

A QUALITATIVE EVALUATION OF USE, ACCESS AND CONCERNS WITH THE
FIRST LEGAL SYRINGE EXCHANGE PROGRAM IN INDIANA: PERSPECTIVES
AND EXPERIENCES OF PEOPLE WHO INJECT DRUGS IN A RURAL
COMMUNITY

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Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Master of Arts
in the Department of Sociology
Indiana University

September 2017

Accepted by the Graduate Faculty, Indiana University, in partial fulfillment of the requirements for the degree Master of Arts.

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ACKNOWLEDGEMENTS

To Dr. Carrie Foote, chair of my thesis committee, I express my sincerest gratitude for fostering my intellectual growth since my first day as a research assistant on the project that would later shape this thesis, all the way through to the final steps of this thesis.

To Dr. Robert Aponte, whose wealth of knowledge on drug use and policy were invaluable to this research topic, I owe a deep debt of gratitude.

To Dr. Joan Duwve, for the sheer amount of knowledge concerning syringe exchange programs and the community this thesis focuses on, and for providing me the opportunity to work as an interviewer on a separate project in the community this thesis studies, I also owe a deep debt of gratitude.

To all three committee members of this thesis, I am greatly appreciative for the time you all have dedicated to supporting this work to its fruition.

To those who participated in the study which supplied the data for this thesis, to the community that is the subject of this thesis, and to all communities affected by the opioid epidemic, I sincerely hope this and all additional research activity focusing on these communities will provide the resources and empowerment needed to overcome the current crisis.

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CHAPTER 1: INTRODUCTION AND BACKGROUND

The percentage of HIV diagnoses attributable to injection drug use (IDU) in the United States has decreased from 8.9% in 2009 to 6.0% in 2014 (CDC 2014; CDC 2015). However, the evolving nature of injection drug use highlights the need for an equally responsive approach to monitoring and reducing the risk of HIV transmission. Recent trends in prescription opioid abuse in rural communities, and the limited resources for mitigating the transmission of HIV among persons who inject drugs (PWID), create a heightened risk for HIV in non-urban areas (Chen 2015; Havens et al. 2013; Rudd et al. 2016; Zibbell 2015). The 2015 HIV outbreak in rural Scott County, Indiana serves as an example of the consequences of these factors. As of June 2015 there were 170 people diagnosed with HIV (ISDH 2015a), making it the largest HIV outbreak in Indiana. As of the most recent count, 220 people in the county have an HIV positive diagnosis (ISDH 2017), suggesting the spread has been contained since. The outbreak resulted from high risk injection drug use practices such as sharing syringes to inject prescription opioids (primarily Oxymorphone Hydrochloride Extended Release, commonly referred to by its brand name: Opana ER), sharing syringes in the process of preparing drugs for injection, and the sharing of other injection equipment for the preparation of drugs such as the cooker, water, or cotton filter (Conrad et al. 2015). Availability of accessible harm reduction services could have mitigated the rapid, unexpected, transmission of HIV in this community.

Syringe exchange programs (SEPs) serve as a mechanism for reducing unsafe injection practices, and thus, for reducing the transmission of infectious diseases such as HIV and Hepatitis C (HCV) (Aspinall et al. 2014; Des Jarlais 2009; Heimer 1998;

Wodak and Cooney 2006). SEPs provide persons who inject drugs with free sterile syringes and other drug preparation equipment, and they facilitate the safe disposal of used syringes through the exchange of used syringes for new, sterile syringes. They can also connect participants with additional harm reduction services such as care providers for infectious disease treatment, medication assisted treatment, and substance abuse counseling. Proactive implementation of SEPs have been shown to reduce HIV transmission across a variety of developed and underdeveloped countries in a cost effective manner; the SEP's operating costs are offset by the money saved from the consequent reduction in HIV transmission and the associated care provision costs (Wodak and Cooney 2005). However, the prevalence of SEPs remains low in the U.S. This is particularly true for rural areas (Des Jarlais et al. 2015), despite the increases in nonmedical prescription opioid abuse many of these areas have been experiencing (Keyes et al. 2014).

As a result of the 2015 HIV outbreak in Scott County, the first legal SEP was established for temporary operation in the state of Indiana through an executive order by the Governor in April 2015 for 30 days (ISDH 2015b), whereupon its duration was extended for an additional year under Senate Enrolled Act 461 (ISDH 2015c). The SEP provides anonymous syringe exchange based on self-reported injection frequency. Upon return of used syringes, SEP participants are provided syringes for a period of one week. The SEP operates out of a centralized location, and it also utilizes a mobile unit to reach clients without access to transportation or who may face additional barriers to visiting the physical location. While the SEP fulfills the traditional function of exchanging syringes, it also provides many other services including HIV and HCV testing, auxiliary injection

equipment (e.g. cookers, cotton filter, and water), harm reduction counseling, referrals to substance abuse counseling, and just recently, pre-exposure prophylaxis (PrEP).

Specific Aims

This thesis provides an evaluation of the Scott County SEP from the perspectives of persons who inject drugs (PWID) in the community through an analysis of the qualitative data obtained from the 2015 “HIV in Southeastern Indiana Exploratory Study.” – CDC Protocol 6776. This in-depth interview and focus group study was conducted by researchers at the Indiana State Department of Health (ISDH), the Centers for Disease Control and Prevention (CDC), and Indiana University Purdue University Indianapolis (IUPUI) to gain an in-depth understanding of the factors that may have contributed to the rapid spread of HIV among PWID in Scott County.

The data analyzed for this thesis focuses on the participant experiences with, and perceptions of, the SEP. It specifically excluded experiences with the SEP on injection drug behaviors and instead assessed overall perceptions of the SEP and experiences using specific services directly related to the syringe exchange program. Specifically, this thesis aimed to:

1. Understand and describe PWID’s experiences using the SEP
2. Understand and describe PWID’s successes with and barriers to using the SEP
3. Identify and describe concerns and areas of improvement for the SEP
4. Based on the findings from aims 1-3, identify successful practices from the SEP that may help with the implementation and use of SEPs in other rural areas.

Findings provide an in-depth understanding of syringe exchange programs through the lived experience and authentic voices of PWID, in the context of a small, rural community.

Background

Rates of opioid abuse and overdose have increased for many rural and non-rural areas across the country (Keyes et al. 2014; Sehgal, Manchikanti and Smith 2012). This trend, the emerging HCV epidemic in rural areas among persons who inject drugs (PWID) (Suryaprasad et al. 2014; Zibbell et al. 2015), and the lack of adequate access to harm reduction in rural areas (Des Jarlais et al. 2015) are prominent factors in the emerging vulnerability to rapid HIV transmission many rural communities face (Van Handel et al. 2016). The HIV outbreak in Scott County, a poor rural community in southeastern Indiana, among PWID (Conrad et al. 2015) has served as a focal point for the intersection of these issues. In response to the largest HIV outbreak among PWID in recent history, the state of Indiana implemented the first legal syringe exchange program (SEP).

The majority of research studies on SEPs focuses on SEPs in urban areas, as this has historically been the setting most SEPs have operated in. This background section provides an overview of the history of SEPs in the US, describes rural communities as it pertains to injection drug use, vulnerability to HIV and HCV, and the occasional study of rural SEPs and contextual differences that may exist when compared to urban settings. It concludes with an examination of the current literature on SEPs and barriers to harm reduction access, thus providing the background for the contribution this thesis makes.

History of Syringe Exchange Programs in the United States

Although syringe exchanges were first introduced in 1983 in Amsterdam (Wodak and Cooney 2005), it was not until 1988 that the first official syringe exchange program (SEP) in the United States was opened in Tacoma, Washington (Singer et al. 1991). However, Singer and colleagues (1995) report that the distribution of clean syringes had been occurring throughout the U.S. for up to two years as a legally unsanctioned activity prior to the implementation of a formalized legal SEP. SEPs began appearing in New York City in 1992, consequently reducing the prevalence of HIV from 50% to 15% among PWID (Des Jarlais et al. 2016). In 1992, 20% of HIV positive PWID in New York City who reported sharing previously used syringes were at risk of transmitting HIV. By 1998, the percent had decreased to 5%. These decreases strongly overlap with the implementation and growth of syringe exchange programs, but the authors point out this can also be attributed to HIV positive PWID leaving the injecting population, the reduction of high risk injection behaviors among HIV positive PWID, and advances in antiretroviral treatment (ART) (Des Jarlais et al. 2016).

In 2000, the funding of SEPs became legal in California, under California Assembly Bill Number 36 (1999), in the event that a state of emergency became declared. Eighteen districts subsequently acted to legalize SEPs. In 2015, Indiana legalized SEPs under emergency circumstances, to be operated for only short periods of time at first, as a result of the HIV outbreak and public health emergency in Scott County, Indiana (ISDH 2015b). The first legal Indiana SEP opened up in Scott County a few days later, with no federal or state funding. A month later, a state bill was passed legalizing SEPs for permanent operation in the state. According to the North American Syringe

Exchange Program Network, there are currently eight SEPs operating in Indiana (2017), and 228 SEPs operating in 35 states across the United States as of 2015.

Rural Areas and Vulnerability to Infectious Disease

Research suggests a dramatic increase in health related harms from injection drug use in rural areas such as overdose and HCV and HIV infections. For example, between 1999 and 2004 rural communities experienced a nearly 250% increase in drug poisoning mortality rates for injecting narcotics, and a 371% increase for prescription opioids (Paulozzi 2008). Current research extends upon these findings, showing that the United States overall experienced a 14% increase in opioid related overdoses from 2013 to 2014 (Rudd, Aleshire, and Zibbell 2016). However, while these data provided a breakdown of overdose rate increases both by state and region, it did not examine overdoses by community setting.

Increases in injection drug use have also coincided with an “emerging epidemic” of HCV among PWID in rural areas. From 2006 – 2012, reported incidence of HCV in rural settings has increased annually by 13%; in contrast, urban areas reported only a 5% increase (Suryaprasad et al. 2014). Indiana had the 4th highest reported number of HCV cases in 2012 (Suryaprasad et al. 2014). Furthermore, Suryaprasad and colleague’s analysis (2014) revealed that 75% of persons both 30 years of age or younger, and recently infected with HCV, report having injected drugs at least once.

Research indicates a trend of increased prescription of opioid medication, and increased fatal and nonfatal opioid overdose, in rural areas over time (Keyes et al. 2014; Sehgal et al. 2012). Estimates show opioid abuse occurs among 26% of those who are receiving prescription opioids (Sehgal et al. 2012). Current research also indicates a

strong positive correlation between opioid prescriptions and the poverty and unemployment rates of an area (Spiller et al. 2009). Scott County's poverty and unemployment rates in 2015 were among the highest in the state -- 19% and 8.9% respectively (Conrad et al. 2015). Data analyzed by the Indiana State Epidemiology Outcomes Workgroup (2015) shows from 2002-2014 Scott County was tied for the highest rate of fatal prescription drug overdoses in Indiana (33.2 per 100,000).

