rapport.

Patient variables. Participants once again stressed the importance of health care providers acknowledging that addiction and its causes and consequences are a complex illness. They also noted that addicts tended to behave in ways that shaped the provider's expectations of an encounter.

Addiction is a chronic disease. Participants emphasized that addiction is a long-term illness not easily amenable to cure and often well out of the addict's control. Improvement in addiction is possible but neither guaranteed nor permanent.

> And I'm not into it right, I've taken a whole bunch of courses in my life right, I am an addict right and that's the bottom line right, you guys aren't going to cure me right, I'm going to be like this the rest of my life right, believe it or not right. (7,505)[7]

Street life is stressful. Injection drug use and street involvement often go hand in hand. Street-involved patients are often worn down by the stresses of transient housing, food, transportation, and income by the time they make it to the health care system.

> Oh you gotta be man. Or you just get wore out you know. And myself I haven't eaten like I said, I haven't eaten for 3 days I'm just wore out tired depressed. You go to work, you go to work and you work your ass off for 6 or 7, 8 hours for probably some prick's not going to pay you so you gotta walk like from 163rd avenue all the way back here after doing like three quarters of a day's work and you get nothing for it and it's just oh, I'm telling you man. It's just maddening, people don't understand that shit you know, but that's what you deal with and then these people in the doctor's office and the doctor himself he doesn't, he can't even comprehend what it's like man. (3,409)

People who suffer from addiction tend to have low self-esteem. A few participants mentioned that many addicts suffered from fragile self-esteem and expected others to treat them accordingly even though they needed to be built up.

> You know and after, after 50 years of trying to beat the addiction, I finally heard someone get up and try to quiet the people and say "I'm an addict." It's a disease I acquired somehow and this is how I deal with it. I don't have to be ashamed about being an addict because that's a big thing for me it was that was I felt less than and so anytime I picked up anything for, I was kind of waiting for people to confirm that for me. (1,183)

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[7] For transcribed quotes in this chapter, Q denotes interviewer; A denotes participant; and (#,#) denotes participant study ID and within-transcript line number.

Belligerence is a side effect of addiction. More commonly, participants described drug injectors as a group prone to aggression and hostility as a result of intoxication, pain, and drug withdrawal. When under the influence of these addiction-related conditions, social interactions are difficult to navigate.

> Well it's so hard you know 'cause you, you know, you're abusive, you're loud or you know this kind of thing you know(...) you just walked 30, 40(...) blocks, 3 or 4 different places probably and finally you get to this point and this prick at some point you're trying to get to see him to help you out you know and so they go you know they interrogate you and you know "You're double doctoring" you're this or you're that. (3,343)

If you treat a health care worker poorly, you will be treated poorly in return. Participants stated that they were usually punished for belligerent behaviour and more commonly rewarded for good behaviour.

> Q: But do you think that they way that you're treated or your care changes when you're being really hostile or aggressive?
> A: Oh ya.
> Q: How does it change?
> A: They can become very uncaring.
> Q: They can become very uncaring. So what do they say or do that's hurtful or uncaring.
> A: Sometimes they won't come by and they won't give you any drugs uh.
> Q: They'll withhold treatment?
> A: Ya in a sense like, they'll make you suffer a little bit, make you wait for food or stuff like that. But if you ask them nicely if you do it nicely they say "Hey, here's some water." and they bring water and food. (6,204)

Drugs are the priority when you're an addict. Addiction not only affects the behaviour and overall health of people who inject drugs; it also changes users' priorities. Drugs play a central role in active users' lives, and all other pursuits, including health care, take a back seat until the need for drugs is met.

> You don't got no dope after a while, how you gonna get more dope so you gotta do other things to get more dope. Right? And then you gotta do crime or you go to work or whatever you gotta do right, it's a habit. (5,110)

Dopesick feels awful. Opiate withdrawal, commonly referred to by users as dopesick, is an uncomfortable, often painful state. Some participants wished doctors would acknowledge this and indicate willingness to alleviate this suffering by prescribing medication more readily.

> Ya, they just can't cut them out, they gotta wean them down eh? Like gradually. I've seen people cry 'cause they have no down like from the doctors. It's kind of harsh but that's how it is. (5,155)

There's a difference between drug seeking and needing pills for legitimate pain. People who inject drugs often suffer from other more chronically painful conditions as well. Participants felt that it was important to differentiate between drug users who needed a prescription for pain versus those who had no medical condition to account for their prescription request.

> He's been good to me, he's treating me more like a junkie than a patient which pisses me off but uh 'cause I didn't go to see him as a junkie I went for my pain in my back and I've had it for 15 years and it comes and goes you know? (2,13)

I need to see a doctor to treat my pain. Because many participants experienced pain for which relief was most effectively obtained through a narcotic prescription, they chose to see a doctor as opposed to another health professional. Pain relief was a key expectation for these visits.

> It's got to be doctors 'cause I mean unfortunately the only relief is pain relief and nerve pain, especially nerve pain is the worst. (2,129)

Doctors sometimes undertreat pain. Unfortunately, participants were ready for this key patient expectation to be unmet by physicians either inexperienced in or otherwise wary of pain management.

> Well he believed me certain pains yes but I guess my expectations were greater than what he thought right so he sort of mixed it up. (6,379)

I don't go to the doctor unless I'm really sick. Participants usually avoided seeking medical attention until their illness had become quite serious. Preventive care was not a priority.

> Ya, I'll see what's happening you know what I mean, if it's serious like I will go right away but if it's just something like a, you know I cut myself or something like if it's not a bad cut I take care of that. I see a doctor when I have to see a doctor. (2,60)

Ultimately, patients are responsible for their own health. There was general acknowledgment that addicted patients play a role in their health care and that a health care provider's response to an addict can be influenced by the actions and commitment of the same addict.

> It's up to you. For myself I know what I've got to do. Nobody can do it but me right, so that's what I'm doing. (5,491)

Health providers help you by making you accountable. Providers nurture patients by empowering them with certain responsibilities, such as secure storage of medications, commitment to behaviour change, and mutual honesty.

> A: It involves changing your bad ways like your bad habits.
> Q: So willingness to change.
> A: Exactly and changing. Not only willingness but making the change that's, that is the only thing you can do to even help change their mind a bit you know? To earn respect you know you've got to give it, you know. Like if I lie to my doctor and he catches me ha, I mean I'm as guilty, I'm more guilty than anything he's ever done 'cause I'm the one that's instigating this you know? (2,369)

Provider variables. Focus group themes of provider familiarity, values, attitudes, experience, and expertise were equally brought up in the individual interviews as being key provider attributes necessary for rapport.

I stick with my family doctor because he knows my history. Many participants were grateful for a family physician with whom they had established a long-term relationship and who had gotten to know their medical history. Where coordination of care for multiple or chronic conditions was involved, they felt the family physician was the most appropriate provider to see.

> Um, I find that my uh for other problems I have spinal stenosis and my that's where I use my family doctor and he kind of ties everything together. He he knows what's going wrong with the Hepatitis he knows what's going on with the addiction he knows what's going on with my mental health, you know he's on top of everything type of thing, he's kind of the general manager type of thing and it seems to work for me and he has made it accessible for me to get to him. (1,34)

It's easier to get along with nurses. Though the family physician was seen as the best opportunity by many to establish long-term rapport, some participants felt that a nursing background tended to be associated with approachability and willingness to meet a patient's expectations.

> Ya, they're much easier to get along with. I don't know, for me it's hard to get along with my doctor right, some of them. The way I see, well yesterday I saw two doctors, the first doctor I had trouble with sort of, I had to talk to him and stuff and I was just starting to, I'm just starting to learn how to speak and stuff eh, in a sense and communicate with people you know and it took me a long time. And hmm. It's been like 5 years since I talked to people you know like it takes a while to get things out of my head. It was a good visit though like cause well my relationship with the nurse was good. 'Cause she gave me, she gave me more than what I needed. (6,349)

I use certain providers because they're knowledgeable in street illnesses. Regardless of the type of health professional, participants were much more comfortable with a provider who showed expertise in addiction, drug-related injury, pain management, and other conditions commonly experienced by street-involved people.

> I've shopped around a lot to find the right doctor and uh finding a doctor who is knowledgeable about the street illnesses you know there's no point in me going to see a doctor who deals with the upper echelon, you know with their illness because those aren't the illnesses I get and they understand it and they see more patients like my self with the same background so they can um they don't have the bias. It feels like they don't have the bias, whether they do or not I don't know. (1,49)

People who suffer from addiction don't get the right treatment because most providers don't understand addiction or pain management. Unfortunately, experts in street illness were hard to find. More commonly, participants found their condition to be mistreated and suspected that few providers were exposed to street illnesses during their training.

> Well, if I know that's it, if I'm coherent to it, and they miss my needle or they miss my spot, ow, I feel it in the morning. That's always, I'll look at it and go, "Who did this". It's just myself I'm thinking like "Who the hell hit my, hit my vein hey, they missed it by half a mile eh" but I can't really say that to any of the nurses or anything or doctors that did it because I don't know who did it. But I ended up just "Ow." (6,220)

Bias often stems from a lack of education. A few participants thought that this lack of training in street illness and addiction was also an essential ingredient in the perpetuation of provider discrimination towards addicts.

> Q: Why? Why were they laughing?
> A: Cause they're ignorant. They're ignorant. They're just ignorant. I don't know why. (8,120)

Most doctors think they're better than users. Participants described most members of the medical culture as quite arrogant, which led to further discrimination.

> A: Uh I don't know, some of them seem a little bit I don't know bossy, some of them snobby.
> Q: Ok. And how do you, and so bossy and snobby, so how does that kind of get in the way of the relationship?
> A: I just don't like it. (4,160)

Some doctors blame people who suffer from addiction for their problems. Participants recounted experiences with these same physicians managing them on the basis that, despite the myriad factors leading to drug addiction, addiction had no other cause than the patient himself and that the patient should therefore accept his fate and take responsibility for his improvement.

> So uh, it's almost like they're playing God with you right. "You're the one that chose to be on this drug." Right. It's almost like you're being punished right. Gee whiz didn't I come here for help? Right you know? I wanted to get off the street drugs right, I want to stabilize my life right, I want to be able to go to work and be a normal person right? And you start to get all this dictatorial stuff right. "Working is a privilege right, and uh you have to earn your privileges last before you have the privilege to go to work right"? (7,517)

Some providers care more about money than about patients. Most participants were also keenly aware that medicine is a business and that many physicians treated their patients in a financially advantageous and not necessarily patient-centered way.

> Well I think with a lot of the doctors, and unfortunately I think this but I don't admit, I'll tell it to you anyways, the doctors at [clinic A] I believe they're into it for the money. I think that they own the drugstore downstairs, they want people going onto that program and dosing everyday(...) so it's a guaranteed paycheque right they can keep people employed in their business and sell their drugs through the drugstore right and they don't want people on carries because they don't make money then. (7,167)

Health care providers are often too busy to focus on their relationship with patients. Many health care professionals are faced with heavy workloads for financial and human resource reasons. Some participants recognized this and didn't expect providers to be able to establish rapport as a result.

> I just not they're not really, they're not really interested you know what I mean, I don't want to take up their time they could be doing something better for someone else you know. (3,268)

Newer doctors truly want to help. Recently trained providers were perceived by some participants as being less hardened by bias, money, and workloads and more attuned to the altruistic reasons for which they chose their profession to begin with.

> The younger doctors, they're hungry and they want the patients and they want to help, they want to help. And they just came out of university and whatever, they're a doctor. That's the (Hippocratic) oath that's what it's all about right? (3,373)

External context. Probes specific to system-level determinants of rapport were included in the interview guide in order to more fully describe themes discovered in the focus groups. Participants confirmed that bureaucracy, legislation, and health care teams did indeed exert an influence on rapport.

A doctor works with a team; you have to deal with them first. Though participants usually wanted to see the doctor, they often had to interact with nurses, counsellors, reception staff, security, and ambulance personnel first. Physicians function within this team setting and their decisions are under the influence of these team members.

> Uh, just sort of "You're here for that reason" or they come and bother you "What do you do for a living." and then they play games like "I'm here because I'm sick" and then you make up weird excuses, the fun of it is just that basically. (6,518)

Nurses can influence a doctor, but ultimately the doctor's in control. Participants related multiple encounters with nurses, though most of these were in the context of a larger team including a prescribing physician. Though nurses had influence on the health care team, nurses in this position were perceived as subordinates to the physician and participants generally felt that they had a less important role in rapport development as a result.

> Ya, nurses are I mean they're influential with doctors, they can basically uh make a decision through a doctor uh what they think right. But generally doctor's the one with the ultimate authority in the office right? (7,650)

Sometimes the student doctor is the go-between. A few participants mentioned providers-in-training as another layer in the team. Participant experience with training varied from tolerable to frustrating; rapport tended to be more tenuous during these more distant encounters.

> …I mean I'm not going to lie to him but I mean I just uh I was surprised he gave me 3 and a half month's worth cause the student doctor said "How much does he usually give you?" I said "It depends on the mood he's in," I said, "A month to three months." And she said "Do you want me to go tell him that?" and I said "Not necessarily." so she went, she asked how much and he said "Give him 3 and a half months." (2,410)

Security staff are a big barrier for addicted people trying to use the emergency. Security staff got involved, understandably, during already negative emergency department encounters. Participants felt that security personnel were biased and overly aggressive toward street-involved patients.

> They're assholes, they're idiots. They got no education most of them, they're just having power trips you know control freaks eh and you go there you're sick simple as that. You don't got there cause you want to sit 17 hours and(…) sleep you know? (3,155)

I don't like going to the hospital because the cops get involved. Participants were also wary of emergency departments because the police were more likely to be around and participants wanted to avoid getting charged.

> A: Ya well I don't like going to the hospital.
> Q: No, why not?
> A: 'Cause when you get stabbed there's fights and the cops come that's why. (5,341)

Paperwork delays my access to care. Medical forms, prescriptions, and referral letters seemed to be a low priority for providers, yet participants felt that providers were unconcerned that their patients' medical conditions were not addressed more expediently.

> You set an appointment and you wait and wait for months down the road to go to see the(…) doctor and they lost your paperwork or "I don't know where it could be, try again next week." You know? And(…) I just waited 3(…) weeks or 4 weeks, they don't care, they don't understand that, there's no compassion. (3,395)

People without identification or coverage have a hard time accessing health care. Not all IDUs qualify to have their Alberta Health Care premium waived, and the associated costs may preclude holding a valid UI, thus limiting access to most medical clinics, hospitals, and lab and radiology services. Loss of this identification is also common on the street, leading to a similar circumstance. Few health care providers have the flexibility to waive their requirement for a valid UI prior to providing service. Users in this situation end up having to engage in fraudulent behaviour to access care, cannot follow through with treatment recommendations, or avoid accessing care altogether.

> Well for the people that don't really have health care numbers or anything right, are not on assistance, they're the ones that have to like really have to play a game on how to jump through hoops try to find a person's number and think about it. The number, use it, stuff like that um. Legal loop holes, well they're not legal, illegal loopholes, assume identities, be different people, stuff like that. (6,510)

<u>I often don't have a choice about which provider I see.</u> In addition to bureaucratic obstacles, the staffing structure of many health facilities is such that users cannot choose the provider they see based on past favourable experiences. Because the health care provider is unknown until the encounter, participants described accessing or not accessing certain health facilities on the basis of their past experiences in general as opposed to the experience with any one provider.

> Oh well, I'm talking now about in the hospital. I think the responsibility lies on the addict to find, or any, on the person, on the individual to find a medical system that works for you. But you go to the hospital you have no choice. You get to the hospital and you say "I want to see Dr. So" and so you get who's next in line and they could be an intern or they could be uh someone just coming out of uni, first second year or whatever. (1,80)

<u>Your choice of health care is usually limited by location.</u> Many downtown Edmonton IDUs have few transportation options available to them. Some participants stated that they could not always choose to see a provider with whom they had good rapport if that person did not work nearby.

> A: Or [clinic A]. You tend to go where the closest place is.
> Q: Ya. So you don't, you don't have a specific doctor you like to go see or a specific nurse or a specific person?
> A: You don't usually have that option. (8,91)

<u>I can't find a family physician who is accepting new patients.</u> The opportunity to establish long term rapport was further constrained by the lack of physicians

accepting new patients, particularly patients with addiction and chronic pain problems.

> But you can't find, nobody to talk to, doctor so they're all booked up they don't want to take any new patients that sort of thing and you've got to walk so far I've got to walk oh shit 20, 30 blocks to see a decent doctor and you get there and you wait in line and wait in line and the next thing you know they're out, they've gone to the hospital or they can't see you you know so you miss the whole thing. And you're, you make another appointment and you know it just gets tiresome after a while. (3,30)

I have to wait a long time to see a doctor. Regardless of whether participants had a regular health care provider or where they accessed health services, most participants alluded to frustrating wait times. The longer participants waited, the more dopesick and belligerent they often became, further damaging their opportunity to establish rapport. Participants were upset that the unpleasantness of withdrawal and pain, though not life-threatening, were not treated with the same priority as other medical conditions.

> Well at the emergencies, especially. You go into the emergency and you've got an OD or you've done too much of something you sit and wait there for 4, 5, 6 hours before anybody sees you and you see people that come in after you getting treatment while you're sitting there and if you raise a ruckus then the security runs you out. (1,55)

Some clinics won't prescribe pills because the doctors don't want to lose their license. Because drugs hold high priority in the lives of IDUs, other health care priorities and patient-provider relationships are seldom attended to unless the IDU's prescription needs are met. Doctors are often wary of the potential implications to their license if their narcotic prescriptions get diverted or otherwise misused, so many doctors choose not to prescribe any. This decision hampers the opportunity to connect with many addicts who will not bother to access care unless there is a reasonable possibility of their prescription needs being met.

> Well it's their life they went to school to get these licenses, they want to be a doctor to help you out there and their clients there, they don't expect their clients to do those kind of things right. (5,419)

Harm reduction provides resources to both providers and patients. Some participants described the increasing prominence of harm reduction programming in Edmonton as a positive influence on both providers and patients. These programs serve as connections for patients to more traditional health services and are also serve to educate providers and advocate for patients.

> Ya I see ya it would help quite a bit cause then doctors would realize that hey there is such a program, this is what this is for, they have someone coming in and you know they it would actually help quite a bit on both ends. (8,497)

Encounter-based variables. Like the focus groups, individual interviews gravitated overwhelmingly to a discussion of the patient-provider interaction during health care encounters. Negotiation tactics—rules, games, and tricks that participants had to navigate in order to have their agenda addressed—were particularly explored using probe questions and are presented as a separate thematic domain. However, other within-encounter issues, such as discrimination and patient-centered care, remained universally important among this study's sample.

The doctor-patient relationship is established by treating the patient like a human being. Participants commonly alluded to being perceived as "second rate", "less than human", and "just another addict" by health care providers. Participants were more satisfied with visits during which they were treated as equals worthy of the same dignity as providers themselves.

> I don't know, it's a whole bunch of things that add up to what I just you know if I go into see my family doctor, when he comes through the door he's got a smile on his face "How you doing [Bob]?". You go in through the emergency, it's "What's the problem?" there's not person it's not a person thing it's an object thing. (1,91)

People who suffer from addiction are treated differently than other patients. Inferiority was one of many negative connotations that providers appeared to associate with addicts. Participants also felt that providers perceived them as unclean, diseased, and not seriously ill. Participants suspected that they were made to wait longer and were less likely to be retained in a physician's practice than other patients.

> Well it's like they're, you have some kind of uh, disease or something that they're kind of looking at you and kind of like scared to touch you or uh. (4,365)

Providers assume that all people who suffer from addiction are drug seeking. Participants described being lumped into the same drug seeking category as other IDUs as soon as health care providers assigned the addict label to them.

> Um, but they that's the first thing they're thinking, everything that all their decisions get filtered through that particular piece of information that you're a drug addict and then they say "Oh, drug addict, oh ok, drug sick, he's here for, he's drug sick". (1,65)

Medical professionals use the same labels for people who suffer from addiction as we use in the drug community. Users of certain drugs tend to behave differently than users of other drugs. A couple of participants described existing street labels for each user type and indicated that providers likely used a similar classification and treated each type of user accordingly.

> See, it's hard to, see everybody's different, every junkie's not the same as the next junkie. Right? Some do crystal meth, some do speed, you got your speeders, your crystal heads, and you got your rock heads and you got your heroin addicts and then you got your people that smoke pot and you got your pill heads. And then you got your alcoholics. And these all different personalities. Some clash with others, they don't get along cause like people that drink don't get along with junkies cause it's two different personalities.
> Q: Do you think those personalities matter when you go see the doctor as well?
> A: I'm sure the doctor thinks too, well they see it right and they see them and then they see them over and over but then [Inaudible word] right. (5,86)

I can tell when providers are biased by their body language. Labelling by providers was evident not only in their treatment decisions and verbal communication, but also in their nonverbal communication.

> Q: So what kind of labels do you get?
> A: I don't know that snobby look, cold shoulder. (4,385)

If somebody finds out I suffer from addiction, the label gets around. Many participants were upset by the lack of confidentiality displayed by health care team members about their drug use. Hurtful labels were easily spread among health professionals, and as a result one individual team member was often capable of damaging the rapport efforts of other team members.

> A: You bet. All the way from the nurses to the doctors 'cause they have that communication like between themselves.

> Q: Ya. What do you think of that communicating between them?
> A: It's necessary but if the wrong information gets passed on...
> Q: So if the wrong info...
> A: If the wrong information gets passed on it's all very negative to get through from one end to the other. (8,129)

I can't do anything about discrimination. Unfortunately participants felt that they had very little control over the bias they encountered in health care settings and had come to expect it as the default.

> Q: So what do you think about that? About assuming things like that?
> A: I don't know, can't do nothing. (4,401)

Doctors treat me like I work for them as opposed to the other way around. The notion of customer service was brought up by a few individuals. Unlike the service sector, many health care professionals did not behave as though their patients were "customers". Instead, IDU patients were afforded minimal control over patient-provider interactions.

> You're a doctor, you work for me. I don't work for you. That's there just isn't that, I'm coming to you for a service, you're getting paid for servicing me, I don't have to put up with you're biases, I don't have to put up with the attitude, I don't have to put up with the you know the sideways looks and when the doctor comes and they're outside the curtain and they're talking and you can hear, you overhear what they're saying and you know, this is another one, you're not treated as an equal as a human being. (1,72)

It makes a difference if a provider cares about me. Despite these negative experiences with labelling and subordination, participants also alluded to highly positive experiences in which certain health care providers demonstrated patient-centered care. These providers showed genuine concern for and interest in their IDU patients' well-being.

> A: Well he seems to um be concerned about me.
> Q: Ok
> A: Mhmm.
> Q: In what way? What sort of things does he talk to you about?
> A: Oh he talks about me and my family, just like a friend, a good friend. (4,44)

It makes me feel comfortable to have a provider who listens to me. Patient-centered providers listened to their IDU patients' requests, considered their point of view in treatment decisions, and were receptive to patient feedback.

> Well maybe too much, maybe too little. It's just, I don't know like, all the expectations definitely like when they can't know what it is maybe a lack of communication, like lack of communication between patient and doctor it's only essential to know what's going on like and to say hey what's wrong, how can I help you or something like that right? (6,244)

It matters that I get explanations for health care decisions. Patient-centered providers were not only good listeners but were also able to communicate their decisions and their reasons for these decisions to patients.

> They have certain I guess logistic talk to them but they explain to me like why I was out, what helps me to get better and what's totally sometimes surprises me like it just clears my understanding of why I'm sort of "why am I here" in a sense right bridges that gap so, they always say things like that so. (6,54)

Health care providers who see a lot of addicted patients develop empathy for them. Some participants believed that experienced patient-centered professionals are better able to appreciate the unfavourable circumstances of their drug-addicted patients and their influence on patient behaviour and expectations.

> If you're working in the community system(…) they're so used to having you also get some empathy. Um, they don't treat you as a "less than" individual. They treat you as an equal that has a kind of problem. (1,99)

Health care workers would treat me differently if they had experienced the life of a person who suffers from addiction. Though professional experience helped to develop empathy, some participants thought that a provider's personal experiences with street life could accomplish the same thing.

> Give them a course in I don't know something. Let them sleep in the street for a(…) week and see how they you know? And maybe they could show a little more empathy to(…) people man. (3,443)

My doctor is there for me. A few participants held their primary health care providers in high esteem because they were available when their patients needed it and were willing to spend time just being with patients.

> Um, just be there right. It's good to have a doctor right. (7,269)

IDU-provider rapport, then, takes place in a unique context and is determined by a multitude of variables. Participants emphasized that addiction needs to be viewed as an illness with far-reaching effects and a burden of suffering. They appreciated having a provider who was knowledgeable, patient-centered, and unbiased. They were routinely frustrated during health care encounters by the bureaucratic obstacles inherent to the health care system.

Negotiation Strategies. Patient-provider interaction in the context of IDU is unique in that drug addiction plays a central role. Disclosure of drug use has several rapport-related consequences and IDUs need to decide to what extent they can be honest with providers. Drug prescription often dominates encounters; without addressing this issue, rapport is of very little importance to many IDUs. It is within this context that health professionals and IDU patients have set up certain rules of negotiation to ensure that their respective expectations are satisfied.

<u>An addicted individual will do anything to get a prescription.</u> The drug is everything to an actively using addict, the prescription of which may be the only reason some users access the health system at all. Even those users with other health care expectations often also have pressing prescription needs. Given this priority, participants said that they would do whatever it took to obtain a physician's prescription, be it slowing down or stopping their injection behaviour, creating plausible stories or strengthening real ones to support their request, withholding the extent of their drug use, engaging in criminal activity such as prescription pad theft and drug diversion, or otherwise compromising their values.

> Well I knew he was serious and I told him I said well, I said "I know I told you this a million times" I said "but words are only words," I said uh "actions prove themselves and give me the time and I'll show you." And so that's what he did he gave me a 3 and a half month per and you find a hole anywhere, and these are old ones, but you find out, look at the, that thing, that's 30 years old I mean but that's uh, there's no fresh holes anywhere so that's what I'm saying so... (2,254)

<u>There is no physician standard for dealing with narcotic requests.</u> The specific negotiation strategies used by participants to procure a prescription varied significantly according to the provider involved. This is because there is no profession-wide standard for when, to whom, and how to prescribe drugs. As some

participants put it, this system or lack of a system essentially forced addicts to "play games" and shop around.

> Depending on how much they give you I mean or what you need will probably determine who you're going to go and see. (6,483)

<u>Some clinics refuse to prescribe any narcotics, even for legitimate reasons.</u> At one end of the spectrum, some physicians were known for their blanket refusal to prescribe narcotics, often accompanied by prominent signage at clinic doors. Participants understood that these physicians felt uncomfortable engaging in such negotiations based on their past experience, but voiced some displeasure at their unwillingness to consider occasional "legitimate" requests. This inflexibility was not conducive to rapport.

> And then and then the person's really got the pain and really needs the meds doesn't get "Well, sorry we don't prescribe narcotics here". (1,276)

<u>Some clinics hand out prescriptions with no questions asked.</u> At the same time, participants described multiple physician practices with a seemingly greater interest in patient volume than individual assessment. Many of these practices were known for their tendency to prescribe narcotics rather easily without first assessing the patient's actual condition. This perceived lack of interest on the part of the provider also impeded rapport development.

> Most of the doctors you get are more like here take 'em go away now. (5,141)

<u>People who suffer from addiction will say what they think their provider wants to hear, regardless of whether or not it's honest.</u> In this unpredictable prescription environment, participants had learned to read each provider's behaviour and observe their prescribing patterns for other users, and present their case in a fashion most likely to curry the favour of a physician.

> Truth don't matter to these people, if a lie will get you what you want they'll tell you anything you know? (2,361)

<u>If you tell the doctor about your drug abuse, he'll cut you off.</u> As a general rule of negotiation, users were careful to disclose only the minimal information necessary to procure their medication. Disclosure of injection, drug diversion, or other forms of

prescription misuse usually led to abrupt discontinuation of existing prescription, and in some cases, termination of the doctor-patient relationship itself.

> A: I'm not going to tell the doctor I'm selling my pills he'd cut me off.
> Q: That's what would happen.
> A: If I came to you and you were my doctor and told you I'm selling my pills do you think you'd keep giving them to me? (5,399)

<u>Health care workers can't help me unless I tell them what I need.</u> Participants also acknowledged that they needed to be honest enough with their physician to relate what they needed if they expected to have their needs addressed. Some disclosure was also necessary to garner a provider's trust and the opportunity for longer term rapport.

> I would say not knowing for them not knowing what I need, if I don't say what I need or what I'm not going to get it you know like, it's just, but if I show them what it is and what I need to get it done to fix it then they really can't really help me right? (6,264)

<u>If doctors read your file they'd know what diseases and drug use patterns you had.</u> Participants needed to disclose at least some of their drug use history because they knew how easy it was for providers to access this information from medical records. Though Study 1's IDU participants related general frustration with medical records and associated breaches in confidentiality, this study's participants felt that documentation was usually a positive thing, and wished in fact that providers would consult their charts more so that their patients did not have to prove the legitimacy of their prescription request.

> Well I imagine it's on my file right, he's one doctor that I had, he's taken over the caseload because the other fella retired. So it's on my file and I just assume he read the file. Like he understands that I have been on methadone and I am on methadone I've gone through all that with him right. (7,281)

<u>Providers follow rules so that they can defend themselves if someone complains.</u> Participants described having to deal with numerous provider-centric rules of negotiation, such as routine questions about drug use patterns, urine drug screens, restricted drug amounts and dispensing frequencies, and limited treatment of chronic pain or addiction-related issues. They felt that providers abided by such rules, not to

maximize patient safety and well-being or comply with professional standards of care, but rather to protect themselves and their license in the event of a bad outcome.

> I don't know, it seems to me like for methadone in particular, most of the doctors are more concerned about protecting their own butts right and simply because most people on methadone, let's face it, a lot of them are messed up, right, they've messed up their lives right. (7,94)

Doctors check to see if you've been injecting. Physicians usually required proof of abstinence from injection to fully comply with their patient's prescription requests. Inspection for track marks, urine drug screens, and other tests of abstinence were common annoyances reported by participants.