HIV has historically not been prevalent among PWID in rural settings (CDC 2016; Young et al. 2013). Prior to the outbreak, Scott County also had a low incidence of HIV, despite experiencing a high risk for rapid HIV and HCV transmission. Shortly after the HIV outbreak in Scott County, the CDC conducted a country-wide analysis to assess country-level vulnerability for rapid HIV or HCV outbreak. Their analysis indicates 220 counties in 26 states are within the 95th percentile for vulnerability; a map highlighting these counties shows a large concentration resides in southeastern Indiana and extends through and around Appalachia (Van Handel et al. 2016). Although the indicators assessed to determine this vulnerability categorized counties along a rural/urban continuum, the analysis itself did not indicate the number of these high vulnerability counties that were rural. However, of these high vulnerability counties, the composition was reported as “overwhelmingly rural” (Van Handel et al. 2016:328).

Healthcare infrastructure in rural communities

A lack of resources and limited capacity can hinder the ability of rural healthcare systems to provide care to vulnerable populations, such as PWID (Edwards et al. 2009; Bradshaw 2007). In turn, this can create barriers to accessing healthcare services. The HIV outbreak in Scott County highlights some of the difficulties residents of rural

communities face when accessing healthcare. Prior to the outbreak, this was especially true for PWID, for whom possessing harm reduction resources such as sterile syringes were illegal without medical authorization (The Policy Surveillance Program 2016) and addiction treatment services were minimal.

Prior to the HIV outbreak in Scott County, operating syringe exchange programs was legally prohibited. Although a few additional SEPs have been implemented in Indiana since the HIV outbreak, the lack of state funding can be a preventative factor in service provision. According to the North American Syringe Exchange Network, there are currently only eight SEPs operating in Indiana, five of which are operating in rural areas (2017). However, 2014 data from the Indiana State Department of Health utilized by the Center for Health Policy at Indiana University Indianapolis (Kooreman and Greene 2016) indicates many of the Indiana counties with the highest densities of HCV are rural and slightly clustered within southeastern Indiana, although still present across the state. This indicates the needs of these particular rural communities are not being met by the local healthcare system. Additionally, Kooreman and Greene's analysis shows that 55 counties (60%) in Indiana have either one or no substance abuse treatment services (2016). Furthermore, the analysis revealed that 35 of those counties (64%) were considered rural counties. They estimated that less than a quarter (24.2%) of PWID in Indiana received substance abuse treatment between 2015 and 2016.

The Need for Syringe Exchange Programs in Rural Communities

Syringe exchange programs provide one of the most important components of HIV and HCV prevention among people who inject drugs: legal access to sterile syringes. Data from an international review of syringe exchange programs indicate that SEPs are

an effective means of reducing HIV infection among PWID (Wodak and Cooney 2005). The study documented research comparing localities with and without SEPs. Results indicate overall HIV seroprevalence declines annually in areas with a SEP (mean rates 18.6% - 5.8%) and increases annually in areas without a SEP (mean rates 5.9% - 8.1%). Furthermore, Wodak and Cooney's review indicates SEPs do not lead to increases in injection drug use among participants (2005).

SEPs can also provide additional services such as opioid dependency treatment (e.g. Suboxone), and can serve as a centralized location to offer this and other risk reduction services, such as connection to general and HIV related health care services (McNeil and Small 2014). Residents of rural communities often face reduced access to medication assisted treatment and other forms of harm reduction (e.g. alcohol pads, information, and condoms) relative to those in urban areas (Berends 2010; Parker et al. 2012).

Despite both the large increases of HCV incidence in rural areas, and the vulnerability of rapid HIV transmission, very little research on rural syringe exchange programs exist. One such study on rural SEP implementation emphasizes that an adequate understanding of the community, and community support and buy in are necessary for implementation (Parker et al. 2012). Examples of relevant knowledge include hot spots for injection drug activity, which helps in identifying ideal locations for a SEP, and relationships with community health providers to provide helpful SEP referrals.

Barriers for PWID to accessing Harm Reduction

Despite the overwhelming scientific support for the effectiveness of SEPs, lawmakers and communities can be reluctant to allow SEPs to operate in their community (McNeil and Small 2014). Community reluctance can be attributed to the prevailing attitude of injection drug use as a criminal activity rather an addiction and public health issue. Additionally, political administrations are not immune to these views despite the strong scientific evidence documenting SEP program outcomes. This was mirrored in Scott County, Indiana, where the first SEP was legally opened in 2015 (ISDH 2015b), after a great deal of reluctance on behalf of the Governor to legalize their implementation. Prior to the SEP, harm reduction resources were minimal at best, and the necessary educational component to promote safer drug use was lacking.

Law enforcement can serve as an additional barrier to accessing SEPs. In 2010 a national survey was conducted among SEP program managers regarding policing among SEP participants. Notable results include: 43% of respondents reported police harassment occurs monthly or more frequently, 31% reported at least monthly confiscation of client syringes, and 12% reported at least monthly client arrests while en route to the SEP (Beletsky et al. 2011). Street level policing can constrain SEP access through the tactics typically used to regulate PWID and the presence of drugs in the community when SEPs are not in place. These can include continued or increased surveillance and a disproportionate amount of “arbitrary arrests” that can reduce the ability of PWID to access harm reduction (McNeil and Small 2014: 156).

An ethnographic study in a large urban area by Small and colleagues (2006) details how a police crackdown of drugs prompted harmful activities among PWID

including rushed injections, injecting in riskier environments, and increased unsafe syringe disposal. Police harassment can reduce the utilization of SEPs as well by making PWID fearful of being seen in close proximity of the SEP (Blumenthal et al. 1997). Additional research suggests real and perceived police harassment can increase the incidence of syringe sharing among PWID (Irwin et al. 2006). Blumenthal and colleagues report SEP utilization had doubled the following year after a police crackdown had subsided, whereas a comparison group in a nearby city maintained a constant rate of SEP utilization (1997). Additionally, increases in police activity in one urban area have been associated with a 28% decrease in syringes distributed as compared to distribution numbers before the increase in police activity (Wood et al. 2003).

In Indiana possession of a used syringe can result in a felony charge and a prison sentence of up to two and a half years (Indiana Code Title 16. Health § 16-42-19-18). The fear of potential arrest can keep persons who inject drugs from returning to or participating in syringe exchange programs. An ethnographic study conducted in Vancouver explored how an intensification of police activity through a drug crackdown reduced the willingness of PWID to carry syringes in public (Small et al. 2006). Participant observation in this study showed the intensified police activity decreased utilization of the local area SEP, and it increased unsafe syringe disposal (Small et al. 2006).

Evidence from a qualitative study indicates a high frequency of police searches can influence PWID to not carry syringes with them or to dispose of them unsafely (Cooper et al. 2005). In some cases PWID may not carry syringes as a form of protection, but this can influence syringe sharing if this occurs after drug procurement. The decrease

in SEP utilization caused by real or perceived police harassment necessarily increases the likelihood of harm through the reduced access to sterile equipment and fear of returning used equipment (McNeil and Small 2014). Additionally, police surveillance of PWID can lead to hazardous injection practices, especially among the homeless, such as hiding drugs or injection equipment in unsanitary areas to avoid detection (Cooper et al. 2005).

The stigma attributed to PWID and injection drug use can serve as another barrier to accessing harm reduction through SEPs and additional healthcare services. Results of one study indicate the stigma and discrimination attributed to persons who inject drugs was the primary reason they did not seek harm reduction assistance of any kind (e.g. SEP, counseling, medically assisted treatment, etc.) (Pokrajac, Nolimal, and Leskovsek 2016). At its worst, the reduced utilization of harm reduction as influenced by stigma can influence syringe sharing (Simmonds and Coomber 2009). For some, the stigma attributed to injection drug use can keep PWID from disclosing their status as a person who injects drugs to family or friends; this may prevent PWID from utilizing the SEP in order to reduce the chances of being seen using it (Parker et al. 2012). Further information from Pokrajac and colleagues' study suggest some PWID may be fearful of the effect treatment participation can have on their current and future career prospects (2016). Several PWID for whom this applies were concerned they would lose their job, or be unable to obtain a new job, if it were discovered they were utilizing services for drug abuse (Pokrajac et al. 2016).

The social stigma attributed to HIV and HCV can limit access to harm reduction and additional forms of healthcare (Williams, Gonzalez-Medina, and Le 2011). In more typical clinical settings, PWID may choose not to disclose their status as such out of fear

of stigmatization (Carlberg-Racich 2016). Some healthcare providers may indeed hold negative stereotypes of PWID (e.g. they are abusing the system or are not invested in their health) (Henderson, Stacey, and Dohan 2008). The non-judgmental, harm reduction philosophy, of SEPs can create a stigma-free environment that can cultivate a sense of trust between PWID and provider (McNeil and Small 2014). This judgment free atmosphere can assist in reducing the stigmatization of injection drug use. SEPs can foster feelings of trust between PWID and service providers. SEP referrals to healthcare services can bridge barriers to services such as HIV care coordination or medication assisted treatment for PWID (Macneil and Pualy 2011).

Factors specific to rural communities may also pose barriers unique to SEPs operating in rural communities. Sherman's ethnographic work within rural communities in northern California (2006; 2013) details the high value on self-reliance these rural communities emphasize, and consequently stigmatize those who depend on public assistance. This ideological preference for self-reliance has been observed in rural Appalachia as well (Coyne, Demian-Popescu and Friend 2006). The stigma associated with relying on public assistance can serve as a barrier to harm reduction services in the event that it influences PWID to not use the SEP. Additional research examines how a lack of knowledge about healthcare and harm reduction resources can prevent people from utilizing the limited resources that do exist in the community (Coyne et al. 2006). Promoting a SEP in a rural area may necessitate a different approach than observed in a more densely populated area.

Background Conclusion

This study will help contribute to the limited literature base for rural syringe exchange programs. Private interview and focus group data will allow for an evaluation of the Scott County SEP based on the experiences of PWID who participate in the program and those who do not. Many rural areas are facing several challenges putting them at risk for a similar outbreak, including high rates of opioid prescription (Keyes et al. 2014), recent increases in the incidence of HCV via injection drug use (Suryaprasad et al. 2014), and lack of health care infrastructure to reduce injection drug related harm (Kooreman and Greene 2016). The emergence of these macro-level trends amidst the lack of literature on rural syringe exchanges emphasize the need for more exploratory research on experiences using SEPS from the perspective of people who inject drugs themselves. This study helps fill this gap in the literature.

CHAPTER 2: METHODOLOGY

This study utilized data from the 2015 “HIV in Southeastern Indiana Exploratory Study.” – CDC Protocol 6776. Conducted between July and September 2015, the researchers used an exploratory qualitative research design (Merriam 2002) consisting of in-depth interviews and focus groups with PWID to gain an in-depth understanding of the factors that may have contributed to the rapid spread of HIV among PWID in Scott County. The exploratory approach was important as relatively little was known about how HIV rapidly spread in the community. This research design allowed for the presentation of rich descriptions of participants’ experience to emerge. The goal of this thesis was more focused and sought to understand the experiences of PWID with the Syringe Exchange Program in Scott County, Indiana.

Sample and Recruitment

To participate in the study, one had to be at least 18 years of age, injected drugs within 12 months of the interview, able to complete an interview in English, and able to provide informed consent. The researchers also attempted to gain a sample that was representative of key characteristics of interest for the HIV outbreak and included: Sex (male, female), Age (<30 years vs older), Type of drug injected (Opana, heroin, methamphetamine), History of sex work, Enrollment in the syringe exchange program, and HIV status. The final sample included 56 PWID who primarily injected the prescription opioid Oxymorphone Hydrochloride Extended Release (hereafter referred to as Opana), and most (82%) had enrolled in the SEP. Sample demographics are provided in appendix A.

Participants were recruited through purposeful location based and snow ball sampling techniques (Patton 2002). Location-based convenience sampling targeted locations in which local PWID often congregated. Examples of these places include referrals from the Syringe Exchange Program and the HIV clinic. Staff at these locations were informed of the study beforehand, and given recruitment materials to distribute to potential participants. Additionally, study staff engaged potential participants in neighborhood locations with reportedly high amounts of injection drug use. In these situations potential participants were given information about the study, and if interest was expressed, escorted to the nearest interview location for eligibility screening and to provide the informed consent. Interested potential participants could engage in this process and be interviewed immediately, or they could create appointments to go through the process at a later time. In a few cases snow ball sampling was used. to recruit additional participants, which involved already enrolled participants recruiting other participants.

Verbal consent was obtained from all participants prior to the private interviews and focus groups. In order to ensure anonymity, no names or identifying information were collected from the participants. Prior to obtaining verbal consent, study staff explained the objectives of the study, expectations of participants, risks and benefits, withdrawal procedures, compensation, protection of personal data, and contact information for key study staff. The Institutional Review Boards from both the CDC and IUPUI approved the ethical and human subjects aspects of the study.

Research Instrument

Both private interviews (n=25) and focus groups (n=31) were conducted by interviewers trained in qualitative methods. Private interviews were conducted with one lead interviewer and one assistant responsible for taking notes, while focus groups had one lead interviewer and one or two assistants to take notes. Interviews occurred in person and were audio recorded with the consent of the participants.

Both methods of data collection relied on separate semi-structured interview guides (see appendix B for the portions of the interview guides pertaining to this thesis). Four focus groups were conducted to help provide an understanding of community norms and beliefs around HIV and HCV, injection drug use and access, and experience with various services, specifically the SEP. Twenty-five private interviews were conducted to help provide individual level data on potentially sensitive topics such as injection drug use and sex practices and also probed about experiences with the SEP.

Interviews were conducted in two private locations within the community: a community church and the syringe exchange program. Both private interviews and focus groups occurred between July and September, 2015. Private rooms were utilized during all interviews. Private interviews ranged from 40 minutes to an hour and 30 minutes, and focus groups averaged about an hour and 30 minutes in duration. Participants were compensated with a \$20 gift card to a local small box store after completing the interviews. Additionally, at the conclusion of the interviews, participants were offered referrals and contact information to all local harm reduction and other available services.

Data analysis

Both focus groups and private interviews were digitally recorded and then uploaded to a secure network hard drive upon which the recordings were removed from the recording devices. The data were then transcribed verbatim into a computer word processing program on a secure computer by transcriptionists or members of the research team, including myself. Transcripts were then cross checked by members of the research team, including myself, to ensure the accuracy of the transcripts by making corrections as needed and double checking that any identifying information of participants or community members were omitted. To ensure intercoder reliability, two researchers engaged in the coding process (line by line, sub coding, and broad coding) separately. The researchers then convened to compare coding schemes and agree on final themes. The qualitative data analysis program, NVivo 10 was used to manage and code the data electronically.

I was engaged in several components of the transcription and data analysis for the larger study during my time as a Research Assistant to the Department of Sociology. My engagement in this study occurred prior to the decision to utilize a portion of the overall data set for this thesis. In addition to transcribing and proofing transcripts, I also assisted with coding for both the private interviews and focus groups and writing draft findings for the entire larger data set. The quotes in the overall dataset, as well as in this thesis, appear nearly verbatim, with the exception of minor edits to enhance the clarity of the data without compromising the substantive meaning or authentic voices of the participants. Examples of these edits include removing inaudible words and

redundancies, clarifying idiosyncratic speech, and adding any substantive researcher contributions in brackets where relevant within the quotes.

For this thesis, I sifted through the findings from the larger study to extract those materials relevant to the thesis's aims: understanding the participants' experiences with the SEP. This process began by searching through the data set in its entirety for related broad and sub codes. Each individual quote was then examined based on two criteria: to ensure the broad or sub code in question contained data relevant to this study, and to ensure the individual quote was relevant to this study. In order to preserve the reliability of the data set for this study, broad and sub codes that were initially deemed irrelevant were presented to the chairperson of this thesis project, wherein the decision to remove a particular sub code from the data set was arrived upon jointly. The final broad codes used from the exploratory study's data set are as follows:

- Focus group: syringe exchange program experiences, syringe exchange program – nonuse reasons and concerns, police experiences, and final thoughts and help suggestions.
- Private interviews: general experiences (SEP), access, harm reduction supplies, SEP nonuse, concerns, and program suggestions, and final thoughts.

All findings presented in this report use pseudonyms associated with focus group and private interview numbers. In some cases the identity of a particular focus group member was difficult to determine. A focus group number, and the gender of the respondent, was used in these cases. See Appendix C for the full list of pseudonyms for both methods of data collection.

CHAPTER 3: EXPERIENCES WITH THE SYRINGE EXCHANGE PROGRAM

Participants in both private interviews and focus groups were asked about their overall experiences with the syringe exchange program (SEP) and further probed about different aspects of the SEP such as the staff, hours of operation, location, and harm-reduction materials provided. This chapter describes those findings in which participants reported generally positive experiences with the SEP. The next chapter describes the participants' SEP concerns, reasons for not using the SEP and concludes with suggestions on how to improve the SEP.

Praising the SEP and Describing Positive Outcomes

Several participants shared general positive experiences with the SEP and in doing so also praised the SEP staff, its overall services, and its beneficial outcomes in terms of reduced arrests and mitigating the spread of HIV. Several in FG1, for example, claimed that "It's [the SEP] been wonderful. They're all so nice over there" "it's the best thing that's ever happened to this town." (F1) Joey (F1) elaborated further, with many others in his focus group agreeing with him: "I talk to quite a few non-injectors, [who are] not even doing it [injecting], and they think this is a very excellent thing... I think all counties should be doing this." Maggie (F2) also reported similar experiences: "I have nothing negative to say about them [the SEP]. I love them to death. I think that's the best thing".

A few others elaborated on why they praised SEP staff, explaining that they were nonjudgmental and caring. Shawna (PI 17) expressed her positive impression of the staff members:

I don't think they could do anything better than what they're doing. And they don't judge you. The ladies that, the one that was in here, I love her. I

mean they don't judge you. They don't judge you at all. They're your friends.

Injection drug use is an often stigmatized behavior; however, many of the participants also spoke of how supportive and accepting the SEP staff were of them as persons who inject drugs (PWID). Tom (F1) commented, "they don't treat us like junkies". Sam (F1) followed up by saying that "they're trying to treat you like you're still human". Others expanded upon the topic:

I love them to death. They're nice people. They don't look down on you, because we're just drug users. A lot of people think you're trash because you're an IV drug user [but] they don't. It's the best thing. I am happy about it (Tracy, F2).

They're really there to help us. Because they ain't looking down on us and they're not giving us that little attitude. They're really acting like they're concerned. They want the best. If we're not going to stop, they still support us (Joey, F1).

Others provided remarks about the SEP services when they were asked about their overall experiences. Kelly (F3) for example, noted how people would run after the outreach van to exchange used syringes for sterile ones:

I think it's a real good program because I've seen people running [up] the road with their containers, to get the new rigs. Usually the needle people stop by once a week if they know you real good, and they come running out to the car with their containers, 'give me the new rigs, here's the done ones'.

Similarly, Melinda (PI 3) said:

I think I'm getting everything I need [from the needle exchange]. I'm sure there's probably services that people need, or I may need, I just haven't realized that I need them. But, they're handing out free needles. They're handing out alcohol pads. They're handing out everything to clean them, and so I think that's one of the best things that's ever happened to this town. I think they think it's [the needle exchange] a great thing because this way they're [community members] not finding dirty needles laying on the streets. People have containers to put them in. people aren't scared to

walk down the road with a needle, so they're not throwing them down. It's a good thing.

Melinda's comment above also shows the positive SEP outcome of reducing the number of used syringes in the community.

While the primary function of the SEP is to provide sterile syringes to PWID, it also provides additional harm reduction materials such as, alcohol pads to sterilize the injection site, cookers for preparing the drug solution, cotton balls to filter the drug solution, and band aids for post injection. Additionally, the SEP provides access to services that reduce harm, such as health insurance, identification, and health care referrals, to list a few. The SEP participants spoke highly of these additional services and harm reduction materials provided by the SEP:

It was all helpful, every bit of it [that they gave us]. About the only thing that people didn't use was band-aids, was about the only thing people didn't use (Tim, PI 8).

Most everybody I know has been going down there. It's beneficial. I mean I wouldn't survive [without it]. I wouldn't know anybody that wouldn't go there and try to get insurance (Tom, F1)...I'm not just talking about the needles. I'm talking about it's helped me get ID's, birth certificate, you know, insurance (Joey, F1).

They started telling us we could get clean needles and alcohol prep pads and, whatever we'd need they bring to us. And they'd sign us all up for it (Scarlett, PI 2).

Some spoke of specific benefits the SEP afforded them. One of the SEP's provisions allows for PWID to possess syringes containing no drug solution if the person has a syringe exchange card. Prior to this, several had reported serving prison sentences for being caught with a syringe illegally. Jessie (F1) reports of a friend: "he did every day five years on one needle [before the SEP]". A major beneficial outcome of SEP membership was that it has kept them out of prison for possessing syringes. Two

participants explained, “We know we’re not going to jail for that needle now as long as we’ve got our [SEP membership] card” (Melinda, PI 3). “If I get caught with one, I may not get in trouble now” (Owen, F4).

While the SEP protects the anonymity of its users, some people did report concerns about whether the SEP actually did provide this protection when they were asked about their general experiences. Many people reported being cautious about the SEP shortly after its implementation, claiming they thought “the cops were in on it”. Several people who had this concern avoided signing up for the syringe exchange at first until receiving confirmation of the SEP’s safety as Rick explained:

And it took me a while to come up here [to the needle exchange] too because I mean I didn’t know if it was a setup or something like that. Like the cops were in on it too. Just trying to find out who’s actually doing stuff and who’s not. But then I had a buddy of mine. He’s pretty much the one that told me to come up here. He pretty much made me [sign up for the SEP]. They don’t even take a name. They don’t do nothing like that. And I come out here and they come out. I try to get up here every week (PI 20).

Melinda (PI 3) mentioned how the SEP’s proximity to the police station – right next door – made people initially cautious about signing up. She then explained that allowing people to enroll without providing personal information was a “big plus” as it reduced people’s fears of the police arresting them if they enrolled, increased trust, and more people signed up.

Most people didn’t want to give their names [to the needle exchange], or their addresses, just to obtain a needle. And, at first, to get the card, most people didn’t want to, but with the card you don’t have to give your name or anything, and so that was a big plus there, because if it were a card [in exchange for] giving a name or an address it would never happen here. They’d just say no. And with them even being closer to the police station now, you would have thought that probably would have stopped people but it didn’t because we know we’re not going to jail for that needle now as long as we’ve got our card. To begin with, it wasn’t good and people was really weary of it. But now, as it’s going through, I’d say it’s better

now. [People have] a lot more trust. At first it was slow getting people to sign up.

While Melinda speaks of the discomfort some people felt about providing potentially identifying information to obtain a SEP card, she observes that people have actually benefitted from the card because it protects them from going to prison for possessing a syringe while carrying the card.