> Like as soon as the doctor comes in he says "Let's see your arms" how is that for, I'm there not for a drug addiction, I'm there for pain for my back and he wants to see my arms. Well have a good look, you want to see my legs, look up my ass if you want, I don't care, you know I mean really it just pisses me off you know? (2,112)

Doctors ask trick questions to see if you're telling the truth. Some participants believed that their health professionals tried to get addicts to give themselves away with their responses to convoluted questions.

> No he's just asking, well he just plays his little games on the computer like uh "Do you hear things" this and that all the what do you call it psychiatry stuff. Right. Try to catch you on trick questions and it doesn't work. (5,271)

Doctors should examine patients because it means they care and are being thorough. Participants felt strongly about the importance of a thorough physical assessment. According to participants, a physical exam offers proof of pain legitimacy, assists in accurate diagnosis, and makes addicts feel like their health care provider cares about them.

> Do some tests, check me out, make me feel like I'm somebody they don't give a shit. They just don't, you know, they just don't seem to care. (3,37)

My provider is in control. These stringent rules, combined with the physician's powerful position as a potential drug supply, ultimately left many participants feeling like they had very little autonomy over their health care.

> I honestly feel like a prisoner of war. (7,458)

Just be straight up with your doctor. Faced with provider rules of negotiation, participants had developed various counter-tactics to advance their agenda in addition to the selective disclosure patterns described above. Some participants believed that it was too difficult to keep track of a set of lies, and preferred to be straightforward with their health care requests and hope for an understanding professional.

> But I tell him straight, I says "Look I'm still doing downs, I'm still doing dope right at least I told you straight up right, I'm still doing that, you can cut me off you can do whatever you want, it's not going to stop me from doing dope right", so he probably figures what's the use of cutting him off now that maybe has these spells to compensate for the dope. (5,361)

Do as the doctor tells you and see what he needs from you. Some participants felt that it was best to compromise if necessary and meet a provider's expectations in order to justify to the provider that their own requests were also worthy of being met. It was also important to these participants that they actively engage in health care encounters and clarify what their provider's expectations of them were.

> A: I just want to be treated with respect but to be treated with respect you've got to earn respect.
> Q: And how do you earn respect?
> A: Well I think by this time when I go see him and show him my clean arms and I'll tell him, "Look anywhere you want you will see no holes." And I said now you know "I'm doing what you want doc and I'm not only doing it for you I'm doing it for me too." (2,278)

I have to convince my doctor that I'm really in pain and not drug seeking. Many participants differentiated between drug seekers and people with legitimate prescription needs, and tried hard to separate themselves from the former group and have their providers perceive their request accordingly.

> But it must be, it must be a dilemma for health care professionals to look at the person, meet the person for the first time and you see this person is obviously in pain, he's saying all the right things, he's got all the symptoms but he could have read them out of a medical book or whatever and uh so they have to make a judgment call. (1,269)

I will speak up if I feel I am being treated unfairly. When users suspected that a provider was not making fair treatment decisions, they advocated for themselves by voicing their displeasure and asking for an explanation.

> I tell it like it is and if they've got a, if they've got a bias towards it if I feel that it's affecting how they're treating me, I'll say something. (1,213)

I let people know about harm reduction. Outside of specific patient-provider encounters, some participants engaged in community advocacy work by educating people about in the harm reduction approach to health care, in the hopes that they and their peers might receive more appropriate care through their efforts.

> Ya like a lot of people ask me about that right and I told them you can come and take the course here and it's and you can carry a kit yourself right and if you're hanging around people that use narcotics like heroin and it's a good idea to have somebody around with one of those kits right because it's just a foregone conclusion that it's going to happen right? (7,733)

Street-involved people can read their doctors and know how the visit's going to go. Regardless of the specific negotiation strategies used, most participants relied on their street-honed instincts to guide them in their assessment of each health care encounter and its likely outcome. Though verbal and non-verbal language and indirect observations of peer-provider encounters provided important clues, participants also alluded to a less tangible "sense" of whether or not things were going well.

> You can tell. Just this or this or for example when they say someone's a racist you can't see it but you can tell so it's the same notion here. You just can tell if they're a human being, it's just a certain sense of you know a sixth sense of you can tell who's treating you right or who's not. (8,37)

So negotiation strategies used during IDU-provider encounters have been developed as a response to the prominent role of the prescription itself. Participants believed that selective disclosure of drug use, game playing, and general dissatisfaction with health care were a direct result of a lack of physician consensus on how to deal with the centrality of drugs, as well as inconsistent assessment of each addict as an individual and not just another drug seeker.

Outcomes of Rapport. The quality of the provider-patient relationship leads to varying degrees of trust, patient satisfaction, provider continuity, criminal activity, and compliance with recommendations. Patients may also decide where to access health care or whether to access health care at all based on their interpersonal experiences.

Honesty instils trust. As discussed in the previous thematic domain, selective patient disclosure is common among IDUs, yet participants were well aware of the importance of at least a certain level of disclosure in the development of rapport. Honesty fostered trusting connections between participants and providers and encouraged providers to meet their patients' needs.

> But when you're dealing on a professional or with someone that's there to help you uh I think that by being honest with them, it gives them more of a trust they trust you more as to what you tell them or when they ask you a question, they leave the answer more openly than if you don't tell them that you've got a communicable disease. (1,436)

I am more satisfied with my care when I think a health care provider cares about me and has listened. Study 2's strong association between patient-provider rapport and patient satisfaction with care was confirmed in follow-up interviews, with all participants agreeing that a positive rapport experience made them happier with their encounter. This association appeared to be moderated by the patient's prescription expectations, but once prescription needs were addressed, rapport was an important determinant of overall satisfaction.

> Q: Would you say it's associated with feeling more satisfied with the visit? More satisfied with your care in general?
> A: Ya, ya, you feel like you're getting help right from someone that cares about you. (7,784)

I will choose the location of my care based on how I've been treated there before. The influence of location was specifically explored in this study because no consensus was reached on its effect during focus groups sessions. It became clear during the individual interviews that location is not a key determinant of rapport, but rather an outcome of rapport. Participants felt that it was more the providers in a location as opposed to the location itself which established good or bad rapport. However, a participant and his peers' experiences with one or more providers in a given facility shaped the overall reputation of the facility and influenced whether they would go back if given a choice.

> A: What's really sad, is the [hospital] has a very bad reputation.
> Q: Really?
> A: Extremely bad.
> Q: Will you avoid going there even if you're close?

> A: Oh ya. Yup.
> Q: Ok, how come?
> A: Why? Bad experiences. (8,98)

If health care workers don't care about my health I don't see why I should care about getting help. Many participants described avoidant or self-care behaviour in response to past experiences with failed rapport. A few participants even felt that failed patient-provider rapport had the potential to aggravate addiction.

> It's the world, [*inaudible word*], it's the world they don't give a fuck. They don't care so why should I. Why should I waste my time walking 60, 80(…) blocks when I can just sit here make a phone call and do some dope. You know, get away from it all, use escape you know. (3,391)

If addicted individuals don't get drugs through a doctor, they will get them through illegal means. Because drug acquisition is central to doctor-IDU encounters and is therefore an unavoidable factor in rapport development, some participants believed that physician unwillingness to negotiate prescriptions with addicted patients set the stage for drug-related criminal activity.

> I'd get a gun, I'd go out and rob a bank and I would, I'm serious, I'm in that much pain, I will do anything to take care of it you know. (2,302)

I'd find another provider if my own provider wouldn't give me the prescription I want. "Double doctoring" is a common behaviour among addicts but it is generally considered unacceptable by providers. However, participants felt that physician reluctance to work with an IDU on prescription matters was directly responsible for provider discontinuity and "doctor shopping".

> I don't know, just I guess different days different docs right? Different amounts sometimes, or different chances you can take with them right? Like I know a lot of people here that do that too right, they switch doctors right, all over the city just everywhere, and there's no really there's no really favouritism, it's just the way addiction is [Inaudible word] it just makes it go here there and like the... (6,469)

Providers who know me are concerned about my health and better able to influence me. For those participants who had the opportunity to establish a long-term patient-provider relationship with someone, rapport was strengthened over time and in turn increased a participant's desire to maintain this continuity of care.

> A: It makes me feel comfortable to have that with a doctor, you don't like to go see someone who doesn't like you right. But I've got doctors that uh they're called pill pushers or croakers that's what they're referred to.
> Q: Oh ya, I've heard of croakers.
> A: So the reason people go to see them is because they accommodate them in what they want but uh then there's other doctors that aren't accommodating in that way but they are more concerned with your health.
> Q: Like your normal doctor that you talked about, is that why you stick with him or are there any other reasons?
> A: Ya. That's generally why, I've been going there a long time since I was a kid. (7,766)

<u>I will follow the advice of health care workers who take the time to care about me.</u> A provider's commitment to patient centered care and provider-patient rapport also encouraged some participants to commit to the relationship by complying with a provider's recommendations.

> Q: Ok. Ok. So uh the opposite then if someone did all the bad things to screw it up, to screw up the relationship would you then just would that would you be completely unhappy when you left, would you not bother listening to anything they had to say?
> A: I'd take the antibiotics and get out.
> Q: Ok. Would you use them? The antibiotics? Maybe?
> A: Maybe.
> Q: Maybe not?
> A: Cause nobody here cares if I use them or not anyways. (1,158)

Though the aforementioned rapport-related outcomes of trust, satisfaction, continuity of care, and compliance have been documented in the general population as well, participants alluded to some less common outcomes of rapport in the IDU setting. The development of IDU-provider rapport influences care-seeking in general, addiction severity, and participation in criminal activity.

Alternative Points of Care. Informal sources of health care within the street community were explored to compare rapport development between formal and informal health care settings. All participants were aware of peers accessing other peers for medication or other health care, and most participants had at least some first-hand experience of this IDU community-based care. Reasons for accessing a peer's services were not consistent across the sample, but certain peer characteristics and rules of negotiation were agreed upon by several participants.

Some of my peers have a reputation for caring. Peers with a reputation for health-related expertise were perceived this way because of their caring, client-centered approach. In this setting, caring often entailed looking after someone's drug needs, but it also involved helping a patient out with general suffering.

> Q: Ok. Would you say there's people in your community who have a reputation for being very helpful with health problems?
> A: Mmm, ya.
> Q: Ya? Like specific people out there?
> A: Ya.
> Q: Ya? How come you think they have that reputation?
> A: Just the way they talk and the way they seem concerned. (4,235)

Peers help each other out without needing any other reason. Most participants felt that when an IDU helped out a peer in need, it was simply because it was the right thing to do. It was also a given for many participants that the help would be reciprocated when it was needed.

> Well it's just their reason for being, their reason for doing what they're doing. They're not doing it for a paycheque, they're doing it for uh to help other people. (1,206)

On the street, all you have to do is be straight up. Participants felt that it was a lot easier to be straightforward with a request to a peer and that game-playing was minimal. There was no need to prove one's legitimacy or change one's injection practices. Peer providers were equally straightforward in their approach.

> Well he gets right to the point and not be judgmental and you know, he just, he'll tell you the way it is [iap]. (8,322)

Money is all you need to get what you want on the street. Participants also acknowledged that financial transactions were involved on the street and not in the doctor's office. Peer drug suppliers seldom needed more convincing than money to help someone out.

> Costs you money on the street right. Pretty simple strategy, "Here I have the money have you got the drugs?" [*Laughter*] You know. (7,560)

My peers only have a reputation for selling drugs, not helping in other ways. Not all participants shared positive experiences with their peers. A couple of participants were wary of peers and did not find them capable of much help because of their own addiction issues.

> They're a bad influence because uh all they're talking about is how much dope they can get like how much they can sell, and get high and do some of this and that you know. (2,323)

You have to know who you're dealing with and what you're getting on the street. Some participants cautioned that until each party got to know each other better, care still needed to be taken during peer-peer negotiations. Like in the doctor's office, and perhaps more so on the street, an addict had to rely on his instincts and disclose only what was necessary to a lesser known peer.

> A: Oh, they, they have to be streetwise on the street.
> Q: What do you mean by that?
> A: You have to play a game and wait and depending on what kind of drugs you got to be experienced, [Inaudible word] sense helps, you just gotta be, you just gotta be yourself basically on the street and find out who you're dealing with. (6,531)

Encounters with street-based care providers therefore share attributes with professional encounters, in that client-centeredness matters and there are business aspects to the encounter. However, street smarts and instincts appear to be more important, and participants generally felt that it is easier to get to the point and avoid extensive negotiation with a peer.

Study Limitations

Similarly to the focus group and cross-sectional studies which preceded these qualitative interviews, this small, inner city agency-connected, primarily male sample may not necessarily represent the views of all Edmontonians who inject drugs. Re-contact of a subset of marginally housed, highly mobile group proved to be a challenge. Again, female and even more marginalized IDUs may have unique experiences with patient-provider rapport. The intention of this follow-up study, however, was to complement rapport-related themes and clarify uncertainties raised in the earlier studies. This purposive sample, gleaned from the preceding quantitative study sample, was ideally suited to these triangulation efforts.

A physician conducted interviews which addressed an interpersonal relationship in which physicians usually held the balance of power. It is likely that participants withheld certain rapport-related opinions and negotiation strategies out of concern for their privacy and subsequent care, and despite reassurances of confidentiality. Paradoxically, the physician's field experience with patients who inject drugs and her association with a trusted harm reduction agency may have facilitated interview rapport by encouraging disclosure and providing a more thorough appreciation for participants' experiences. The interviewer also excluded any of her patients from participation to ensure consent was completely voluntary and interview content was free from any bias due to direct patient-provider contact.

Demographic, rapport-utilization, and drug use information were collected at the beginning of the interview, but unfortunately no clear thematic emphasis was noted for any of the attributes collected. It had been anticipated, for example, that differences in rapport experiences might be found between users who preferred opiates and those who preferred non-opiates, since physicians are a potential source of opiates but not for most other illicit drugs such as cocaine. No such pattern was found. It is possible that cocaine-preferring users visit physicians for opiates in order to support their habit by trading or selling the prescription. It is also clear from existing quantitative data that Edmontonians who inject drugs are frequently polysubstance users, the majority of which use opiates at least occasionally. Thus the centrality of drugs remains, regardless of drug of choice.

Summary

People who inject drugs have a unique relationship with their health care providers. The relationship is determined by several pre-existing patient and provider characteristics, the context in which care takes place, and the degree of bias and patient-centeredness experienced during the encounter itself. Addiction and drugs provide the background for a complex set of provider and patient negotiation strategies. Successful rapport is associated with positive health-related outcomes, whereas failed rapport may lead to care avoidance and crime. Street-based care is a legitimate alternative for many IDUs.

Chapter 6: Discussion

People who inject drugs suffer from a disproportionate burden of illness, yet despite the potential benefits of primary health care, they tend to access health care services in a delayed fashion if at all. Though structural barriers clearly play a role, interpersonal barriers to health care utilization have also been identified but not fully characterized. This thesis sought to describe the nature of rapport between Edmonton inner city IDUs and their health care providers. Specifically, its objectives were (1) To explore how provider-patient rapport relates to IDUs' experiences of health care and subsequent care-seeking behaviour; (2) To explore factors that facilitate or prevent the development of rapport between users and their health care providers; (3) To describe and compare formal health care services to informal, peer-based points of health care in Edmonton's injection drug using community; and (4) To test the hypothesis, derived from SDT, that perceived autonomy supportiveness of a primary health care provider would be positively associated with service utilization among IDUs.