Finally, participants unanimously agreed that the SEP was beneficial because it stopped the HIV outbreak. Loretta (PI 8), for example, spoke of how it reduced the risk of transmitting HIV, “The needle exchange has helped a lot. I know that sounds ridiculous because we’re giving people needles to get high on, but it’s better than them dying from HIV”. Frank also noted, “It’s [the SEP] stopped the spread, have you noticed the number of HIV [cases] since May hasn’t really changed from May until now (F4). Similarly, Owen emphasized having sterile syringes available was critical to stopping the spread of HIV, “I think that it [the HIV] probably peaked on the amount of people. I’m assuming now because people’s more aware of using clean needles” (F4).

Several people spoke of how having a SEP in the community earlier would have prevented the HIV outbreak: “We love it, it’s just a little damn too late, you know what I mean? You should’ve done this 2012. It woulda never happened (George, PI 18). Should’ve been a long time ago. We could’ve prevented a lot of stuff” (Larry, PI 22). Others, however, offered a slightly different view, claiming that while the SEP was necessary and should have been implemented prior to the HIV outbreak, it would not have prevented the spread of HIV entirely:

I think they do a great job. And, everybody says well if they would’ve had the needle exchange program, a long time ago, it [HIV] wouldn’t be here today. I don’t agree with that. I think it would still be here, but it wasn’t, it

wouldn't be as bad. I think that maybe um, it could've saved maybe a lot of people. But, I hate saying it like that because I guess that I think it's a great thing that we have the needle exchange program. Because, and they're really great people, and I don't want you to think, or anybody else to think that I'm down on them cause I'm, that's definitely not where I'm going with it. But, maybe, if they would've had it here, you know, awhile back, it could've prevented, a lot of it. Maybe save some people (Molly, PI 24).

I think that if they would've had that a long time ago, I mean, it [HIV] might've still been here, but I don't think it would have been as bad. I think that's really a blessing to this town, they really needed that. Cause I don't understand how this town didn't realize that there was a problem here. I really don't. I don't know why they didn't try to do something (Judy, PI 6).

Overall the participants agreed that having a SEP would have greatly decreased the spread of HIV in their community had it been there before the HIV outbreak.

Hours and Time

When the SEP was first implemented, it was in a temporary location with longer hours of operation, six to ten hours a day and seven days a week (ISDH 2015d).

However, after the outbreak had been successfully contained, it was relocated to a permanent location and the hours/days of operation were reduced to five days a week in three to five hour blocks of time, typically from late afternoon to early evening. We explored experiences with hours of operation as well as wait time to get harm reduction supplies.

All of the participants who commented on wait time reported positive experiences. According to Danny (F2) “[It takes] five minutes to [get your equipment]”. Mark and Jessie (F1) claimed that it took them less than 15 minutes to receive their equipment, and another remarked that “[the wait time is] good enough for me”.

While participants in the SEP were generally happy about the short wait time for receiving harm reduction equipment, there were mixed opinions about the SEP's hours of

operation. The reduced hours of operation weren't an issue for a couple of people. "I've never really had a problem with [the hours of operation] because any time I call her she's always there for me" (Haley, F2).

However, several others were critical of the hours of operation. These criticisms primarily centered upon the reduced hours of operation and inconveniences these posed to SEP participants. While many of the PWID interviewed reported being out of work, Marvin (PI 5) explains how the hour of operation change could be inconvenient for someone working full time:

Let's say I have a job and the hours don't permit me to, if I don't live where its available then I don't have that privilege and so, I mean it's not going to do me any good. They have since changed the hours it used to be like every single day, and now it's like the needle exchange is only open for three hours Tuesday. I came here on Tuesday and the place is closed. What if I work a job to where it doesn't allow me to get here, how am I going to get my needles? And if I had to use every six hours, and I mean I *had* to use every six hours or it [withdrawal symptoms] was bad. So I mean if I can't get my needles and I can't shoot up and I am that bad off, I mean that's at least to me that's going to be like an end of the world type of scenario...that's going to be really bad. Personally I think that it should be like a 24 hour service, because addiction doesn't take a break, addiction is a 24 hour thing.

In addition to the inconvenience the SEP's hours may pose for someone working full time, Marvin's claim also illuminates other inconveniences the hours may pose on PWID. These include geographical barriers people in rural communities face as well as the severity of withdrawal symptoms PWID may face if they are unable to inject.

The SEP's reduction in hours was also a little confusing for some. Joey (F1) talks about waiting for the SEP to open because he thought they were open in the morning when they actually opened several hours later:

Time is going to hell. Now, you don't even have it open at 8:00 in the morning and it's telling me that it's not opened until 3 in the afternoon

...I'm huffing and puffing, I just rode a bike that far and I turn around and wait until 3:00 [for the SEP to open].

Karen (PI 10) also discusses her confusion in determining the hours of operation at the permanent location when it first moved:

...Every time I do come up here, to Austin, to buy my drugs, it's usually closed. It's either too early or it's too late. I'm never here at the right time. It's usually from like 3:30 to 6:30 I think it is, or something.

The elicited responses indicate the SEP is usually open during the late afternoon on certain days of the week. However, this may not work for all who are using the SEP. A couple of participants provided feedback on how these hours could be shifted to be more accommodating for those with different schedules. Rick (PI 20) suggests changing the hours so that the SEP is open sometimes during the morning as well:

The hours are kind of tricky but there needs to be a set day they're open in the mornings and sometimes they're opened in like the evenings, instead of all just being in the evenings, they just throw a morning in there every once in a while.

Jeff (PI 21) suggested moving away from being open for three hours at time during the late afternoon, to being open twice a day, morning and evening, for two hour periods each:

I think their hours are good to an extent. Morning times, if they could switch it from, like maybe be open 2 hours in the evening, 2 hours in the morning. Like 9 to 11, and from 4 to 6. Instead of 3 to 6, you know. Or, just 10 to 11. Just because the morning people are looking for them. And, if they don't have new ones, you know what they're going to do; they're going to use used ones. And, most people get their fixes on in the morning.

The Outreach Van

The SEP in Scott County also operates a mobile unit, or outreach van, in addition to its physical location. This mobile unit fulfills the same primary function of the SEP by

bringing harm reduction supplies to PWID in exchange for used syringes. When asked about their experiences with the outreach van, some of the participants were initially suspicious. Joey (F1) reports that he “thought it was the swat team”, and Liz (F3) says other people were initially cautious about it because “they were scared at first” of the van. Liz also describes how her friend’s initial apprehension transformed over time to be more familiar and accepting of the van:

Yeah, it [the outreach van] used to be [a concern]. I mean we used to have it come park at our house, and then these people would come to our house, and scared to death. We finally talked them into talking to her and they leave, because I mean they thought that the cops was like sending these people to them. People are used to it now (Liz, F3).

Most however overcame these initial fears and reported very positive experiences with the outreach van. Maggie (F2) claimed “I think it’s awesome [that the SUV comes to us].” Willie (F3) provided positive remarks of his interactions with van staff: “It’s been good with me. The ladies are nice, and they’re genuine, and they try to keep it as confidential as they can”. Participants expressed their gratitude toward the outreach van for bridging proximity and transportation related barriers. Scarlett (PI 2) discusses how the SEP is too far for her to walk to:

We never go over there [to the SEP] though. She was always [walking] cause she wouldn't have a vehicle, she was always coming over there to us [with the outreach van]. [It's] too far to walk. She's really nice her and the blonde headed friend is both really nice people.

This quote indicates the distance that individuals in rural communities may face and how the outreach van helps.

The outreach van has helped bridge additional barriers. Sam (F1) reports how the outreach van has been helpful in delivering sterile syringes and harm reduction supplies despite being on house arrest: “if you’re on house arrest, they deliver it. I call them up,

yes, because I'm not allowed to leave the house no more." Some participants reported using the mobile unit more frequently than the physical location as Melinda explained, "I've been up there [the SEP's physical location] one time I think to get needles, but they deliver to me (PI 3). Similarly, Maggie said,

I ain't been to the new place. I get mine delivered, and she's very good about bringing them on time every week to me. So I've been to the old place maybe four times, and then she just started bringing them to me. So I'm lucky on that (F1).

Although frequent use of the van might be attributable to the variety of barriers these individuals may face such as transportation, it may also be attributed to the convenience the outreach van offers people. A couple of participants report how convenient it is to call the SEP and schedule a delivery during a particular timeframe. Nancy (F4) describes this process: "if you call them, they will [come to you]. They come to our house like every Thursday so we don't have to [go to them and this is a good service]. It's really good."

Earlier it was noted that the SEP's hours of operation were inconvenient for some of the participants. For those who did not have the available time to visit the SEP, the van offers an alternative timeframe to receive harm reduction materials. Ross (PI 11) noted that he "likes on Fridays that if you don't have time to go there, you can call them and they'll deliver to you."

Some participants relied on the outreach van to protect their status as a person who injects drugs. While visiting the SEP in person is an indicator of injection drug use, not all PWID want to disclose this status to others. Some, such as Jerald (PI 4), reported that it might be embarrassing: "I would like it to be delivered. I wouldn't want to have to go get them. It's kind of embarrassing. I'd get embarrassed about it. I don't know why, I

just do.” Others may not want to disclose their status as a person who injects drugs to their friends or family:

It’s [the outreach van] not really a big necessity. No, I don’t have a lot of neighbors, so, no, it wouldn’t cause any big things or nothing like that if they saw the Health Department truck in my driveway. Now, maybe something with mom or dad, if they came over and seen that they were there, that might cause something (Karen, PI 10).

The SEP’s Harm Reduction Supplies

SEPs typically provide persons who inject drugs with sterile syringes in exchange for used syringes. While this is a critical element in harm reduction provision, there are additional hardware involved in the injection process that can also facilitate infectious disease transmission. Some of these items include the cooker in which the pill is prepared, the water used to prepare the drug solution, and the filter used to separate the drug solution from the un-injectable portion of the pill. The SEP in Scott County also provides these additional items involved in the injection process to minimize the risk of harm. Other related harm reduction items include condoms, educational materials and wound cleansing materials. Participants provided feedback on the usefulness of these materials and whether they used them. When not used, they explained why.

Syringes

Participants in all four of the focus groups, as well as a couple of the private interviews, provided generally positive experiences with, and their opinions of, the syringes, both quantity and size, distributed by the SEP. Providing syringes to SEP participants has helped PWID avoid alternative, and illegal, sources of syringes. The SEP has also helped educate PWID on proper syringe use and disposal methods:

And the new needles are amazing because before I would have to go to the store and buy them, and lie to them that I’m a diabetic, or say that they’re

for my grandpa or something, and you could only do that I think once every two weeks. So it's nice that you can actually have new needles and stuff...And if we don't get enough, then all you have to do is speak up and they're right there to help you get more if you need them. The main thing is they don't want you to reuse the needles, and they don't want them disposed of incorrectly. So they do everything in their powers to help you in that aspect, and to help you, period, I think with using (Karen, PI 10).

Syringe quantity was a topic of discussion primarily among participants of the first focus group. A couple participants reported the number of syringes they receive: "they only give me 140 syringes. The first time they gave me 200. That last me a full week" (Frank, F4). "I'll use a 100 in the box, bleach em out and throw them in the box" (Joey, F1). "I started at like 35 and now I'm up to 105 [syringes per week]" (Sam, F1). Others, such as Sam, explained that they received a high quantity of syringes because they now know to only use one syringe per injection event: "that's why it [the number of syringes I receive] went up [from 35 to 105 per week], because I only use mine one time now" (Sam, F1). When Sam initially went to the SEP he underreported the number of times he actually stuck himself as he did not realize he was supposed to use a sterile syringe each time. Over time, he became educated so more accurately reported the amount of syringes he needed.