A multi-method approach was used to address these objectives. First, as a preliminary exploration of patient-provider rapport development and its outcomes, qualitative focus group interviews were held with both individuals who inject drugs as well as health care providers with experience in the care of IDUs. Second, quantitative self-reported sociodemographic, IDU behavioural, health, and health care utilization data as well as retrospective administrative utilization data were collected from a larger sample of IDUs to examine the association between the rapport-relevant concept of perceived autonomy supportiveness of a primary care provider and health care utilization outcomes. Finally, follow-up qualitative interviews were conducted with a subset of IDU participants from the quantitative study sample to further characterize rapport determinants and outcomes, specific negotiation strategies, and alternate points of care in the Edmonton IDU context.

Review of Findings

People who inject drugs have distinctive characteristics and experience unique interpersonal dynamics when obtaining care from a health professional. Patient-provider rapport in the context of IDU may share some determinants and outcomes with rapport in non-IDU contexts, but such IDU-specific issues as the addicted condition, drug prescriptions, discrimination, and information disclosure all appear to have a significant influence on the development and importance of rapport.

Focus group interviews (Study 1). Initial IDU and provider focus group sessions uncovered some key determinants of patient-provider rapport within the context of the care of drug injecting patients. Both IDU and provider participants agreed that *patients* who inject drugs tend to present with unique and complex health care concerns as a result of their addiction, associated experiences of withdrawal and pain, and street involvement. Patient behaviour is often accordingly hostile, and patients tend to present in crisis if at all. As a result, many drug injecting patients are not well-equipped to foster positive health care relationships even before a health care encounter occurs. *Providers* also bring certain pre-existing characteristics to health care encounters. They hold a position of authority in the patient-provider relationship and may choose to use this position in a positive or negative way. They may or may not have IDU-specific training and expertise and the continuity of their contact with individual IDUs may vary depending on their work situation. Their ability to engage in self-reflection, take responsibility for their actions, and develop empathy for their patients may fluctuate based on the attitudes they hold toward IDU. Patient-provider encounters are also influenced by *external* factors. Traditional health care systems are commonly not well set up to serve marginalized groups such as addicts due to time, space, and resource constraints as well as differences between traditional and harm reduction service paradigms. Providers often fulfill specific roles within health care teams who influence their work and convey group attitudes. Thus, a provider and patient's efforts to establish rapport may be hampered by these external constraints.

With respect to the health care *encounter* itself, drug injecting patients and health professionals behave in ways which are either conducive or destructive to rapport. Both IDU and provider participants in this study alluded to the importance of patient-centered care. Key patient-centered provider behaviours include demonstration of care and concern, approachability, listening skills, shared decision-making, shared expertise, explanation of one's actions, and general support. Provider authenticity and interest in making a connection are also important. Conversely, all-too-frequent discrimination and trivialization of the patient agenda on the basis of a patient's IDU status severely damage rapport. Emotional responses from both parties and the relative success in controlling these responses also play a role in rapport development. Patient expectations of discrimination, breaches in confidentiality, and the centrality of drugs in the user's life set a tone of selective disclosure and complex negotiation strategies during health care encounters. Honesty is important, but dishonesty is often needed in order to fulfill an IDU's expectations for the visit. Drug injecting patients have to deal with strict provider rules and the provider's team members before getting what they want, and rely on storytelling, compromise, and intuition to get there. Both IDUs and providers are aware of this process and recognize the strong influence it has on the tenor of the patient-provider relationship.

Cross-sectional rapport-utilization study (Study 2). The quantitative data collected for this study complemented the focus group findings and provide a further sense of how rapport might influence an IDU's health care choices. Having a regular physician, and thus having the opportunity to experience rapport with a health professional on a long term basis, was associated in this study with a lack of judicial restraint, less reliance on the drug trade and other criminal activity for drug acquisition, and fewer drug-related expenditures. It was also associated with longer term drug use, more attempts at cessation of drug use, and less frequent experience of drug withdrawal. Though the direction of these associations cannot be ascertained from this study, and addiction stability may increase a patient's ability to develop long-term health care relationships, engagement in a long term patient-provider relationship may equally play a positive role in that IDUs may expose themselves and their communities to fewer crime-related risks and may be better placed to stabilize their addictions. For those IDUs with a regular physician, perceived autonomy supportiveness by a primary health care provider was associated with IDU satisfaction with care as well as decreased night shift presentation and decreased EMS transportation to the ED. Though perceived autonomy supportiveness was only marginally associated with disclosure of drug use and not with overall ED use, the latter two were associated with each other, i.e. disclosure of drug use to a primary care provider was associated with less ED use, and non-disclosure of drug use was associated with more ED use. If perceived autonomy supportiveness of the health care provider and disclosure of drug use are treated as correlated indicators of rapport, then these results suggest that rapport appears to play an important role in the timing and location of health care as well as overall patient satisfaction with care. A positive doctor-patient relationship may allow IDUs to obtain health care when their condition is less severe and where providers are better able to engage the patient in long-term disease management and preventive care.

Follow-up qualitative interviews (Study 3). The final set of individual qualitative interviews confirmed and expanded on many of the findings from the focus group and quantitative studies, and provided further insight into the nature of within-encounter negotiation and the differences between traditional and street-based health care encounters. Patient, provider, external, and encounter-based *determinants of rapport* were once again identified by participating individuals. Patients who inject drugs bring the culture of addiction and street life, and associated behaviours and reduction in the priority of health care, to the health care encounter. Patients make a distinction between requiring drugs for pain control and requiring drugs to support an addiction, though this differentiation does not always exist for providers. Provider expertise in street- and drug-related illness, familiarity with IDU patients, and past experiences also contribute to the success of a health care encounter. Unfortunately, pre-existing provider arrogance, blame, and low prioritization of patients serve as barriers to success. Aside from the potentially positive influence of harm reduction programming, participants felt that the system in which providers worked, in particular the primary care provider's position and accessibility within a larger team, bureaucracy, long wait times, limited choice of provider, and the protection of a professional's license, further stymie rapport-building efforts for both parties. Participants also commented extensively on the importance of limiting provider bias towards IDU and preserving patient humanity, maintaining confidentiality and availability, sharing responsibility, and engaging in two-way communication and empathetic, patient-centered care.

Rapport negotiation in the care of people who inject drugs is an elaborate social process shaped by a variety of factors. Drugs and drug acquisition play a leading role in the lives of actively injecting patients, and this role needs to be acknowledged if any opportunity for developing rapport is to exist. Participants felt that there should be profession-wide standards for handling drug prescription requests, but that no such standards exist. As a consequence, patients who inject drugs learn to adapt to highly variable physician practices. Patient disclosure to a provider is dependent on what the patient thinks the provider wants to hear. Selective disclosure is important in order to prove the legitimacy of a patient's request, but over-disclosure may terminate the health care encounter and even the relationship altogether. Patients rely strongly on their instincts to guide their approach, and will advocate for themselves and their peers if they feel that a provider's actions are inappropriate. In contrast, participants felt that providers rely heavily not only on their professional training but also on their position of control and their ability to place provider-centric conditions on the health care encounter. Negotiation in the health care setting shares some qualities with street-based negotiation, in that IDUs need to follow their instincts and be guarded when sharing personal information with a peer, though even more so than with a health care professional. Peer-based or *alternate points of care* were further distinguished from traditional points of care in that peers were commonly described as more caring and altruistic. It is also generally easier for IDUs to get to the point with a peer. Participants also recognized, however, that some peers became street doctors or purveyors of drugs not to help others but solely for their own financial or addiction ends.

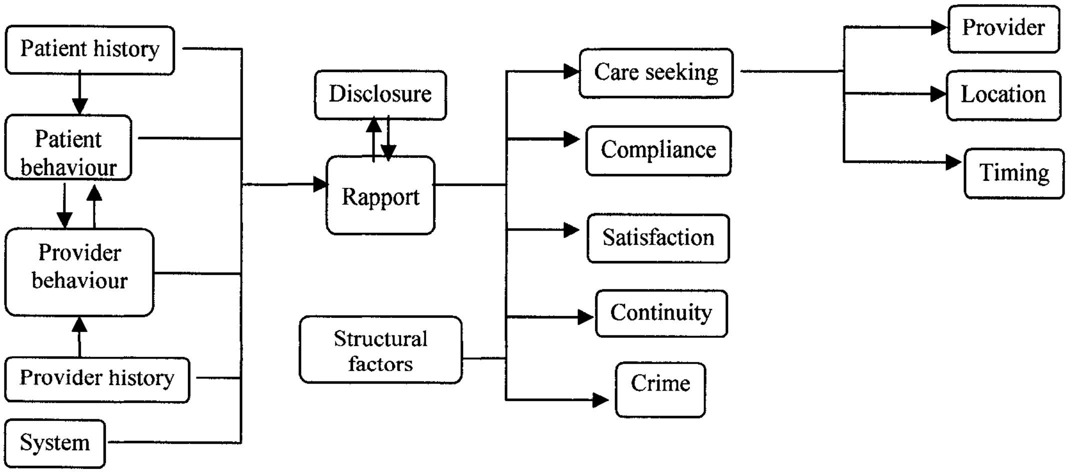
Participants confirmed the existence of multiple *outcomes of rapport*. Strong patient-provider rapport builds trust and patient satisfaction. The patient is more likely to see one provider and less likely to engage in "double doctoring". The patient is also more likely to follow through with a provider's recommendations. On the other hand, weak patient-provider rapport may discourage the IDU from seeking care at a particular location or from seeking any formal health care whatsoever. Because the IDU's expectations have not usually been addressed in such encounters, the person who injects drugs may turn to criminal activity to have their needs met. Thus, as demonstrated in the preceding cross-sectional as well as this qualitative study, rapport plays a crucial role in the IDU's health care choices.

Significance of Findings

Rapport, then, may be defined by people who inject drugs in a way distinct from that of the general population. Study participants confirmed that rapport involves many of the central tenets of the patient-centered clinical method—provider-patient communication, partnership, empathy, and continuity to name but a few (McWhinney, 1988; Cegala, 1997; Beck et al., 2002). Similarly, rapport includes many of the autonomy supportive elements identified in Self-Determination Theory, such as information exchange, shared decision-making, and empathy (Deci et al., 1994; Williams et al., 1998). However, participants also equated rapport with disclosure of drug use to a provider; this is, perhaps, an IDU-specific manifestation of patient-provider trust. In addition, participants made it very clear that rapport cannot exist nor be further developed unless a patient's drug acquisition needs are appropriately addressed. Bearing in mind this revised IDU definition of rapport, several factors are involved in its development, and a variety of service utilization outcomes depend on its influence.

Figure 5. Determinants and Outcomes of IDU-Provider Rapport.

Within a joint context of drug acquisition and health care needs...



How does provider-patient rapport relate to IDUs' experiences of health care and subsequent care-seeking behaviour? Positive patient-provider relationships, especially longer term, open relationships in which the patient who injects drugs feels comfortable voicing his drug-related concerns, are associated with positive health experiences and outcomes. In an environment of strong rapport, the patient and provider are better able to trust one another and the patient is more likely to be satisfied with the care received. Furthermore, because of this therapeutic interpersonal relationship in which the patient perceives that he or she matters, the patient is more likely to follow through with provider recommendations, access one health care provider on a routine basis, and seek out health care advice on a more timely basis. The rapport-related outcomes identified in these studies are not unlike established satisfaction and compliance outcomes reported in the literature on patient-centered care (Stewart, Brown, & Weston, 1989). Conversely, negative patient-provider relationships, particularly those in which patients who inject drugs do not feel that their expectations have been acknowledged, may play a major role in provider discontinuity, doctor shopping, delay in care-seeking, and avoidance of care. Criminal activity and its associated health and social risks may also be escalated as people who inject drugs seek other means of meeting their expectations. These negative outcomes are not commonly cited in rapport-related literature for the general population. In the literature specific to IDU populations, there clearly are several structural barriers to provider continuity, appropriate timing of care, compliance, and patient satisfaction, including competing priorities, a dearth of enabling resources, and bureaucratic obstacles (Downing et al., 2001; Chan et al., 2004; Drumm et al., 2003). However, interpersonal barriers to these same rapport-related outcomes have also been cited to a lesser extent (Weiss et al., 2004; Regen et al., 2002; Drumm et al., 2003; Pach et al., 2003). The research reported here strengthens the suggestion from these other studies that patient-provider rapport matters greatly to IDU health care outcomes, and confirms rapport's importance in the Edmonton inner city IDU context. The suggestion from Study 3 that participants linked failed patient-provider rapport to drug-related criminal activity suggests another as-yet poorly described health and social impact of rapport for this population.

What factors facilitate or prevent the development of rapport between users and their health care providers? A myriad of patient, provider, system-level, and within-encounter factors interact to assist or hinder IDU-provider rapport development. Patients who inject drugs often present in crisis and with unique needs associated with addiction and street life. Their behaviour is frequently unorthodox from the non-user's perspective but is a normal manifestation of their illness and life circumstances. Providers who care for drug injecting patients vary in their addiction and street expertise, past experiences, attitudes, and approaches to a position of authority. The external context in which health care encounters take place has not been set up to meet the often non-traditional needs of marginalized groups such as people who inject drugs or facilitate their access to care.

The provider-patient encounter itself provides the primary opportunity for rapport development. Some key issues drive the likely success of rapport-building efforts. First, perceived or real provider bias against IDU and patients who inject drugs, regardless of whether it is the primary provider or a team member, is likely to damage if not destroy rapport by discouraging patients from opening up or following through. In contrast, the maintenance of a drug using patient's dignity and very humanity creates a favourable rapport environment. Second, the provision of patient-centered and autonomy supportive care is central to effective IDU-provider rapport. Patients who inject drugs appreciate a provider's efforts to convey empathy, create a partnership in which common ground can be reached between both parties, and allow two-way communication to occur safely. Third, drug acquisition is an overwhelming priority for most individuals who inject drugs, and health care encounters are no exception. Failure to address this key patient expectation during the encounter effectively obviates the opportunity for further rapport development. There is a lack of a physician-wide standard for dealing with drug prescription requests, and many providers adhere to non-individualized prescription rules and patterns; this encourages many IDUs to selectively disclose information and devote much of the encounter to proving the legitimacy of their request via carefully crafted stories, physical findings, and offers of compromise. The relative success of these negotiation strategies in fulfilling the patient's and provider's agendas contributes to the extent of rapport established between the two parties.

The IDU-provider rapport literature identifies many of the above determinants of rapport. Higher level bureaucratic obstacles, wait times, and unrealistic client expectations create an unfavourable milieu for rapport (VanderWaal et al., 2001; Porter, 1999; Drumm et al., 2003), as do a provider's negative attitudes towards IDU, inexperience with addiction and pain management, and concerns about disregard for their authority (Yedidia & Berry, 1999; Clarke, 1993; Gerbert et al., 1991; Breitbart et al., 1999). Patients who inject drugs assign a lower degree of severity to illness and priority to health care (Morrison et al., 1997; Noël et al., 2006), and their street-appropriate behaviour does not translate well to the health care context (Wild et al., 2003b; Grund et al., 1996). Discrimination against people who inject drugs and associated selective disclosure are commonly described; on the positive side, provider empathy, listening skills, flexibility, and concern remain important (Weiss et al., 2004; Drumm et al., 2003; Regen et al., 2002). What are not well described in the literature are the selective disclosure, proof of legitimacy, and other IDU negotiation strategies developed as a response to inconsistent, provider-centric standards for drug-related requests during health care encounters. Negotiation no doubt occurs in other communities but the specific strategies used may differ from those described by members of Edmonton's inner city community. In addition, the research findings presented here emphasize the influence of addiction itself on an IDU entering a provider-patient relationship, and de-emphasize the importance of pre-existing self-efficacy and personal motivation as reported in other publications. Instead, participants confirmed the importance of perceived autonomy supportiveness by their primary care provider at the time of the encounter itself, which may subsequently lead to improved self-efficacy and intrinsic motivation as posited in Self-Determination Theory.

What informal, peer-based points of health care exist in Edmonton's injection drug using community, and how do they compare to formal health care services? Participants accessed their peers for health care needs, and some participants, particularly those without an identifiable family doctor, cited peers as their primary point of health care. However, qualitative study participant experiences suggest that many peer-based health care encounters are limited to obtaining a prescription from a "street doctor" as opposed to any other primary care provision or consultation with a Natural Helper. Also noteworthy is that other participants view their peers' ability to help with a certain level of suspicion and tend to avoid informal points of care as a result. There does not therefore appear to be a specific pattern of use of peers for health-related problems. Nonetheless, among those participants who reported accessing peers for their health-related needs, patient-centered care is a primary reason for doing so. Though negotiation strategies are usually simpler on the street, some approaches, such as reliance on instinct and careful disclosure of information, are similar to those used in formal health care settings. In keeping with the previously documented, generally favourable response of other IDU populations to peer outreach programming and lay caregivers (Drumm et al., 2005; Regen et al., 2002; Taylor & Jasperson, 2001), these research findings suggest that a significant proportion of Edmontonians who inject drugs are comfortable accessing care from their peers and see them as a legitimate alternative to formal health care. Though not all users may be reached via peer outreach initiatives, there may be potential positive health outcomes from supporting these peer-patient relationships.

Is perceived autonomy supportiveness of a primary health care provider positively associated with service utilization among IDUs? Perceived autonomy supportiveness of a primary health care provider, as measured by the Health Care Climate Questionnaire administered in Study 2, is associated with higher patient satisfaction with care, and to a lesser extent with decreased EMS transportation to the ED and decreased night shift presentation to the ED. These satisfaction and timely access outcomes of positive rapport were confirmed during follow-up interviews. Similar rapport-related constructs—compassion, two-way communication, and adaptability, for example—have previously been shown to have a positive influence on IDU health care outcomes (Weiss et al., 2004; Regen et al., 2002). Confirmation of this association between rapport and health care experience and utilization in the research presented here suggests that the HCCQ may be a useful way to measure patient-provider rapport in the context of IDU health care. The HCCQ's use in this setting may, however, need to be augmented by measures of drug use disclosure and fulfilment of drug prescription expectations to fully capture the IDU's concept of rapport.

Limitations

All three studies in this series were exploratory in nature and therefore small in size. Small, purposive samples are common in qualitative research, where the purpose of the research is not to extrapolate findings to larger populations but rather to explore under-researched areas of inquiry or deepen one's understanding of previously observed phenomena. With respect to the quantitative sample, the cross-sectional study sample size was constrained by termination of funding and therefore recruitment efforts, as well as the limited availability of participant UIs. Though most participants were willing to consent to UI release, few had valid UIs readily available at the time of the interview or returned to provide this number within the time frame allowed, and the research team did not have ethics board approval to obtain UIs through third party channels. Ideally, the quantitative study would have benefited from a larger sample size, as it was underpowered to predict many other rapport-utilization associations. However, the use of mixed methods to address the research objectives and the similarity of findings across all three studies strengthens the likelihood that the observed associations between rapport and health care utilization indeed exist.

Sampling was also non-random. Truly random sampling would have been impossible with a population known for its mobility, limited telephone access, negative experience with authority figures, and general marginalization. The most feasible means of access to the population of interest was to employ chain-referral and purposive sampling techniques in partnership with community agencies who serve IDUs. The resulting study population represented the best connected and likely least marginalized IDUs in Edmonton's inner city. Females, younger and newer users, severely ill individuals, and those users in treatment or in jail were under-represented because they tend to access participating agencies outside of usual business hours if at all. These groups may have responded differently. For example, females who inject drugs may possibly behave differently than their male counterparts; they may also prefer female health care providers, or perceive a greater provider-patient power differential as a result of their gender.

The findings presented here likely also overlap with both the general population as well as other marginalized populations such as people infected with HIV, urban Aboriginals, the marginally housed, crack cocaine users, and sex trade workers. It is reasonable to assume that these other marginalized groups also experience stigma during health care encounters, share certain frustrations with provider inexperience and bureaucratic obstacles, and respond similarly to failed rapport with a change in health care utilization. This may explain the lack of a difference between participants and a more general inner city population with respect to EMS transportation rates, diagnoses, or disposition patterns. A non-IDU inner city control group would have addressed this concern but was beyond the scope of this exploratory research. Alternatively, the population of interest could have been expanded beyond people who inject drugs to include street-involved individuals or inner city residents in general. Had this approach been taken, however, the influence of addiction and drug prescription on the encounter would have appeared deceptively minor despite playing an unmistakably central role for participants. Though crack cocaine users may have even these addiction-related issues in common with the study population, Edmonton agencies are currently able to provide only minimal harm reduction programming specific to these users and recruitment may have been difficult. However, given the local context of polysubstance use, it is likely that the experience of crack cocaine users is also represented in this body of research. Nonetheless, despite likely overlap with other groups, people who inject drugs experience patient-provider rapport in a unique way.

Further to sampling constraints, there are also limitations to the data collection methods chosen. For the quantitative study, a combination of self-report data and retrospective administrative data were collected. Self-report data are prone to recall bias and may reflect what respondents ideally believe of themselves or perceive the interviewer to want as an answer. Multiple interview items may have contributed to patient fatigue and inaccuracy of subsequent responses. However, to improve their validity, self-report data were augmented by administrative data and triangulated with qualitative interviews.

Administrative data are limited by the availability and validity of collected UIs. Diligence in initial documentation by front-line staff, data entry, and choice of utilization measures maintained by the data custodian pose additional potential limitations. Indeed, fewer UIs were available than had been anticipated, and other Edmonton inner city research raises the possibility that the actual UIs employed by participants during the study period differ from the ones presented to the research team or that those UIs presented are employed by several individuals (Owens et al., 2005). A more reliable identifier unfortunately does not exist. Problems were also encountered with the comprehensiveness of wait time data to the point that this measure could not be examined. Administrative data rely heavily on physician contact and sparingly on contact with other health care team members. Capital Health data in particular are limited to encounters which occur within Capital Health facilities and offer no insight into community physician, community nursing, or peer utilization patterns. Nevertheless, collected data demonstrate an association with rapport and service utilization based on available measures and justify more comprehensive study of this association.

A retrospective study design was chosen to test the hypothesis that perceived autonomy supportiveness of a primary health care provider would be positively associated with service utilization among IDUs. As a result, it cannot be determined from this study whether a causal link exists between perceived autonomy supportiveness and utilization. It is even possible that the relationship between the two is cyclical rather than linear. However, a cross-sectional approach to this little-tested hypothesis has allowed the determination of a rapport-utilization relationship before examining the direction of the relationship.

The dual role of the primary researcher as both researcher and inner city primary care provider held the potential for role conflict, participant response bias, and preconceived data interpretation. As described in the preceding chapters, significant efforts were made to mitigate these potential problems, including blinding of the researcher to identifying IDU participant information whenever possible, exclusion of those participants who had previously received care from the researcher where blinding was not possible, and review of the researcher's analysis by another researcher as well as Streetworks staff and participants. The researcher's previous field experience may conversely have increased participant comfort and improved analytic accuracy.

Further Study

The demonstration of an association between IDU-provider rapport and health care utilization warrants additional examination in a larger, prospective cohort study. The use of the HCCQ as a baseline rapport measure could be complemented by drug use disclosure and successful drug acquisition measures to reflect the IDU understanding of rapport. Additional utilization outcome measures derived from administrative data might include the number of visits to a primary physician and the number of different physicians seen; these data are available from Alberta Health and Wellness. Self-report items assessing which, if any, forms of criminal activity participants engage in after being denied a prescription could further elucidate the relationship between failed rapport and crime.

Both the determinants and the outcomes of rapport revealed in these studies have not been thoroughly explored among the most marginalized members of Edmonton's IDU community. New sampling strategies may need to be used to determine whether these research findings apply to less well connected IDUs or to users of crack cocaine and other street drugs. Recruitment strategies could involve the formation of additional partnerships with other local agencies, such as those agencies targeting sex trade workers or people living with HIV. Recruitment at night using mobile needle exchange services is another possibility.

Potential solutions to the rapport-related problems uncovered in this body of research have not been systematically assessed. Peer outreach, provider education, and patient education initiatives, though informed by existing research, risk lacking in comprehensiveness, accuracy, and acceptance without additional stakeholder consultation. The development of prescription-specific clinical practice guidelines in particular appear to be a favoured approach by participants; however, participants did not offer any consistent recommendations as to their content. Such practice guidelines would not only be subject to legal and ethical requirements, such as the need to recognize and prevent further deterioration of an addiction, but would also need to balance general approaches with individual patient needs. In addition, the existence of educational opportunities and published practice standards does not guarantee their use by their intended audiences. Further focus groups involving the expertise of people who inject drugs, front line health care professionals, health promotion experts, and professional licensing bodies may be an ideal venue in which to determine the ideal, most feasible strategies to effect a positive influence on IDU-provider rapport.

Implications

Bearing in mind this need for a formal consultation process, there are several possible ways in which IDU-provider rapport can be enhanced. The simple inclusion of patients who inject drugs in both research dissemination and future direction may foster a better relationship with health care providers as a whole. The significant expertise of lay health providers would be an invaluable asset to health educators and policymakers. In the other direction, patients who inject drugs stand to benefit from educational initiatives around existing professional standards for the management of addiction as well as an orientation to the biomedical cultural model and the health care system. Such initiatives, jointly with other advocacy work like outreach worker accompaniment to medical appointments, may improve IDUs' ability to navigate health care encounters and communicate their needs.

Provider-specific interventions are also warranted. Health professional training, in particular medical training, has traditionally relied on a systems-based approach (e.g. cardiology or gynaecology); dedicated time to knowledge and skill acquisition in the systems-independent areas of addiction, pain management, harm reduction principles, and cultural competence would enhance existing curricula devoted to the patient-centered clinical method. Training opportunities need not only be at the undergraduate level or classroom-based, but also include field experiences and exposure during post-graduate education, continuous professional learning, and workplace orientation. As with patients in other clinical training environments, patients who inject drugs could take an active role in the training and assessment of students.

At the health care system level, existing professional standards for the prescribing of controlled medications and the management of addiction and chronic pain may warrant review and consideration of the patient-provider relationship as recommended by research participants. Other practical interventions include the provision of financial and infrastructure support for harm reduction and other inner city primary care initiatives, such that associated providers can devote more attention to cultivating rapport. The use of ombudspersons and / or cultural liaisons (i.e. individuals with prior street or injection experience) in health facilities could further bridge the divide between street-involved IDUs and formal health care service providers.

Conclusions

Patient-provider rapport in the health care of people who inject drugs is determined by multiple patient, provider, and system characteristics such as provider expertise and attitudes, patient behaviour, and the illness of addiction itself. Within the IDU-provider encounter, rapport is improved or worsened in response to the level of perceived discrimination and autonomy supportiveness on the part of the provider as well as the relative success of negotiation strategies used by both parties to fulfill their expectations. Drug acquisition is central to patient-provider encounters and dictates provider and patient behaviour; selective disclosure of patient information is the norm. Peer-based points of care may be an acceptable, autonomy supportive alternative for many people who inject drugs. Effective patient-provider rapport has the potential to improve IDU compliance with recommendations, timing of health care access, provider continuity, avoidance of criminal activity, and satisfaction with care.

The relationship between a person who injects drugs and a primary care provider has an important impact on the patient's health. Nurturing this relationship holds the potential to significantly improve health outcomes for people who inject drugs.

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Appendix A: IDU focus group information letter and consent form

Title of the Project: Social Dynamics of Injection Drug Use (2): Pilot Study
Principal Investigator: Dr. C. Wild, supervisor (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Background. Injection drug users (IDUs) are at risk of poor health. However, they may have to put off getting health care for various reasons. One of the challenges that users face is the relationship they have with their health care providers. We know very little about this relationship.

Purpose. A group from the University of Alberta is working with Capital Health, Streetworks, and Boyle-McCAuley Health Centre. We are trying to better understand the needs and strengths of the IDU community. The purpose of this study is to explore the relationship between IDUs and their health care providers. We are asking you to participate in this session to share your point of view as an IDU.

Procedures. This session will take place in Boyle Street Community Services. It will last no more than two hours. Refreshments will be provided. Two interviewers, some fellow users, and Streetworks outreach workers will be present. There will be no health care providers present. We will hold a separate session with them. We will audiotape and transcribe the session to help us review your comments. With your consent, we will re-contact you to participate in a review session lasting no more than one hour.

Potential Benefits. You will help us understand the relationship between IDUs and their health care providers. This study may identify ways to improve this relationship. You will receive information and referrals to services that you ask for.

Potential Risks. We may ask personal or sensitive questions that may upset you. You may leave the interview if you feel uncomfortable. If you are very upset, we will refer you to health services.

Confidentiality. We will keep your name confidential. We will use only a code number on the interview sheets. Nobody will ever be able to link your answers to you personally. You can refuse to answer any question. You can stop the interview at any time. We will keep all information confidential, except when professional codes of ethics and/or legislation require reporting. We will report all of the information gathered with no way to identify you personally. No one except those people at the session, including staff from any of the agencies involved in the study, or any other agency, will know what you have said. We will store all study data for at least 7 years after the study has been completed. We will keep study data in a secure area accessible by only the research team. After that time it will be destroyed.

Freedom to Withdraw. You are free to withdraw from the study at any time without penalty or loss of your financial reimbursement. Your right to treatment at any agency will not be affected by whether you complete the interview or not.

Reimbursement of Expenses. To thank you for your time and information, we will give you $20 for participating whenever each session ends.

If you have concerns about this study, call the Health Research Ethics Board at 492-9724. You may also contact the investigators at any time during your participation in the study.

Title of the Project: Social Dynamics of Injection Drug Use (2): Pilot Study
Principal Investigator: Dr. C. Wild, supervisor (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care or your financial reimbursement.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No
Do you consent to being contacted in the future for a follow-up session?	Yes	No

This study was explained to me by: ______________________________

I agree to take part in this study. Yes No

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee	Date

A copy of this consent form has been given to you to keep for your records and reference. Thank you for your consideration.