The participants who discussed the size (i.e. gauge and length) of the syringes the SEP provided reported generally positive experiences and opinions. The participants describe why these aspects of syringes are important. Syringes with too low of a gauge (i.e. they are too wide) can have undesirable effects on those who use them: "sometimes you get the wide [gauge]. I mean that puts bruises on me. They hurt me... [Using the wrong size is] how you miss. You don't want scars like that for the rest of your life" (Joey, F1). Lisa and Danny discuss how prolonged injection drug use can increase the

syringe length a person needs: “I think most of them prefer the long tips, like the first ones they passed out (Lisa, F2) ... After a while, the veins seem they want to hide, you can’t find them, and you have to have that long one to reach it” (Danny, F2).

Cookers

PWID use a cooker to prepare a drug for injection. Opana ER, requires a heat source and water to remove the pill’s binders and plastic coating in order for it to be converted into a drug solution. Given that Opana ER was the primary drug injected, most participants reported using the bottom of a soda can, rather than the bottle cap type cookers provided by the SEP, for this process:

But we just use a pop can [for a cooker]. We cut the bottom of it off and just use that to cook them on because when you cook them on the bottom it gets really black, and that black stuff, it gets on you, it goes everywhere, so you don’t want to ruin your spoons (Melinda, PI 3).

Others reported using a spoon or a cookie sheet in the oven to prepare the pill for injection.

The SEP provides sterile bottle cap size cookers for PWID to use and recommend only using a cooker once. Despite the extra safety the SEP cookers provide, the participants largely had negative opinions of these cookers: “the little tin cap [the cooker] ain’t worth shit” (Brad, F3). Several people in the first focus group reported the SEP cookers are too small to prepare Opana, and therefore, inadequate for preparing the drug solution:

You can’t cook Opana in [the cookers from the SEP] (Jessie, F1). It’s too little for Opana. They only thing I use it for is to pour water in (Tom, F1). [Its] too thin for Opana (Carrie, F1). Opana requires a pop can sized [cooker]... something that can cook it down (Jessie, F1).

There were additional cooker concerns. Tracy (F2) expresses confusion regarding the cookers: “I don’t use them. I wouldn’t even know how to use one.” The SEP provided cooker is relatively small and metallic. These features can also cause the cooker to become really hot after the necessary amount of heat to prepare the drug is applied to it, as Joey (F1) explains: “they need a little handle on those silver cups so you’re not burning yourselves. They burn themselves. I’ve seen quite a few of them get burnt.” A couple of people from the fourth focus group report bypassing this issue by creating a homemade handle for the SEP’s cooker: “the cookers, like he was saying, they’re pretty good. You’ve got to hold them with pliers” (Jay, F4). However, several of the participants report that the bottom of a soda can is preferable to the SEP’s cookers: “those little bitty old grey caps? Hell no, we never used them. It would have to be the size of a pop can, the bottom I’m talking” (Melinda, PI 3). So overall, the SEP provider cookers were inadequate and rarely used by the study participants.

Filters

The SEP provides cotton filters for PWID to use during the drug injection process. Filters are used to prepare drugs to inject and reduce harm by separating the drug solution from other particles that can be harmful when injected. The filters provided by the SEP resemble a smaller version of a cotton ball. Many of the participants indicated dissatisfaction toward these filters explaining that they were “too little” to be of use for injecting Opana. Jessie (F1), for example, explains: “I thought that was kind of a waste because they’re too small.” Tom (F1) expands upon this by claiming the filters the SEP provides cannot absorb enough of the drug solution: “You can’t even draw nothing up with them for when you stick it in me.”

Additionally, several of the participants report not using the SEP-provided filters because they are made of cotton and explained that they were afraid of contracting an illness referred to as, “cotton fever”, something they incorrectly believed was associated with using cotton filters. Robert (F3) describes cotton fever can be caused by loose cotton getting pulled up into the syringe: “the cotton fiber, the tighter it is, the better it is, man. When it’s loose like that, you get cotton fiber up inside the rig [syringe].”

Participants across all four focus groups, and one of the private interviews, report using a cigarette filter, rather than the SEP-provided filter, to filter the drug solution. Melinda (PI 3) reports not knowing anyone who uses a cotton filter: “I’ve never seen anybody use those [SEP cotton filters] either. Everybody cuts the top of a cigarette filter off, a clean filter, and uses that, and it works perfect.” This widely stems the notion that it will reduce the risk of getting cotton fever relative to other cotton filters. For example, Sarah (F4), reports: “if you use [cotton] off of like a Q-tip or something, you get cotton fever and it makes you deathly ill so we use cigarette filters.” Several participants from the first focus group share the process for using a cigarette filter to filter out the drug solution:

You just cut off the end of a cigarette and use that (Tom, F1). Buy a cigarette, a clean cigarette (Carrie, F1). We use this [cigarette filter] and we cut it in half, is what we do. That end of the cigarette (Jessie, F1) they sell them at the tobacco store (Tom, F1). They sell them by the bags (Jessie, F1).

Additional Harm Reduction Materials

The SEP distributes alcohol pads to cleanse the injection site, and they also distribute plastic vials of distilled water to use in place of unsterile water from other sources. All of the focus groups provided their experiences and opinions of the alcohol

pads, but this was not discussed directly in any of the private interviews. Reported opinions toward the alcohol pads were generally positive. One respondent reported SEP staff provide PWID with alcohol pads by the box: “they give you a whole box of alcohol wipes, and I do like that they do give you a whole box. It comes with like 100 in it” (Maggie, F2). A couple of individuals from the third focus group used them for activities outside their intended use, such as wiping the needles off or wiping any leftover blood away. While a couple participants from the first focus group reported favorable attitudes toward the alcohol pads, a few others reported not using the alcohol pads very often because they did not understand why they were provided:

I don't use the prep pad, not the alcohol pads. I don't understand why they're giving them out (Jessie, F1). I don't see [others] using [the antiseptic pads] (Carrie, F1). I just put them in my own little safety kit (Joey, F1). The only thing I use [are the] alcohol pads (Tom, F1). The alcohol ones are great (Jessie, F1).

Participant opinions of the water provided by the SEP were evenly distributed between positive and negative. A couple were confused about the purpose the water was intended to serve. According to Tom (F1), the small plastic tube the water comes in indicates the water “is not for injection.” This led to confusion for some as Mark explained, “they give it to you for injection... but it says right on the package not for injection” (F1). Some reported negative opinions of the water and believed the water was unsafe for injection. Mark (F1) explained, “it's straight salt water. You can't shoot it in your veins ... you can't. I got sick every time I used it.” Tracy (F2) reports that some use the SEP water only if the individual doesn't have access to another water source: “unless she was out in the car shooting up or something because I've seen people driving down the road, you know, because they can't wait, they're using the water shooting up.”

Others report more positive experiences with the water the SEP provides. Sarah (F4) reports that she likes it because “you ain’t got to share them or nothing with nobody.” Karen (PI 10) likes the individual water vials because they are “convenient.” While Rick (PI 20) reports liking the water because “you know you’re getting clean water with it” as opposed to other sources PWID in the community may draw water from, such as “out of the sink.”

Harm Reduction Materials for Sexual Intercourse

Participants in two out of the four focus groups provided their opinions on the harm reduction items the SEP provides for sexual intercourse. Condoms were the primary item of discussion for items of this nature. Some of the participants from the first focus groups provided supportive feedback: “I think that’s awesome [that they give out condoms] (Mark). Yeah, it is nice (Carrie).” Joey from this focus group did provide some suggestions for additional items that may be preferable, such as female or latex free condoms:

I think more [women’s condoms] need to come out. It would be nice if it would be 50/50 hand out of women’s [condoms and men’s]. Yes, could you get some [latex free condoms], some people are allergic to latex, something to get. It’s not like I’m screwing anyone or nothing, but they’re allergic to latex, so they don’t [use condoms].

A couple people from the second focus group reported favorable attitudes toward these materials despite not being sexually active: “if I was [having sex], I would use them” (Tracy).

Educational Materials

Participants in two out of the four focus groups provided their opinions on some of the educational materials the SEP provides to promote low risk behavior. A couple of

people did find the information helpful: “It’s been a useful experience (Sam, F1). Very useful (Joey, F1). Very helpful (Tom, F1).” However, people typically reported that the information was not very useful for them. Tom (F1) went on to say that most PWID do not learn anything new from the materials: “for people that’s been using, they pretty much they know [that information].” Some reported having read it, but then threw it away: “I read it the first time (Mike, F3) and then throw it away after that, because I’ve already read it (Brad, F3).” Another reported some of the PWID do not read the educational materials provided with other harm reduction supplies:

Most of these people, they don’t even know what’s in the dang bag [the SEP provides to participants], honestly. I mean I’ve actually sat and talked to these people but I don’t think they really listened to me (Kay, F3).

Others report the information may not be useful for them personally, although it is useful for people in their lives that do not inject drugs: “it’s like our family members that don’t use. That’s who it’s helpful to or our friends...like my mom found it very useful” (Jessie, F1). Tom (F1) discusses providing this to family members while trying to withhold from them his status as a person who injects drug:

Some people probably don’t want to tell their mom that they’re doing it... so it’s easier to give them the information that they got given to them so they can read it and maybe give them a better understanding of it, instead of you trying to explain it to them because a lot of people don’t want to explain that to their grandma, or their mom, or whoever.

Summary

Participants reported several positive experiences with the SEP for themselves and the community. The participants unanimously agreed the SEP helped contain the HIV outbreak. Participants also praised the SEP staff’s generosity and their nonjudgmental attitudes. Additional positive experiences discussed include the legal

protection for carrying syringes that SEP participation provides and the additional harm reduction materials the SEP provides.

Data collection was conducted shortly after the SEP's hours of operation were reduced when relocating from the outreach center to the permanent current location. While a couple of participants reported neutral attitudes toward the reduced hours, the majority of participants held unfavorable opinions toward this. Unfavorable attitudes expressed include: the hours of operation can be inconvenient for those who are working and for those living outside of town without reliable transportation, and the reduced days and hours of operation can limit access to sterile syringes in the event a person who injects drugs is experiencing withdrawals but does not possess a sterile syringe. A few responses indicated the SEP was only open at certain times of the day; these participants expressed this was inconvenient for those with specific schedules, and that PWID in the community might benefit from being open during the morning on certain days or during multiple points in the day for shorter periods of time.

While a couple of the participants were initially suspicious of the outreach van, the majority of participants reported positive opinions and experiences with it. Responses explain how the outreach van has helped bridge some of the barriers to harm reduction PWID in the community may face. For example, some participants report living outside of town and lacking reliable access to transportation. For them, the outreach van helped bridge the large distance to the SEP. The outreach van was also reported to protect the status of those injecting drugs by eliminating the need to visit the SEP in person and consequently increase the risk of unintentionally disclosing the individual's status as a person who injects drugs. The convenience the outreach van offered was an additional

source of praise. In the event an individual was unable to reach the SEP's physical location during its operating hours, a couple participants reported the outreach van could visit them a day or two later.

The vast majority of responses toward the syringes the SEP provided were positive. Furthermore, the SEP helped participants avoid sharing and using unsterile syringes, and it provided a suitable place to dispose of used syringes. In addition to these educational benefits, the SEP also helped educate participants on the correct number of syringes to obtain during their visits to the SEP; many SEP participants were initially underreporting the number of syringes they needed as they accounted for the multiple injections that often took place during the injection episode as one injection rather than multiple injections.

Participants reported mixed opinions toward several of the additional harm reduction materials the SEP offered. The cooker used to heat the pill and prepare the drug solution was often reported as not meeting the needs of PWID. Those who endorsed this opinion reported the cooker was too small to hold all of the drug solution and it would burn the user while applying heat to the pill to create the drug solution. The majority of responses toward the filter the SEP provided were critical as well. Participants explained the filter was too small, and incorrectly explained all cotton filters were more likely to cause a disease referred to as cotton fever relative to cigarette filters, the filtration method of choice. Participants expressed mixed opinions toward the small vials of distilled water the SEP provided; some of the participants reported these vials were convenient, and others reported they did not believe the water was safe to use for injection.

The SEP also provides harm reduction materials for sexual intercourse. Participant responses solely discussed the condoms the SEP provides to visitors. Responses toward the condoms were mixed; some participants provided positive feedback, and others expressed the desire for additional options, such as female condoms. Finally, the SEP provides educational materials on a variety of subjects such as proper syringe use and information on HIV treatment. Relatively few participants expressed opinions toward these educational materials; however, those who did so did not find them very useful for themselves but did find them valuable materials to educate friends and family members in the community who did not inject drugs.

CHAPTER 4: SEP CONCERNS AND SUGGESTIONS FOR IMPROVEMENT

Both the focus groups and private interviews explored whether the participants experienced any negative outcomes from using, or implementing, the SEP. We also explored why some people might not use the SEP and barriers therein. Finally, we asked participants if they have any suggestions on how the SEP could be improved, especially around increased use of the SEP and getting more participants to enroll.

Concerns that there are Negative Outcomes of the SEP

Four concerns were raised regarding the implementation of the SEP that relate to negative outcomes. Several people mentioned concerns regarding ambiguity over whether syringes were legally safe to carry when enrolled in the SEP and how this unknown could facilitate people improperly disposing of syringes on the ground. Others noted increased police harassment following SEP enrollment and overall implementation. Then a minority of participants in the sample expressed concerns that the SEP would increase drug use (N=3) and the amount of used syringes in the community (N=3). These claims, however, rest in contrast to the literature which provides strong evidence that SEP's do not lead to increases in drug use or increases in the number of syringes discarded in community areas.

Concerns Regarding Legality of Carrying Syringes

Many participants in both the focus groups and private interviews vocalized concerns about the extent of legal protection offered by enrolling in the SEP and holding a SEP membership card. While possessing a syringe is typically illegal unless medically authorized, the card PWID use to participate in the SEP also allows them to legally carry syringes.

Some explained, however, that the SEP serves only Scott County and its residents, “if you go to Clark County or somewhere, you’re still going to jail” (Sarah, F4). Marvin (PI 5) also vocalizes the disadvantage of the SEP’s protection limit: “so if I happen to get pulled over in a different county then I’m probably screwed because a syringe is a D felony.”

Others were unclear of the parameters of the law that allows SEP participants to carry syringes. This subject was debated within the focus groups. Two of the four focus groups contained verbal disputes between participants regarding the limits of their legal protection. The first focus group disputes whether having residual drug solution or blood in the syringe is legal:

One time there was a little bit of blood in that needle... We asked them over [at the SEP] what if we left a little bit of blood [is that ok?] (Joey). You can go to jail for that (Jessie). If you’ve got a used needle on you, you go to jail for using it (Sam). No, ___ said it could be used or dirty, as long as there was no drugs inside of it (Jessie). As long as they don’t test for drugs (Tom).

Tom (F1) expands upon this by saying the legal protection regarding residual blood or drug solution depends on the police officer the PWID interacts with: “she said if they [the police officer] wanted to pull it [a syringe] out and test it to see if it had dope in it, and it tested [positive for drugs or blood], you could go to jail for that.” However, there was consensus within this focus group that none of the participants had personally had an encounter with a police office in which their syringes were checked for residual drug, nor had they known anyone this had happened to. An exchange within the second focus group also indicated some of the participants were unclear on specific legal protections afforded to them by participation in the SEP. Some of these participants also lacked clarity on whether carrying a used syringe fell within the purview of their rights:

I thought it was if you had your card...Once you got your card, [I thought it was ok to carry a used syringe] (Maggie). Yeah, I did too, that's what I thought. Yeah, yeah, you don't have to have it in no packet (Danny). It's supposed to be in the pack or in the red [sharps] container, correct? That's what my husband told me (Casey). Well hers comes in a bag...As long as you had your card ... (Tracy). Because if it's not ok, what's the point of even having the needle program if you've got to have it [in a bag or the box]...That's what I thought too, as long as you had your card, you're good (Maggie).

When probed, the participants in the third focus group all agreed that it was illegal to carry a used syringe even if the individual possesses a SEP card. Some of the participants in this group explained this in greater detail:

No [its not ok for you to carry around a used needle that is not in the box...so if you were at a friend's house and did not have your box, you could get in trouble] as they can get you for the residue [within the syringe] (Steven). If you get pulled over, the cops will take you to jail for possession if it's been used. [The card is] only used for the needle, not the residue inside the needle (Brad)...As long as the needle's new, and you've got the needle card, you can look at a cop laugh at them and they can't do a damn thing (Kelly).

The importance of the SEP card itself was another issue for Casey (F2), who goes on to describe how possessing a card is irrelevant in comparison to properly disposing of the syringes by storing them in a sharps container:

[My husband] gets on to me if I actually put a needle somewhere, not in the red container because I'm like oh well you have a card. It doesn't matter if you have a card, he told me, he said because the simple fact that if it's not in the red container, or if it's not brand new in the pack, and somewhere else, then I can get in trouble for it. He said even if I have the card. That's what he was told when he enrolled in the needle exchange. If [someone] gets pulled over, and a syringe is found in the vehicle, it's like my husband was told, if it's not in the red [sharps] container, or if it's not brand new in the pack, you'll be charged for it even if you do got a card for the needle exchange.

Shawna (PI 17) however, believes the SEP offers great legal protection. She explains how her mother still has a SEP card because she was previously incarcerated for

having a syringe in her house despite not injecting drugs herself. She goes on to explain how several members in her household participate in the SEP, but have legal protection despite having large quantities of syringes in one location:

She went to jail for one broke needle, like I told you. Now, it's so different. You can't go to jail. She don't do drugs. She wanted that needle card, you know. You can get in trouble with your cans and stuff like that, your pill it's a felony. It don't count, the pill, the cans, and stuff, it only counts for the needle. You can only not in get in trouble for your needle. Like I said, we had 800 needles and there wasn't anything they could do because they were sending us the needle cards. Which if you think about, each person gets 110, 140 needles, that's 900 needles we had in the house.

While the SEP card allows for SEP participants to possess syringes, most believed it has strict limits on possessing many of the related items that coincide with injection drug use (e.g. pill, used syringe). Miles (PI 25) explains his belief that many SEP participants are fearful of possessing a syringe because the legal consequences of possessing these related items are steep:

Still right to this day, it's a D felony, if you don't have that card. Or if it's dirty. If it's been used, it's a D felony, whether you got the card or not. So therefore, it makes people scared of the fact, to have a needle in their possession. If they come in your house and find one, that's two D felonies, it's maintaining and possession. So that's two D felonies you're hit with right there. If they find one in your car, that's two more, that's a D felony, for maintaining.

These findings show that the participants struggle with syringe protection policies and what exactly is safe to carry when enrolled in the SEP.

Concerns Regarding Increased Police Harassment

Other participants reported increased harassment from police because of their participation in the SEP. Participants from focus group three noted “if they see you there, they will harass you” (Willy), “I’m in the needle exchange and I’ve been straight up harassed” (Steven), and Kay explained how some people she knew were visited by the

police shortly after they enrolled in the SEP, “almost everybody, when they first started doing it, they went over and got needles from them. They did a probation check on them the next day. There’s three different houses on our street that happened to.”

Another participant notes that some PWID who do not participate in the SEP out of fear of police involvement try to obtain sterile syringes from those who do participate in the SEP:

Every day, they come to our house and they’re like ‘can we have a needle?’ And I’m like, ‘Well, why don’t you just go get your own?’ And they’re like, ‘No, there’s no way I’m going over there’. Because of the cops. They say that well the cops know, the cops know who goes in and out over there. They see you getting needles, they know you’re on drugs, it’s a hard chance they’re going to pull you over, come into your house (Diane, PI 9).

Maria (F4) also reported having “my card in my pocket right now but I wouldn’t dare walk down that street with a needle” because “the police here want to stop you ... and then they want to search them”.

Additionally, some of the participants described instances in which they personally experienced harassment by the police. Shawna (PI 17), for example reported a police officer trying to catch her with a syringe while having a young child with her, despite having a SEP card, which provides legal protection from carrying syringes on their person if it has not been used:

You’re allowed to carry [one needle if you have a SEP card], but it’s got to be new. You can’t have no drug in it, no blood in it. I got caught with a needle and got busted. The sheriff _____, I give him a hard time, because he pulled my needle out in front of a little boy, and I cussed him all to hell. I said ‘why the hell did you pull that out in front of that little kid.’ He’s like ‘why the hell you got that?’ I said ‘I’ve got a needle card, buddy.’ I said ‘that little boy didn’t know I had a needle until you pulled the son-of-a-bitch out. He said ‘you’re a little smartass.’ ...I gave him hell over that little kid. ‘You shouldn’t have had it in your pocket.’ ‘You shouldn’t have

pulled it out of my god damn pocket, he didn't know I had that.' [He] made me sit on the couch outside.

A participant from the first focus group provides a more detailed description of her experience with increased police patrol after enrolling in the SEP, claiming the police deliberately drove around her house multiple times in a row:

Not only pass your house, but they're staring at you every time they go by. We live like two blocks from the [Syringe Exchange] program, so we're like literally two blocks from the police station. But when you're literally making an effort to circle my house, turn right on ___ street, and go around and come down first and keep doing that over and over, and staring right at us, we know they are trying to catch us doing something wrong. ...It's annoying when we ain't doing nothing to bother you. And if we are doing something to bother you, you probably ain't going to catch us, so go watch somewhere else.

Joey (F1) reports a similar instance of a police officer driving multiple times around the residence he was visiting, and then stopping him upon his departure from the residence:

I've ridden many of times with a bike without a light, and why all of a sudden a state boy wants to say, 'you might want to go back home and put a light on that bike.' Like he already knows what time it is, and here I [am], public intoxicated, let's put it that way, and he already knew because he was already circling the place, the whole place, for about 4 or 5 times.

A few participants also reported instances of increased police patrol overall after the implementation of the SEP: "I think they're watching more (Joey, F1). They like to sit and watch people and try to scare them (Carrie, F1). They drive around my house (Sam, F1)." One person from the third focus group remarked the police were "trying to catch you off your guard." Some also reported police harassment for minor law infractions that others who don't inject drugs may not experience. Chris (F4) for example, received "a ticket for walking in the middle of the road", or according to Owen (F4) "for walking on the wrong side of the road." Mike (F3) reported multiple instances of harassment "for no apparent reason. Just because they said I was suspicious." Another

person from the fourth focus group reports “they gave somebody a ticket because they didn’t have a bell on their bike.”