Appendix B: Provider focus group information letter and consent form

Title of the Project: Social Dynamics of Injection Drug Use (2): Pilot Study
Principal Investigator: Dr. C. Wild, supervisor (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Background. This study is part of a larger exploration of the social context of injection drug use, within the drug using community itself as well as within the health care setting. Providing physical tools for safer injection is necessary, but not sufficient, for the prevention of HIV and HCV transmission. We need to understand social relationships among injection drug users and how these influence protective or unsafe injection practices. In an earlier study, we conducted in-depth interviews with people who inject drugs about their relationships and designed a new instrument (Assessment of Risk Contexts, or ARC) to measure social aspects of IDU. We hope that ARC will help us and other service providers to modify outreach programs and treatment services. Interpersonal issues also play a role within the health care setting. Although injection drug users are at higher-than-average risk of poor health, they may underutilize and delay utilization of health care services for a variety of reasons. The rapport between injection drug users and their health care providers is one of the potential barriers to health care utilization faced by users, but not a lot is known about this relationship.

Purpose. The University of Alberta's Addiction and Mental Health Research Lab is working with Capital Health, Streetworks, and Boyle McCauley Health Centre to help us better understand the social and environmental contexts surrounding injection drug practices and health care utilization. The purpose of this study is twofold: (1) to review and provide feedback on the newly developed Assessment of Risk Contexts (ARC) instrument, and (2) to explore the development of rapport between injecting drug using patients and their health care providers and the influence of rapport on health care utilization. You are being asked to participate in this study to share your point of view as an experienced provider of health services to injection drug users.

Procedures. After receiving your consent for participation, we will e-mail or fax you a copy of the ARC instrument and ask you for your written feedback on the instrument questions, including the wording and appropriateness, as well as the relevance of the questions to your daily practice with injection drug users. Review and feedback of the instrument will take approximately one hour of your time. You will be asked to bring your copy of the instrument to the focus group session, at which time we will hold a brief group discussion about the instrument in addition to a discussion about rapport between injection drug users and their health care providers. This focus group interview session will take place at the Boyle McCauley Health Centre and will last no more than two hours. Refreshments will be provided. Two moderators and other health care professionals will be present. There will be no injection drug users present; a separate session will be held with them. The session will be audiotaped and transcribed verbatim to assist with subsequent analysis. With your consent, you will be re-contacted via fax or e-mail to review and provide brief written feedback on the rapport-related themes arising from the analysis of this session; this second request for feedback should take approximately fifteen minutes.

Potential Benefits. You will help us improve a new instrument to measure social relationships and their potential relationship to injection practices and health care utilization. You will also help us better understand the nature of the rapport between injection drug users and their health care providers from the provider's perspective. The findings of this study may identify possible ways to improve this relationship and may assist you in developing intervention strategies for people who inject drugs.

Potential Risks. We may ask personal or sensitive questions that may upset you. If you are uncomfortable during the interview, you may leave the interview. If you are very upset, we will refer you to counselling services at your request.

Confidentiality. Your name will be kept confidential, and only a code number will be used on the interview sheets. Nobody will ever be able to link your answers to you personally. You can refuse to answer any question and you can stop the interview at any time. All information will be kept confidential, except when professional codes of ethics and/or legislation require reporting. All of the information gathered from the interviews will be reported with no way to identify you personally. No one except those people at the session, including staff from any of the agencies involved in the study, or any other agency, will know what you have said. All study data will be kept for at least 7 years after the study has been completed, in a secure area accessible by only the research team. After that time it will be destroyed.

Freedom to Withdraw. You are free to decline participation or withdraw from the study at any time without penalty.

If you have concerns about how this study is being conducted, call the Health Research Ethics Board at 492-9724. You may also contact the investigators at any time during your participation in the study.

Title of the Project: Social Dynamics of Injection Drug Use (2): Pilot Study
Principal Investigator: Dr. C. Wild, supervisor (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No
Do you consent to being contacted in the future for your feedback on study findings?	Yes	No

This study was explained to me by: ______________________________

I agree to take part in this study.	Yes	No

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee	Date

A copy of this consent form has been given to you to keep for your records and reference. Thank you for your consideration.

Appendix C: IDU focus group questions

Demographic information (collected prior to audiotaping and recorded on a separate sheet for each participant)

Age
Gender
Education level completed (elementary school / junior high school / high school / post-secondary diploma or degree)
Number of years engaged in IDU
Preferred point of health care (hospital physician / family physician / other community physician / community nurse / peer / none)
Self-reported health status (good / fair / poor)
Drug of choice (opiates / cocaine / amphetamines / other)

Focus Group Questions

1. What do you do to get help when you're not healthy?
    Why?

2. Think back to a good experience you've had with health care. Describe it for me.
    Why was this experience good?

3. Think back to a *bad* experience you've had with health care. Describe it for me.
    Why was this experience bad?

4. What might make you willing to see a doctor or nurse?
    What might keep you from seeing a doctor or nurse?
    Does it matter if you see your regular doctor or nurse?
    Does the person's profession, for example, doctor vs. nurse, matter?

5. What do you expect from a visit to a doctor or nurse?
    Do you think this is what the doctor or nurse expects?
    Are your expectations usually met?
    What happens when you tell a doctor or nurse that you inject?
    How does location, such as in-hospital vs. out-of-hospital, change how you are treated? Which hospitals and clinics are good ones? Why?

6. How do you get your point across when you go see a nurse or doctor?
    Does your strategy change depending on the location?
    How is your communication strategy the same as the one you use on the street?
    How is your communication strategy *different from* the one you use on the street?

7. What do health care workers say or do that make you feel comfortable?
    What do health care workers say or do that make you feel *un*comfortable?

8. How might a patient say or do things that help the doctor-patient relationship?
    How might a patient say or do things that *hurt* the doctor-patient relationship?

Appendix D: Provider focus group questions

Demographic information (collected prior to audiotaping and recorded on a separate sheet for each participant)

Age
Gender
Occupation and workplace
Number of years in health care
Estimated number of IDU patient encounters per week

Focus Group Questions

1. What do you expect when providing care to an injection drug user?
    - What is your role during these encounters?
    - What are their most common presenting complaints?
    - What are their most common diagnoses?
    - What diagnostic codes do you tend to use in the IDU setting? Why?
    - Do you think injection drug users share your expectations of health care encounters? Why / why not?

2. Think back to a good experience you've had while providing care to IDUs.
    - Describe it for me.
    - Why was this a good encounter?

3. Think back to a *bad* experience you've had while providing care to IDUs.
    - Describe it for me.
    - Why was this a bad encounter?

4. How might rapport be important in the health care of injection drug users?
    - What are the consequences of good rapport with injection drug users?
    - What are the consequences of *poor* rapport with injection drug users?

5. When caring for IDUs, what patient behaviours and personal characteristics help establish rapport?
    - What behaviours and personal characteristics *hinder* the establishment of rapport?

6. When caring for IDUs, what health care provider behaviours help establish rapport?
    - What health care provider behaviours *hinder* the establishment of rapport?

7. How do interactions between the IDU, the primary provider, and other members of the health care team influence the development of rapport?
    - What are the effects of IDU-*primary* provider rapport on subsequent health care?

Appendix E: Assessment of Risk Contexts (ARC) Interview Protocol

Study ID ______

ASSESSMENT OF RISK CONTEXTS (ARC) INTERVIEW

Draft version 0.7

Date (mm/dd/yy)

Location 1 BMHC
2 Coop
3 Other

Interviewer (initials)

Time (minutes)

Interviewer notes (record after completing the interview)

1 Male
2 Female

Is the information collected in the interview significantly distorted by the participant's misrepresentation?

1 No
2 Yes
3 Not sure

Is the information collected in the interview significantly distorted by the participant's inability to understand?

1 No
2 Yes
3 Not sure

Introduction

Thanks for agreeing to participate today. In this interview, I will be asking you a series of questions about **yourself, what kinds of drugs you use, your injection practices, and your opinions about other drug users.** ***I'll also ask you questions about who you hang out with. Remember: everything that we talk about is strictly confidential. No one other than the research team will ever see your answers.***

The whole thing will take about an hour and a half. But, we'll take a break half way through. Remember, you can also stop at any time and you can skip any questions you like.

SECTION 1

ABOUT YOU

1. How old are you? __ years

2. What is your gender?
1 Male
2 Female
3 Transgendered

3. Which of these groups do you identify with?
1 White
2 First Nations
3 Metis
4 Other _____________

4. What is the highest level of education that you have attained? (*Please mark one box with a checkmark*)
1 Some Junior High school
2 Completed Junior High school
3 Some high school
4 Completed high school
5 Some college
6 Completed college
7 Some undergraduate university
8 Completed undergraduate university
9 Some graduate university
10 Completed graduate university

5. *(Are you in a relationship right now?)*
What type of relationship is it?
1 Single (includes never married, widowed, separated, divorced)
2 Legally married
3 Common-law/living as married
4 Same sex couple
5 No response
6 Other ______

6a. Have you had any children? (If no, skip to #7)
1 No
2 Yes → How many? ____
3 Don't know
4 Refused

6b. Do you look after them?
1 No
2 Yes → How many? ____
3 Don't know
4 Refused

6c. What percentage of your time have you spent looking after your children in the past 30 days?
________%

7. What is your current legal status? *(Check all that apply)*
On parole
On probation
Serving a conditional or community sentence
Under bail, pending charges, or warrant
Fines
Other
Under no judicial restraint *(None of the previous options apply)*

Now, I would like to ask you some questions about your living situation.

8a. How long have you lived in Edmonton? _________ *(If 'current age', skip to Q9a)*

1 = days
2 = weeks
3 = months
4 = years

8b. Where did you live <u>just</u> before you came to Edmonton? ___________
8c. In the last year, did you leave Edmonton for 2 weeks or more?
1 No
2 Yes → Where? ________________________
3 Don't know
4 Refused

9. ***I'm going to read a list of places you may have slept in the last 30 days.*** Which of these places have you slept in during the past 30 days? *(Check all that apply).*

A. **Own apartment/house** -(#)- (length)	E. **Friend's Place** -(#)- (length)	I. **Reserve or Settlement** -(#)- (length)	M. **Hospital** -(#)- (length)
B. **Boarding house/hotel /furnished room** -(#)- (length)	F. **Family member's place** -(#)- (length)	J. **Couch surfing** -(#)- (length)	N. **Street** -(#)- (length)
C. **Transition Housing** -(#)- (length)	G. **Camps (squatting)** -(#)- (length)	K. **Detox** -(#)- (length)	O. **Don't sleep (walk all night)** -(#)- (length)
D. **Hostel/Shelter** -(#)-- (length)	H. **Working out of town (rigs/camp)** -(#)- (length)	L. **Jail/prison** -(#)- (length)	P. **Other** __ -(#)- (length)

10. Do you live with anyone? *(Mark **all** that apply with a checkmark)*
1 Alone
2 With family
3 With friends
4 With partner
5 With roommate(s)
6 With other residents (e.g., in a shelter)
7 With children
8 Other: (please specify) ____________________

11. How would you describe your living situation? *(Would you say...)*
1 Very unstable
2 A little unstable
3 Neither unstable or stable
4 A little stable
5 Very stable

12. How satisfied are you with your living situation? *(Would you say...)*

1 Very unsatisfied
2 A little unsatisfied
3 Neutral
4 A little satisfied
5 Very satisfied

13. How easy would it be for you to change where you're living right now if you wanted to? *(Would you say...)*

1 Very difficult
2 Difficult
3 Neutral
4 Easy
5 Very easy

14. Does your living situation change depending on the season?

1 No
2 Yes
3 Don't know
4 Refused

15a. Where does your mail go? *(Record first 3 letters of postal code)*____
15b. Is this postal code different than your current residence?

1 No
2 Yes
3 Don't know
4 Refused

Now, I am going to ask you some general questions about your income. I'm interested in wherever you get your money, legal or not.

16. How much cash/money did you make in the past 30 days? *(Includes legal and non-legal sources of income as well as assistances cheques)*

1 $0-$100
2 $100-$500
3 $500-1000
4 $1000-2000
5 $2000-3000
6 $3000 +

17. How much could you get for all your stuff if you were to take it to the pawn shop today?
1 $0-$100
2 $100-$500
3 $500-1000
4 $1000-2000
5 $2000-3000
6 $3000 +

18. In the last 30 days, have you been legally employed? *(Does not include 'under the table' work)*
1 No
2 Yes→ How many days in the last month have you worked on average? ___
3 Don't know
4 Refused

Next, I would like to know how easy it is for you to get the following things.

19. How easy or difficult is it for you to get the food that you need?
1 Very difficult
2 Difficult
3 Neutral
4 Easy
5 Very easy

20. How easy or difficult is it for you to be physically alone when you want to?
1 Very difficult
2 Difficult
3 Neutral
4 Easy
5 Very easy

21. How easy or difficult is it for you to get clean water to wash yourself?
1 Very difficult
2 Difficult
3 Neutral
4 Easy
5 Very easy

22. How easy or difficult is it for you to get the drugs you use?
1 Very difficult
2 Difficult
3 Neutral
4 Easy
5 Very easy

Now, I would like to ask you about your drug use, injection practices, locations where you might inject, and situations which may happen when injecting with other people.

23. At what age did you start regularly injecting? ________ (age)

24a. Are you able to fix yourself? If yes, do you ever need help or prefer to be fixed?
1 No
2 Prefer not to fix myself, but I can. By Whom (*Relationship Only*)? __________
3 Sometimes I need help to fix By Whom (*Relationship Only*)? __________
4 Yes By Whom (*Relationship Only*)? __________
5 Don't know
6 Refused

24b. Do you actively try to hide where you inject on your body from other people?
1 No
2 Yes
3 Don't know
4 Refused

25. How many times, if any, have you stopped injecting for a period of 6 months or longer?
_________ (number of times)

26. ***We also know that there are many ways to pay for drugs.*** In the last 30 days how have you paid for your injection drugs? (Check all that apply)

☐ Prescription
☐ Trade other drug, pills, alcohol, or drug of choice
☐ Non-Specific "Favours" (Allow someone to sleep at my place, allow someone to fix at my place, baby sitting, running)
☐ *We are Friends... and friends share drugs*
☐ Receive payback for sharing drugs previously
☐ No payment required in any form
☐ Boosting/Trading stuff
☐ Sex exchange
☐ Selling/Dealing drugs
☐ "Chipping in"/contributing to group purchase
☐ Taking the drug/Stealing
☐ Other: __________________________ *(specify)*

27. How much money *(cash)* have you spent on drugs in the last 30 days? __________

Now I would like to ask you about you about the drugs you've used in the past 30 days and how you have used them.