Concerns the SEP Will Increase Amounts of Syringes in the Community

Another concern a few participants vocalized was about how the large quantities of syringes the SEP was distributing will increase the amount of syringes littered throughout the community. While this is a common concern among SEP critics, there is no research that supports this concern; rather the evidence indicates SEPs do not lead to an increase in the number of syringes discarded in open areas of the community. These participants were concerned of the effect this may have on children in the community who come across a used syringe that was disposed of on the street or another public location. One focus group participant with children worries that not all of the syringes the SEP distributes will be properly exchanged. He describes finding syringes in his yard in the past as well as currently:

I’ve got four young boys, and my girls, man, hate shoes. They can’t stand shoes. They run around barefooted. And my girls lay down and they get a tan. My boys got to play in the dark. They’ve got to pretend he’s a fisherman in the water hole. And [he finds] rigs [syringes] out of my garden, Coke cans in my garden, and my woodpile. My kids get in the woodpile to start a bonfire, there’s a fire pit out back, you know, there’s rigs. These rigs from these guys that want to give out rigs. But the ones [syringes] that’s not getting returned, they wind up still in my yard. I mean used to you found them in your yard anyway, but now I’m finding them in my yard twice as bad, ten times worse now (Robert, F3).

Mike, also from focus group three, claims that PWID who do not have children are more likely to engage in this behavior, “I think people are throwing their nasty needles and stuff down are the people that doesn’t have kids. If you have a child, you understand.”

Shantel (PI 1), like Robert, believes the SEP is distributing too many syringes,

“why would you give them two hundred at a time? I can see like five or ten daily, make them come everyday don’t give them no two hundred at a time because that’s too many. They’re passin out too many needles to these people. Who shoots up ten times a day?”

She also expresses worry about the effect this large quantity of syringes could have on the number of syringes in the community, and consequently, on children in the community:

So what if they just throw those needles down that they just used and give little kids AIDS who may step on ‘em or something. Or Hepatitis, hepatitis lives on the surface for thirteen days, HIV dies immediately [when exposed to air]. I know that but what if there’s blood still in that syringe and if they step on it and it pushes it into the child’s foot? That’s where I’m at with it. I think they should give those people one time injection use and that’s it. Not the ones they can pull back and reuse and reuse. Yeah, I feel like they should give them something that cause them to automatically lock or something that pulls the syringe back up... I’m looking out for the children ‘cause you know there’s people here beyond us, so I mean they need to be watched.

She offers a potential solution to this issue by suggesting the SEP distribute only single use syringes rather than the current syringes that can be used multiple times.

Casey (F2) touches upon the limits of legal protection offered by participation in the SEP which may explain why people improperly discard used syringes on the grounds. She claims that because the law does not protect against residual drug within a syringe, people are more inclined to quickly discard such a syringe if police are near:

...With the police saying that the needle has to be actually inside the plastic brand new, or inside the red container if it’s been used, it’s still putting my children and all of the other children in the community at risk, because let’s say my son is running after the ball and it goes into the field next to our house where the abandoned trailers at, and he reaches down to pick up that ball, he’s not just picking up his ball, he’s picking up the rig that somebody threw out. Because why? They [PWID] can’t have it in their pocket because well, damn, they’re not carrying their red container down the road with them.

While some of the participants discussed their concerns that the SEP may lead to an increase in the number of syringes that are disposed of in public locations or private residences, several other participants described the motive people possessed for discarding syringes in the community. All of these descriptions include the individual avoiding detection from the police with a used syringe. In reference to police presence, one person remarks, “well, they get scared if they see a cop car coming. They figure they’re probably should throw it” (Danny, F2). Miles (PI 25) expands upon this by claiming that the SEP’s presence has not decreased the number of syringes in the community, and goes so far as to attribute the spread of HIV to the relationship between the police and PWID in the community:

Yeah, they’re still throwing them away because they’re scared, man.
Yeah, they’re scared to get caught with them, man, because if they got them in their car, from their house to wherever they need to drop them off, and they don’t have the red box, for instance, to put them in, and they get caught with them dirty rigs, hey, they’re hit with a D felony. So, yeah, I mean the law is really causing a lot of the HIV spreading.

Another participant implies that quickly disposing of a syringe by throwing on the ground is common practice when a police officer is nearby, “look [though], how many times have a cop got behind you and you just throw that needle out in the ditch though?” (Liz, F3). These explanations of why people may improperly discard syringes despite the SEP, correspond to the concerns described previously about ambiguity regarding what is legally safe to carry when it comes to syringes and being enrolled in the SEP.

Concerns the SEP is Enabling Persons Who Inject Drugs

Only a few participants voiced concerns about the SEP because they believed it was enabling injection drug use. This is another common unsupported concern among SEP critics as the evidence clearly shows SEPs do not influence injection frequency.

Robert (F3) believed the SEP was normalizing injection drug use when it should continue to be a negatively regarded behavior: “You’re basically giving us everything there is that we need to be junkies except for pills. You’ve given us everything that they could be junkies. Everything.” Or as Becky (PI 7) says, “it’s basically tellin’ people it’s ok to get high. It’s ok to put a needle in your arm. I believe yeah they’re just sayin’ it’s ok to get high ‘cause they’re given free needles.” Another participant raises the concern of some people taking advantage of the free syringes the SEP offers by selling the syringes to other PWID:

Well you know some of them use the needle exchange because they don’t have HIV and they don’t want to catch it and that’s a grateful thing, but some of em take advantage of it to, to be able to sell em and have needles to use to get high with and some of them sell em so they can get high. I mean that’s why they want it. It ain’t to help em. It’s a place where they can get a free needle (Shantel, PI 1).

Only three out of the total 56 participants raised the issue of the SEP enabling and promoting injection drug use.

Concerns Regarding Barriers to Using the Syringe Exchange Program

Participants shared several concerns that posed a barrier to using the SEP. The vast majority of these concerns had to do with police related issues such as close proximity to the police station and increased harassment and surveillance by the police should they enroll. Two additional barriers to SEP use related to concerns that Child Protective Services would learn of drug use if they enrolled in the SEP and take their children away as well fear of being outed as a person who injects drugs.

Police Related Barrier Concerns

1. The SEP's Location and Proximity to the Police Station as a Barrier

All four focus groups, and 11 out of 25 of the private interview participants, discussed how the proximity of the police station to the SEP impacted both attitudes of the SEP as well as SEP usage. They explained that the SEP operates within a building offering other healthcare services. However, this is the next building over from the police station. A small alley and some parking space for both buildings separates the two. While the entrance to the SEP faces away from the police station, the risk of being seen entering the SEP is still present. While some participants had no concerns about the proximity to the police station, an equal number did express concerns, some to the point of keeping them or others they knew from visiting the physical location. However, responses did not indicate whether the SEP's close proximity to the police station prevented participants from enrolling in the SEP or utilizing the outreach van.

Some commented generally that they were not concerned about the location, and did not give much attention to the issue. For example, Danny (F2) said, "It don't bother me. I'll go inside. I don't care where it goes". And Shantel stated, "It's in a good place" (PI 1). Isaac (PI 12) discussed how the SEP's location is actually convenient because it is located where most of the drug activity takes place:

No I always come to them. I think [the location] is good because this side right here of town--is where a lot of it's [drug activity] going on at and plus it's clean, but they need to keep this place clean. You know, like use a measure to actually clean it and make sure that nothing gets stolen or nothing like that out of it.

It just happens that the police station is also located in the same area as the drug activity.

Others expressed limited or no concerns about the SEP's proximity to the police

station because SEP participants are given legal protection for possessing syringes containing no drug solution as long as they have their SEP membership card:

I don't care. I mean, it don't bother me [that the SEP is] right next to the police station. I mean, if you're scared of the police, I mean, look. I'm not a cop, I don't snitch on people so, there's no reason to be scared of them. I haven't done nothing wrong. I mean, they're giving me the needles in there so when I walk out, they can't do nothing to me so there's no reason to be scared (Ross PI 11).

I thought about it a little bit. I don't think they're really ... they might be watching people. I don't think they're going to [arrest people] because it's not illegal once you get a card (Jerald, PI 4).

And with them even being closer to the police station now, you would have thought that probably would have stopped people but it didn't because we know we're not going to jail for that needle now as long as we've got our card (Melinda, PI3).

The legal exemption the SEP card provides reduced some people's fear and concerns about the location next to the police station.

Karen (PI 10) offers a different explanation of why the SEP's location concerns her, but doesn't stop her from using it:

Well, I mean it's not nice that it's right next to the police station, you know. I mean, a lot of people were worried about even coming to begin with, because they were worried that they were working with the police but once a lot of people heard they don't even use your name, that's when it really started to pour in, I believe. So, I mean, yeah, being next to the police station, not cool, but the dealer is also just across the street. It's not a big deal. We know, a lot of people now know that this place is not ran by the police.

This quote also mentions the SEP's proximity to the town's drug activity, just as a previous quote did, as well as the anonymity in enrollment, to provide a rationalization for using the SEP despite its proximity to the police station.

Participants in two of the focus groups and one private interview reported not using the SEP physical location themselves, or reported knowing people who do not use it because of its proximity to the police station.

They won't come [to the SEP] because they're probably just afraid (Jessie)...Because of the police station. The police station is a bad idea (Joey)... They're not going to go near the police station (Jesse). They're afraid the cops are going to see them and follow them around (Haley). And then you turn to see what drug house they go into to see where they're getting their drugs (Jesse F1).

Responses from the third focus group were similar:

It's right by the police station...it should be in the center of XXX street (Steven). [It should be] as far away from the police station as possible (Kay)... It [the location] sucks (Brad).

While participating in the SEP is legal, some people believe that using the SEP will indicate to the nearby police their status as a person who injects drugs, as referenced by Shawna (PI 17): “not many people visit here, because if you visit here they're going to know you do pills. It's like I said, they know who does pills. Nobody's ignorant.”

2. Fears of Increased Police Surveillance and Harassment as a Barrier to SEP Use

Study participants also shared their overall experiences with the police in the community in relation to using or not using the SEP. A considerable portion of their reports regarding this pertain to police harassment in relation to their status as persons who injects drugs or as a barrier to accessing the SEP. However, a couple of the participants did indicate supportive attitudes toward to police. Melinda, for example, explained in detail her belief that the police are not harassing PWID, and how the SEP card offers sufficient legal protection for possessing a syringe:

I've never been harassed by them. I think they are accepting it because they have to. It's not because they want to; it's because they have to. [Nobody's concerned] because even with it being that close to the police station, everybody feels safe with their card. People feel safe with it, with

their card, people who go there. And if you don't feel safe to go in there, you can always have it delivered. I just have it delivered because I don't have a vehicle. I think that the police have to accept it, and that's the only reason it's working because if they didn't have to accept it, I can guarantee that they would have already taken all of us to jail (PI 3).

Similarly, Karen (PI10) explained that the police could monitor all of the individuals visiting the SEP in order to entrap them on charges outside of their legal protection, but instead they have chosen not to as they too see the benefits of the SEP for the community:

And the police, I think honestly think that [they're here to help] too. I mean the police could sit right there and watch every single user come up here and get needles. But they also know that the users that are coming here to get needles are users that are thinking about how they're using, and thinking about somewhat of the community because they're not disposing of the needles in ways that shouldn't be disposed of, to hurt other people. So I think the cops kind of stay backed away, because this is a good place, and this is a good place for us to come to and for them to speak to us.