28a. In the **last 30 days**: **Which** of these **drugs** did you use? *(Please read the list and mark **as many** boxes as applicable in column I on the following pages with a checkmark)*

28b. In the **last 30 days**: On **how many days** did you use **each drug**? *(Please read the drugs marked with a checkmark and indicate the number of days of use in column II on the following pages).*

28c. **How** did you take **each drug**? *(Please mark the letter(s) of the route of administration in column III on the following pages. [**O**ral, **N**asal, **S**moked, **I**njected]*

		Drug	**# of days in the last 30 days**	**Route of admin.**
☐	a.	Alcohol		
☐	b.	Marijuana		
☐	c.	Cocaine		
☐	d.	Crack		
☐	e.	Oxycontin/Oxycodone (greys)		
☐	f.	Dilaudid (dillies)		
☐	g.	Percocet or Percodan		
☐	h.	Methadone (from treatment)		
☐	i.	Methadone (from street)		
☐	j.	T3s, T4s (any codeine)		
☐	k.	Morphine (liquid)		
☐	l.	Demerol		
☐	m.	Heroin		
☐	n.	Talwin & Ritalin		
☐	o.	Speed/methamphetamines/ crystal meth		
☐	p.	Ecstasy/MDMA		
☐	q.	Valium and Benzoodiazepines		
☐	r.	Downers (e.g., barbiturates)		
☐	s.	Speedballs		
☐	t.	Hash		
☐	u.	Mushrooms		
☐	v.	Acid		
☐	w.	Inhalants		
☐	x.	Kadian (Morphine Sulphate)		
☐	y.	Codeine Phosphate/Sulphate		
☐	z.	Other: ______ *(specify)*		

People inject in a variety of locations. I'd like to ask you about the places where you have injected drugs in the last 30 days

29a. In the last 30 days, in **how many** of the following places have you injected drugs?

29b Of all the times you injected in the last 30 days, **how many days** did you inject in these locations?

29c **How many** other people were using drugs (injection and non injection) at this location?

A. **<u>Your own</u> apartment, room, house or living space** ___ (# of times) __ (# of people)	E. **A car or other vehicle?** ___ (# of times) __ (# of people)	I. **Massage Parlour or Escort Agency** ___ (# of times) __ (# of people)
B. **Your <u>partner's, friend's, or relatives'</u> apartment, room, house, or other living space** ___ (# of times) __ (# of people)	F. **Service Facility (Co-op, BMHC, etc)** ___ (# of times) __ (# of people)	J. **Prison** ___ (# of times) __ (# of people)
C. **An <u>acquaintance's or stranger's</u> apartment, room, house, or other living space** ___ (# of times) __ (# of people)	G. **A public facility (e.g. library, LRT, or mall)** ___ (# of times) __ (# of people)	K. **Some other place** Specify:__ ________ ___ (# of times) __ (# of people)
D. **An abandoned building (but none of the previous)** ___ (# of times) __ (# of people)	H. **Some place outside (e.g. camp, a park, an alley, or a vacant lot)** ___ (# of times) __ (# of people)	L. **Some other place** Specify:___ _______ ___ (# of times) __ (# of people)

30. <u>How many</u> of these places were "shooting galleries"? __

31. <u>How many</u> of these places were "crack houses"? ____

32. <u>In the last year</u>, how often have you had trouble getting the following things you need to fix? *(Display scale below and review response options. Record response in the table provided below).*

1 Never	2 Rarely	3 Sometimes	4 Often	5 All the time	6 NA

Supplies	Weekdays	Weekends	Do you pick up these supplies? 1 = No 2 = Yes 3 = Sometimes
A. Needles			
B. Water			
C. Filters			
D. Ties/Tourniquet			
E. Container			

Now I'm going to ask you some questions and I would like you to tell me how often, if at all, this happened to you in the last year. You can answer using this scale *(Display scale below and review response options).*

1 Never	2 Rarely	3 Sometimes	4 Often	5 All the time	6 NA

How often has this happened to you in the last year…?

____ 33. When I am really high and fixing with a group of people, I can't pay attention to everything that is going on around me.

____ 34. I am worried about getting a virus because sometimes spoons and rigs can get switched when other things are going on.

____ 35. I picked up enough new needles for everyone I fix with.

____ 36. I stopped someone from putting a used rig into a shared spoon/container.

____ 37. I fixed beyond my normal limit.

____ 38. I have been dope sick.

____ 39. I fix with strangers.

Now I would like to ask you some health questions. Remember, nobody but our research team will know your answers.

40. Have you ever gone for formal addiction treatment for your drug use, for example, from a doctor, MMT, or an AADAC treatment program?

1 No
2 Yes
3 Don't know
4 Refused

41. How satisfied are you with your life in general?

1 Very unsatisfied
2 A little unsatisfied
3 Neutral
4 A little satisfied
5 Very satisfied
6 Don't know
7 Refused

42. In general, would you say your <u>physical</u> health is: *(Read the list below and mark **one** box with a checkmark)*

1 Excellent
2 Very good
3 Good
4 Fair
5 Poor
6 Don't know/can't say

43. In general, would you say your <u>mental</u> health is: *(Read the list below and mark **one** box with a checkmark)*

1 Excellent
2 Very good
3 Good
4 Fair
5 Poor
6 Don't know/can't say

44a. Do you have at least **one doctor** that you see regularly for **general health care** (e.g. check ups)? *(Please mark **one** box with a checkmark)*

1 Yes → Proceed to Q44b
2 No → Proceed to Q45

44b. How many times have you seen your regular doctor in the past year? _________

44c. Does your regular doctor know the extent of **your drug use**? *(Please mark **one** box with a checkmark)*

1 Yes
2 No

45. How many other doctors have you seen in the past year? ________

46. If you have a choice, where do you prefer to get your health care? *(Please mark **one** box with a checkmark)*

1 Own (family) physician
2 Nurse
3 Peer
4 Hospital physician
5 Other community physician
6 None

Now, I would like to talk to you about your relationships with doctors. For the following 6 questions, please answer according to your experience with the doctor you see most often for health care reasons. *(If you do not see one doctor regularly, please answer the questions based on your usual experience with doctors. Display scale below and review response options.)*

1 Strongly Disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly Agree	6 NA

| _____ 47. I feel that my doctor has provided me choices and options.

| _____ 48. I feel understood by my doctor.

| _____ 49. My doctor conveys confidence in my ability to make changes.

| _____ 50. My doctor encourages me to ask questions.

| _____ 51. My doctor listens to how I would like to do things.

| _____ 52. My doctor tries to understand how I see things before suggesting a new way to do things.

| _____ 53. I am really satisfied with the care my doctor gives me.

Now I would like to talk to you about infectious diseases, like hepatitis and HIV

54. Based on your current situation and behaviour, how would you **rate** your **risk of getting infected** with **Hepatitis C**? *(Please read the scale and mark* ***one*** *box with a checkmark)*

1 Very unlikely
2 Unlikely
3 50/50
4 Likely
5 Very likely
6 Hep C+

55. Based on your current situation and behaviour, how would you **rate** your **risk of getting infected** with **HIV**? *(Please read the scale and mark* ***one*** *box with a checkmark)*

☐ Very unlikely
☐ Unlikely
☐ 50/50
☐ Likely
☐ Very likely
☐ HIV+

I'd like to know a bit more about your health. This next part of the interview asks some sensitive questions so I'd like to give you some privacy to complete the questionnaire yourself. First, we will review the instructions for the survey together so you know how to fill it out. It will take about 10 minutes to complete. Remember, nobody but our research team will know your answers.

(Review with the interviewee the instructions for BBV-TRAQ, which is provided at the back of the interview package)

(Assess the interviewee's literacy level at this time): ***Would you like help to go through this questionnaire? Remember, some of the questions are sensitive and you can refuse to answer any question at any time.***

(Administer BBV-TRAQ)

Why don't we take a 10 minute break.

END OF SECTION 1

Study ID:__________

SECTION 2

YOUR BELIEFS

We have talked with many drug users and many spoke about general rules that people may or may not follow. We are trying to understand what you think about these rules. For each of the following statements, then, I want you to tell me how much you personally agree or disagree with the following statements. You can answer using the same scale *(Display scale below and review response options).*

1	2	3	4	5	6
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	NA

Group Health

How much do you agree that….

_____ 1. …It is your responsibility to tell people your own viral status (e.g. Hep C and/or HIV) when fixing together.

_____ 2. …It is other people's responsibility to keep themselves safe when fixing with others.

_____ 3. …If you get a virus from somebody when you are fixing together, it is their fault.

_____ 4. …You always try to use with someone in case something bad happens, like an OD.

Practice – Location

How much do you agree that….

_____ 5. …You will fix anywhere, even if kids are around.

_____ 6. …People have to use safely at your place or you will kick them out.

_____ 7. …You will leave a situation if people are using in a risky way.

1	2	3	4	5	6
Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	NA

Practice "I"

How much do you agree that....

_____ 8. ...You will use anywhere because you don't care what others think.

_____ 9. ...You like to fix alone.

_____ 10. ...When you are dope sick, you are desperate to get a fix no matter what.

_____ 11. ...When you are feeling really emotional, you do not follow your own rules for fixing safely.

_____ 12. ...If you are uncomfortable in a situation, you can wait or will turn down available drugs.

_____ 13. ...You inject to fit in and so that you are not left out.

Relationships

How much do you agree that....

_____ 14. ...You only share needles and equipment with your partner and no one else.

_____ 15. ...Your partner influences how much you fix (*inject only*).

_____ 16. ...You will end up with the same virus (Hep C or HIV) as your partner regardless (injecting or sex)

_____ 17. ...You feel closer and more bonded with people when you share equipment with them.

Social

How much do you agree that....

_____ 18. ...It is difficult to be around people who fix if you are trying to quit injecting

_____ 19. ...You have to be careful that someone you fix with doesn't overdose you on purpose.

_____ 20. ...You are picky about who you will fix with.

_____ 21. ... If you ever had to share needles or equipment it is low risk because you and the person you fix with know how to share equipment safely.

1 Strongly Disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly Agree	6 NA

<u>Community</u>

How much do you agree that....

____ 22. ...It is alright to fix with anyone, including strangers.

____ 23. ...When someone allows you to fix at their place, you have to follow the owners' rules. (fixing rules, behaviour, cleanliness)

____ 24. ...When people have to use the same needles and equipment, there are rules about who fixes first.

____ 25. ...When people have to share equipment and needles, the person who bought the drugs gets to fix first.

____ 26. ...When people have to share equipment and needles, the person who says they have <u>no viruses</u> fixes first (e.g. Hep C and/ or HIV).

____ 27. ...When there are not enough needles and equipment for everyone, whoever is most likely to intimidate others fixes first.

____ 28. ...It's okay to draw out of the same spoon as long as everybody uses a clean needle.

____ 29. ...When people fix more often(like with cocaine) their exposure to HIV changes.

END OF SECTION 2

SECTION 3

WHO YOU HANG OUT WITH

Part 1

In the last section, we talked a lot about what you believe. Now, I would like to ask you some questions about how you see yourself in comparison to other injection drug users in Edmonton. You can answer using this scale *(Display scale below and review response options).*

Provide an example to clarify the process: e.g. Compared to other researchers, I am lazy...a lot more than other researchers. REMEMBER this is not a frequency question, it is about the participant compared to other IDU.

1 A lot less than other users	2 A little less than other users	3 Other users and I are the same	4 A little more than other users	5 A lot more than other users	6 NA

(Record participant's rating)

| _____ 1. Compared to other drug users in Edmonton, I get depressed....

| _____ 2. Compared to other drug users in Edmonton, I have to hustle to get by...

| _____ 3. Compared to other drug users in Edmonton, I get my own way when I want to...

| _____ 4. Compared to other drug users in Edmonton, <u>I take and use used</u> equipment from people...

| _____ 5. Compared to other drug users in Edmonton, <u>I give my new</u> equipment to people...

| _____ 6. Compared to other drug users in Edmonton, I can take care of myself...

| _____ 7. Compared to other drug users in Edmonton, I can score drugs...

| _____ 8. Compared to other drug users in Edmonton, I am fixed by others...

| _____ 9. Compared to other drug users in Edmonton, I get respect...

| _____ 10. Compared to other drug users in Edmonton, I inject drugs...

END OF SECTION 3.1

Part 2

Now, I want you to think back over the last 30 days about the people you've had <u>more than casual contact with</u>. Let's make a list of these people. Please remember that the information you give us is confidential and will only be used to help us learn how to help people stay healthy.

Step 1: List Generation

Please tell me the first initial of the people you've had more than casual contact with in the last 30 days. *(Maximum 10 people)*

- *Let's start with the people you have used any drugs with in the past 30 days. This could be injection or non-injection drugs, could be alcohol, pot, crack, meth, or any other kind of drug. Now you may not know their initials but that's okay. We will use XY for males and XX for females*

(This could include)

- *People you party with*
- *Date/John/Trick*
- *Outside/Alley*
- *Dealer*
- *Inmate*

(Write down initials in space provided below)

Step 2: Contacts Chart

Now I am going to ask you some questions about each person on your list and fill in this chart with your answers. Again, everything here is confidential *(Proceed to fill in chart on the following page).*

1. (Record nominee initials)

2. (Record gender of nominee) 1 = Male
2 = Female
3 = Transgendered

3. (Record age of nominee, can be an approximation)

4. Have you had any sexual contact with this person in the past 30 days?
1 = Yes
2 = No
3 = (?) Don't know
4 = Refused

5. How long have you known this person?
1 = days
2 = weeks
3 = months
4 = years

6. How do you know them? (See cheat sheet)

7. Could you easily borrow money from this person if you had to?
1 = Yes
2 = No
3 = Sometimes
4 = (?) Don't know
5 = Refused

8. Do you trust this person to take care of your stuff if you had to leave it with them?
1 = Yes
2 = No
3 = Sometimes
4 = (?) Don't know
5 = Refused

9. If you had to, could you ask this person for help if you were being hassled by another person?
1 = Yes
2 = No
3 = Sometimes
4 = (?) Don't know
5 = Refused

Now I would like to talk to you about your drug use with this person.

10. Do <u>you</u> access drugs from this person?
1 = Yes
2 = No
3 = Sometimes
4 = (?) Don't know
5 = Refused

11. Does <u>this person</u> access drugs from you?
1 = Yes
2 = No
3 = Sometimes
4 = (?) Don't know
5 = Refused

13. Do you fix together? (If no, skip to next section of ARC)
1 = Yes
2 = No
3 = (?) Don't know
4 = Refused

How long have they injected for?
1 = days
2 = weeks
3 = months
4 = years

14. Have you <u>fixed together</u> in the last 30 days?
1 = Yes
2 = No
3 = (?) Don't know
4 = Refused

15. Which drug(s) did he/she fix? <u>(Refer to cheat sheet)</u>

16. What did you fix? <u>(Refer to cheat sheet)</u>

17. What is their HCV serostatus?
1 = (+) Positive
2 = (-)Negative
3 = (?) Don't know
4 = (R) Refused

18. What is their HIV serostatus?
1 = (+) Positive
2 = (-)Negative
3 = (?) Don't know
4 = (R) Refused

Thank you for taking the time to help us with this interview. Do you have any questions for me? Can I refer you to anyone at this time?

Is there anything else you would like me to know?

END OF INSTRUMENT

Appendix F: Cross-sectional study information letter and consent forms

Title of the Project: Social Dynamics of Injection Drug Use (3): Field Testing
Principal Investigator: Dr. C. Wild (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Background. Clean injection equipment is not enough to make sure that people are not at risk. We need to understand social relationships among injection drug users. To do this, we designed a new instrument to measure social relationships. This instrument, called Assessment of Risk Contexts (ARC), may help us design outreach programs and treatment services. We need to test the ARC with people who inject drugs to see if it works.

Purpose. A group from the University of Alberta is working with Capital Health, Streetworks, and Boyle-McCauley Health Centre. We are trying to better understand the needs and strengths of the injection drug using community. You are eligible to volunteer for the study if you have injected drugs in the last 30 days or more. If you have been in formal addiction treatment (e.g., AADAC) in the last 30 days, you cannot take part in this study. However, if you have only attended self help groups, you will be able to take part.

Procedures. We will be asking people who inject drugs to complete an interview. We will ask you about your injection drug use and your beliefs. We will also ask you for your Alberta Health Care number. The interview will last about an hour and a half. At the end of that time you will have a chance to talk about any worries you might have and to ask questions.

Benefits. You will help us understand the health and needs of people who inject drugs. You will receive information and referrals to services that you ask for. To thank you for your time and information, we will give you $20 for participating whenever the interview ends.

Risks. We may ask personal or sensitive questions that may upset you. If you are uncomfortable during the interview, we will stop. If you are very upset, we will refer you to health services.

Confidentiality. We will keep your name confidential. We will use only a code number on the interview sheets. You can refuse to answer any question. You can stop the interview at any time. We will keep all information confidential, except when professional codes of ethics and/or legislation require reporting. No one except those people at the session, including staff from any of the agencies involved in the study, or any other agency, will know what you have said. We will store all study data for at least 7 years after the study has been completed. We will keep study data in a secure area accessible by only the research team. After that time it will be destroyed.

Freedom to Withdraw. You are free to withdraw from the study at any time without penalty or loss of your financial reimbursement. Your right to treatment at any agency will not be affected by whether you complete the interview or not.

Reimbursement of Expenses. To thank you for your time and information, we will give you $20 for participating whenever each session ends.

If you have concerns about this study, call the Health Research Ethics Board at 492-9724. You may also contact the investigators at any time during your participation in the study.

Title of the Project: Social Dynamics of Injection Drug Use (2): Pilot Study
Principal Investigator: Dr. C. Wild, supervisor (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Sheet? Yes No

Do you understand the benefits and risks involved in taking part in this research study?
Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care or your financial reimbursement. Yes No

Has the issue of confidentiality been explained to you? Do you understand who will have access to your records? Yes No

This study was explained to me by: ______________________________

I agree to take part in this study. Yes No

Signature of Research Participant	Date	Witness
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee	Date

A copy of this consent form has been given to you to keep for your records and reference. Thank you for your consideration.

Study ID:__________

Alberta Health Care Number Consent Form

As a part of this study, we are asking you to give us your Alberta Health Care number so that we can find out how many times you saw a doctor between November 2005 and November 2006. We will also find out which hospitals you have been to, how you got there, how long you had to wait and/or be admitted, and your reason for going. We will NOT have access to which doctors you saw or what you were prescribed.

The information we collect from your health records is confidential. It will NOT be released to anyone outside the research team. NONE of the information we collect will be added to your medical records. NONE of the information we collect will impact your ability to get health care.

If you do not have your Alberta Health Care number with you today, you may give it to us anytime over the next month. We will NOT attempt to track down your number ourselves.

If you decide NOT to provide us with your Alberta Health Care number, you may still participate and this will not affect your payment today.

Name: ______________________

Alberta health care #: _______________

Signature: _________________

Appendix G: Blood-Borne Virus Transmission Risk Assessment Questionnaire

Instructions

- Please consider the following questions carefully and answer each one as accurately and truthfully as you can. All questions refer to your behaviour in the past MONTH / 4 week period.
- Try and remember that the only correct answer is an accurate and honest answer.
- Remember that the information you provide will remain completely confidential.

Part 1: INJECTING PRACTICES

Record your responses to each of the following questions by circling the answer option that you think is most relevant to you.

1.1 In the last month, how many times have you handled another person's used needle/syringe *(eg. to dispose, to break-off needle)* at a time when you had cuts, sores or lesions on your fingers and hands?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.2 In the last month, how many times have you sucked or licked left-over drugs from a spoon or other mixing container which had been used by another person?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.3 In the last month, how many times have you sucked or licked a filter which had been used by another person?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.4 In the last month, how many times have you sucked or licked a plunger after using it in a mix which has been used by another person?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.5 In the last month, how many times have you injected a drug that was filtered through another person's filter?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.6a In the last month, how many times have you injected a drug that was prepared in another person's used spoon or mixing container?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.7)

1.6b On those occasions how often did you clean the spoon or mixing container before using it?

Never Rarely Sometimes Often Every time

1.7 In the last month, how many times have you injected a drug prepared with water which had been used by another person?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.8 In the last month, how many times have you injected a drug which had come into contact with another person's used needle/syringe?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.9a In the last month, how many times have you injected a drug that you prepared immediately after 'assisting' another person with their injection *(eg. injecting them, holding their arm, handling their used needle/syringe; touching their injection site to feel for a vein, to wipe away blood, or to stop bleeding)*?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.10a)

1.9b On those occasions, how often did you wash your hands before preparing your mix?

Never Rarely Sometimes Often Every time

1.10a In the last month, how many times have you injected a drug that was prepared by another person who had already injected or assisted in someone else's injection?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.11a)

1.10b On those occasions, how often did the person preparing the mix wash their hands before preparing the mix?

Never Rarely Sometimes Often Every time

1.11a In the last month, how many times have you been injected by another person who had already injected or assisted in someone else's injection?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.12a)

1.11b On those occasions, how often did the person injecting you wash their hands before injecting you?

Never Rarely Sometimes Often Every time

1.12a In the last month, how many times have you injected with a needle/syringe which had been handled or touched by another person who had already injected?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.13a)

1.12b On those occasions, how often did they wash their hands prior to handling the needle/syringe that you used?

Never Rarely Sometimes Often Every time

1.13a In the last month, how many times have you injected with another person's used needle/syringe?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.14)

1.13b On those occasions, how often did you rinse it with a combination of full-strength bleach and water *(ie. the '2x2x2' method)* before you used it?

Never Rarely Sometimes Often Every time

1.14 In the last month, how many times have you injected with a needle/syringe after another person has already injected some of its contents?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.15a In the last month, how many times have you touched your own injection site (eg. to feel for a vein, to wipe away blood, or to stop bleeding) soon after 'assisting' another person with their injection (eg. injecting them, holding their arm, handling their used needle/syringe; touching their injection site to feel for a vein, to wipe away blood, or to stop bleeding)?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.16a)

1.15b On those occasions, how often did you wash your hands before touching your own injection site?

Never Rarely Sometimes Often Every time

1.16a In the last month, how many times has another person touched your injection site *(eg. to feel for a vein, to wipe away blood, or to stop bleeding)*?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to Question 1.17)

1.16b On those occasions, how often did the person wash their hands before they touched your injection site?

Never Rarely Sometimes Often Every time

1.17 In the last month, how many times have you wiped your own injection site with an object *(eg. swab, tissue, hanky, towel, etc)* which had been used by another person

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.18 In the last month, how many times have you used a tourniquet *(eg. medical tourniquet, belt, rope, tie, cord, etc)* which had been used by another person?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.19 In the last month, how many times have you received an accidental needle-stick/prick from another person's used needle/syringe?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

1.20a In the last month, how many times have you re-used a needle/syringe taken out of a shared disposal/sharps container?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

(Go to PART 2)

1.20b On those occasions, how often did you rinse it with full-strength bleach before you re-used it?

Never Rarely Sometimes Often Every time

Part 2: SEXUAL PRACTICES

Record your responses to each of the following questions by circling the answer option that you think is most relevant to you. Please remember that in the last month refers to the month before you commenced current drug treatment.

2.1 In the last month, how many times have you engaged in unprotected vaginal sex with another person ***(ie. penetration of the vagina with the penis)*****?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.2 In the last month, how many times have you engaged in unprotected vaginal sex with another person ***(ie. penetration of the vagina with the penis)*** **during menstruation?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.3 In the last month, how many times have you engaged in unprotected vaginal sex with another person ***(ie. penetration of the vagina with the penis)*** **without lubrication?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.4 In the last month, how many times have you engaged in unprotected anal sex with another person ***(ie. penetration of the anus with the penis)*****?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.5 In the last month, how many times have you engaged in unprotected oral sex with another person ***(ie. lips and tongue come into contact with the vagina, penis and/or anus)*****?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.6 In the last month, how many times have you engaged in unprotected manual sex with another person ***(ie. fingers and hands come into contact with the vagina, penis and/or anus)*** **during menstruation?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.7 In the last month, how many times have you engaged in unprotected manual sex with another person ***(ie. fingers and hands come into contact with the vagina, penis and/or anus)*** **after injecting?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

2.8 In the last month, how many times have you engaged in unprotected manual sex with another person ***(ie. fingers and hands come into contact with the vagina, penis and/or anus)*** **without lubrication?**

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

Part 3: OTHER SKIN PENETRATION PRACTICES

Record your responses to each of the following questions by circling the answer option that you think is most relevant to you. Please remember that in the last month refers to the month before you commenced current drug treatment.

3.1 In the last month, how many times have you come into contact with another person's blood *(eg. through fights, slash-ups, self-mutilation, accidents, blood-sports, occupational, pimples, blood nose, etc)*?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

3.2 In the last month, how many times have you been tattooed by someone who was not a professional tattooist?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

3.3 In the last month, how many times have you been pierced *(eg. ear or body)* by someone who was not a professional piercer?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

3.4 In the last month, how many times have you used another person's used razor *(eg. disposable razors, razor-blades)*?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

3.5 In the last month, how many times have you used another person's toothbrush?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

3.6 In the last month, how many times have you used another person's personal hygiene equipment *(eg. nail file, nail scissors, nail clippers, tweezers, comb, brush)*?

No times Once Twice 3 - 5 times 6 - 10 times More than 10 times

Please make sure that you have answered all relevant questions correctly.

(Source: Fry, C., Rumbold, G., Lintzeris, N. (1998). *The Blood Borne Virus Transmission Risk Assessment Questionnaire (BBVTRAQ): Administration and Procedures Manual.* Melbourne: Turning Point Alcohol and Drug Centre.)

Appendix H: IDU Interview Information Letter and Consent Form

Project Title: Social Dynamics of Injection Drug Use: Follow-up Interviews (Study 4)
Principal Investigator: Dr. T.C. Wild (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Background. People who inject drugs are at risk of poor health. However, they may have to put off getting health care for various reasons. One of the challenges that users face is the relationship they have with their health care providers. We know very little about this relationship.

Purpose. A group from the University of Alberta is working with Capital Health, Streetworks, and Boyle McCAuley Health Centre. We are trying to better understand the needs and strengths of the injection drug user (IDU) community. The purpose of this study is to explore the relationship between IDUs and their health care providers. We are asking you to participate in this session to share your point of view as a person who injects drugs.

Procedures. This session will take place in Boyle Street Community Services. It will last no more than two hours. Refreshments will be provided. Only you and the interviewer will be present. We will audiotape and transcribe the session to help us review your comments.

Benefits. You will help us understand the health and needs of people who inject drugs. You will receive information and referrals to services that you ask for.

Risks. We may ask personal or sensitive questions that may upset you. If you are uncomfortable during the interview, we will stop. If you are very upset, we will refer you to health services.

Confidentiality. We will keep your name confidential. We will use only a code number on the interview sheets. You can refuse to answer any question. You can stop the interview at any time. We will keep all information confidential, except when professional codes of ethics and/or legislation require reporting. No one except those people at the session, including staff from any of the agencies involved in the study, or any other agency, will know what you have said. We will store all study data for at least 7 years after the study has been completed. We will keep study data in a secure area accessible by only the research team. After that time it will be destroyed.

Freedom to Withdraw. You are free to withdraw from the study at any time without penalty or loss of your financial reimbursement. Your right to treatment at any agency will not be affected by whether you complete the interview or not.

Reimbursement of Expenses. To thank you for your time and information, we will give you $20 for participating whenever each session ends.

If you have concerns about this study, call the Health Research Ethics Board at 492-9724. You may also contact the investigators at any time during your participation in the study.

Project Title: Social Dynamics of Injection Drug Use: Follow-up Interviews (Study 4)
Principal Investigator: Dr. T.C. Wild, supervisor (University of Alberta; 492-6752)
Co-investigator: Dr. G. Salvalaggio, student researcher (University of Alberta; 492-6753)

Do you understand that you have been asked to be in a research study?	Yes	No
Have you read and received a copy of the attached Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this research study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care or your financial reimbursement.	Yes	No
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records?	Yes	No

This study was explained to me by: ______________________________

I agree to take part in this study.	Yes	No

______________________________	____________________	____________________
Signature of Research Participant	Date	Witness
______________________________		____________________
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

______________________________	____________________
Signature of Investigator or Designee	Date

A copy of this consent form has been given to you to keep for your records and reference. Thank you for your consideration.

Appendix I: IDU Interview Questions

Demographic information (collected prior to audiotaping and recorded on a separate sheet for each participant)

Age
Gender
Education level completed (elementary school / junior high school / high school / post-secondary diploma or degree)
Number of years engaged in IDU
Preferred point of health care (hospital physician / family physician / other community physician / community nurse / peer / none)
Self-reported health status (good / fair / poor)
Drug of choice (opiates / cocaine / amphetamines / other)

IDU interview questions

Think about your experiences with health, illness, and health care over the past year, focussing on the relationship you have had with nurses, doctors, and other health care team members you've dealt with.

1. What do you do when you aren't healthy (for example, you have a bad cough or a rash)?
    - Where do you go for help? Why?
    - Who do you go to for help? Why?
    - Does the person involved (your regular doctor vs. any doctor vs. a nurse, for example) matter? Why / why not?
    - Does location (e.g. a specific hospital or clinic) matter? Why / why not?

2. How does being dope sick, being in pain, or urgently needing your drugs for any other reason change where you go or who you see to get help?

3. Are there times where you would rather see a nurse than a doctor?
    - Why / why not?
    - How is your relationship with nurses different than your relationship with doctors?

4. Would you ask someone from the street (family, friend) to help you instead or as well?
    - Why / why not?
    - Are there people in your community who have a reputation for helping people with health problems?
    - Why do you think they have this reputation?

5. Some people see no one for health problems. Why?

6. How sick do you have to be to ask for help from a doctor or nurse?
    - Why?
    - Why do you go to see a doctor or nurse?
    - Do you ever go to a nurse or doctor to prevent illness (for example, a blood pressure check or a diabetes check)? Why / why not?

7. What do you expect (or want) from a visit to a doctor or nurse?
    - What do you think the doctor or nurse expects?
    - Are your expectations met? Why / why not?
    - What might make it hard for a doctor or nurse to meet your expectations?
    - What do you think are the reasons that doctors (even "good" doctors) have a hard time prescribing certain drugs?

8. What negotiation strategies do you use when you go see a nurse or doctor?
    - How are these strategies the same as those you use on the street?
    - How are these strategies different from those you use on the street?
    - What happens if your typical strategy backfires?
    - How might your strategy be different from the one your nurse or doctor uses?

9. How does your experience of health care change if someone knows you inject?
    - What labels do you experience when you use health care services?
    - What gets in the way of being totally honest with your doctor or nurse?

10. What do health care workers say or do that you find helpful?
    - What do health care workers say or do that you don't find helpful?

11. How might a patient say or do things that help the doctor-patient relationship?
    - How might a patient say or do things that hurt the doctor-patient relationship?