However, these two participants had attitudes that contrasted with others who commented on police experiences. Others who commented did believe the police were keeping a closer watch on them since the implementation of the SEP and some even voiced suspicion that the SEP itself was being operated by the police. Participant claims include both actual instances of harassment and concerns or fear of potential police harassment.

As indicated in the previous chapter, some participants, like Joey (F1), were suspicious of the SEP and initially believed it was being operated by the police.

I thought it was entrapment. It was scary the first time going in there because I went in there and I said is this a set-up, is this entrapment. I said 'why do you want to know my address?' The very first [time], I said 'can I have it on record if I leave with these needles out of this building, and if I get pulled over, you're going to pay my bond.' And they said 'you will not get in trouble as long as you do not have drugs on you.'

Marvin similarly explained how this fear that the SEP is working with the police has influenced PWID to avoid participating in the SEP:

Another thing is some people are like they won't come because they're sketched out by 'ooh they're going to write my name down and give it to the cops are going to get me or the cops are going to be watching me'. They're all paranoid about the thing, so they're not going to do it [participate in the SEP] (PI 5).

Tracy (F2) explains the anxiety these individuals feel in further detail, claiming they believe the police will arrest them in their homes, "they think that our name's down, our address is down... they've got them down and the cops can come in and bust you at any time." Tracy further elaborates that the fear of the "cops in on it" has even kept some people, including herself, from participating in the SEP:

[A lot of people think that] if you're getting into the needle program, [the cops are] going to look and saying they're going to come in and bust you for maybe having drugs in your house. That's why a lot of people don't want to do it, because that's why I didn't want to do it for a while.

Jesse (F1) also notes that individuals who sell drugs and inject are especially unlikely to use the SEP, "The drug dealers, they're like 'I'm not going to use that program, that way they don't get my name and follow me.'"

A couple of participants explained in more detail how fear of the police, or negative experiences with the police, have acted as a barrier to participating in the SEP even when they were enrolled. George (PI 18) for example described how he sometimes was hesitant to exchange his syringes because police tended to stop him, for a minor infraction, as he's walking to the SEP:

Two weeks in a row I got stopped by a state cop and gave a warning—both times—for not walking on the right side of the road, and walking in the road. He wanted me to walk a foot off the road, even if there isn't a sidewalk, and be on the opposite side where the traffic's coming at me. If not he's gonna give me a ticket—25 dollars next time he catches me. Both

times it was on a Wednesday—when they give away needles here—I was scared to death. I did not want to bring my needles here because if I did and they were dirty, he could fucking get me. So I wouldn't do it.

Shortly after reporting this, George discloses reusing syringes to avoid getting stopped by the police on the way to the SEP, “I didn't have needles for a while. Me and my old lady were getting 'em out of the... the sharps [container]. 'Cause I wasn't gonna risk it.”

Chris (F4) also reported concerns over exchanging his syringes out of fear the police will investigate his used syringes for residual drug during the frequent occurrences the police stop him as he walks to the SEP alongside the road:

I got a warning the other day from a state cop, and I was literally behind my house on the road. He claims that I was walking in the middle of the road. I'm very cautious. I have a pregnant wife. I am not going to walk in the middle of the road. He claims I was. Whatever. Fine. I was gun shy. We only get one day to exchange [syringes]. I was gun shy about going back up there and exchanging my needles. [If] he catches me out, he's going to check those for residue. He's going to pop me for possession... And I've been in prison a lot. I go in and out of prison, and it's just like they stay on me because they know I'm in prison, they know I've got a record, and they know I'm on paper. That, paper means I'm on probation or on parole. So any little thing, they can send me back [to prison].

SEP Nonuse and Concerns Due to Stigma

Study participants discussed their experiences with stigma associated with injection drug use. Some said the stigma PWID face acted as a barrier to their participation in the SEP. Such participants reported trying to protect this status from the public. Jerald (PI 4) reports, “I don't know [why I'm not enrolled in the needle exchange]. I guess I was kind of scared somebody would see me.” Diane (PI 9) adds another aspect to this by saying “some people don't want other people knowing their business. Where they use needles, and if they're seen over here [at the SEP] then, they know what's going on”, indicating that being seen walking in or out of the SEP

automatically labels a person as an injection drug user. Kay (F2) indicates, “they’re saying that they’re embarrassed [to use the SEP], they don’t want to go look bad”

A couple of participants reported being concerned about, or not using the SEP, because they do not want specific people in their life to discover their status as a person who injects drugs. Melinda (PI 3) for example described one such experience of a man who was hiding his drug use from his parents:

I know this one guy, he lives with his parents, and he just goes to Walmart to get them, or he has somebody bring them to him because he lives with his mom and dad and they don’t know that he shoots up, so he can’t very well have a big container sitting there that he can throw empty needles in or have supplies of them lying around. So I think that’s more of the people that’s not using it, is the people who are trying to still keep it hid from their parents. And that’s younger kids.

Another participant describes a person who injects drugs with a relatively prominent community member as a relative:

Her mom’s a school teacher here at [the] high school right now. There’s no way she could go there [to the SEP]. I mean whenever these people’s family don’t know that they’re getting high, they’re not going to go put their selves out there to [go to the SEP] (Liz, F2).

In addition to keeping one’s status concealed from family, PWID who work may want to prevent their coworkers or superiors from discovering their status as well. Shantel (PI 1) describes this as a reason she and a couple others do not use the SEP:

There is but a couple of us [who don’t use the needle exchange], or few of us won’t go to that [SEP], and I believe that’s because of our pride and what we do in our work and we’re afraid [of] how people will look at us. I’m worried about like the people we work for how would they judge us. How would that make us look to them? [They might think] ‘hey, they’re dope heads, why would we let them work for us?’

Concerns with Child Protective Services

A final barrier to using the SEP had to do with fears of losing one’s children. Two individuals who participated in private interviews echoed concerns about how their

involvement with the SEP could cause an intervention with Child Protective Services (CPS) that could result in the parent losing their children. Scarlett (PI 2) discusses how a relative of hers currently has a case with CPS, and is afraid SEP staff may tell CPS if she participates in the SEP:

I'm trying to get my niece to come down here, but she won't 'cause she's having trouble with CPS over her kids. She's afraid that they'll [the SEP staff] say anything. I said they can't say anything, it's confidential. She's afraid she'll get reported to CPS and they take her kids.

Another related concern includes the barriers that mothers without access to child care may face. This acts as a barrier when the individual decides not to visit the SEP because she does not want to bring her child. The idea of bringing her child with her to the SEP can also create fear that CPS may consequently become involved. Diane (PI 9) says, "I know somebody who was wanting to come over but she didn't have a baby sitter and she was like 'Ah, there's no way I'm taking my kid over there and CPS getting called on me.'"

Suggestions for Reducing Barriers to SEP Use and Related Negative Outcomes

At the conclusion of the focus groups and private interviews, participants were asked for ways they felt the SEP could improve. While they had many suggestions, ranging from increased medicated assisted treatment to providing food and housing services, here I only report on those dealing specifically with some of the barriers to using the SEP mentioned in this chapter as overall, participants were mostly satisfied with the syringe provision aspects of the SEP.

Suggestions to Address Police Concerns

Several participants reported concerns regarding both the proximity of the police station to the SEP and relations between the police and SEP participants. A common

theme here were concerns with the limits of the legal protection associated with participating in the SEP, specifically as it pertains to the possibility of being arrested for possessing syringes with residual drug left in them. Participants indicated the difficulty of carrying used syringes that do not have trace amounts of drug solution within them. A couple participants suggested the idea of allowing a grace period, after the SEP's implementation, wherein SEP participants are given a window of time where legal consequences are not imposed upon them for possessing syringes with trace amounts of drug solution. Kay (F3) says this could reduce the number of syringes found on the ground, "maybe they wouldn't throw them away like that [on the ground], or throw them out, if [we had] something like that [a warning or grace period of some kind]." Brad, also in the third focus group, says police should give individuals a warning for their first offense of carrying a syringe with trace amounts of drug solution left over, "they should give us [a warning first]. If I've got a rig in my pocket, yeah if you tested it, it might come up very, very, faint [for traces of drug solution]."

The proximity between the SEP and the police station was also a commonly cited concern among participants (the two buildings are separated by a road and parking space). A couple participants suggested a fence be constructed between the two buildings as a means of minimizing the concerns SEP participants experience with the SEP's close proximity to the police station. Tom (F1) suggests that a fence will keep PWID from seeing the police station as they visit the SEP, and thus, will reduce the anxiety some experience when they visit the SEP:

If they put a barrier, a privacy fence up there, probably nobody would even have a problem with it [the police station being across the street]. It's just the point that if they can see the police station when they're going in there, and everybody's used to it being illegal [to carry syringes], and they

haven't gotten a hold of the concept that you're not going to get in trouble for having it with that card.

Frank reported sneaking up to the SEP's entrance, which faces away from the police station, to avoid being seen visiting the SEP by the police. He reports a privacy fence will keep police from seeing people visiting the SEP, which he believes will reduce the likelihood of police harassment:

I come up ___ [street] and sneak up to it [the SEP] to make sure that the cops don't see me pulling into it. I try to make sure that I keep the building between me and the cops, because they will pull you over. If they see you leaving there and they see you walk out with a big ole bag, they're going to pull you over (F4).

Suggestions for Improving Syringe Disposal

The improper disposal of syringes was a commonly cited concern among participants, particularly as it pertained to the possibility of syringes being discarded on the ground. Some of the participants offered suggestions for procedures the SEP could implement in order to reduce the potential for syringes to be discarded on the ground. Chris (F4) suggests that the SEP spend more time educating participants on properly disposing of syringes.

He suggests this could take the form of a single class meeting for new participants: there just needs to be education on your needles, not just a quick we'll get you in here and out 5 minutes. No. Before you receive that card [for membership in the SEP], there needs to be an hour class you need to take on adequate disposal.

Additionally, Chris and another participant raises concern with the idea of distributing syringes to those who are "mentally unstable" by reporting they might discard them in the community:

They could give them to a mentally unstable person that goes and just chucks them into a school yard or a daycare center. They don't know who they're giving them to. I'm just asking who are you giving them to? The

man that you're giving them to, is he so unstable that he's going to go start throwing them into a daycare center? (Chris, F4).

Frank (F4) suggests a class or assessment for those who are mentally ill to “make sure they're stable” before the SEP distributes syringes to them.

Anne (F4) suggests the SEP should provide participants with children a lock box to store their syringes to reduce the risk of children accessing the syringes and harming themselves:

They [also] don't ask you if you have children at home. And they should. People who have small kids at home, they need to know that you have children at home. [The SEP should] give them a little insight, this is what you need to do, make sure you are doing this... If you have kids, give them a lock box, or something to keep everything in and keep it locked so that their child cannot get into it.

Suggestions on How to Increase Use of the SEP by PWID

Earlier findings detail the various reasons reported for which some PWID do not use the SEP. A couple of the participants provided suggestions for increasing SEP participation among PWID in Scott County. Some of these participants, such as Mark (F1), suggest, “more advertisement for needle exchange hours.” In an effort to reduce the general concern some PWID feel toward the SEP, Jesse (F1) suggests advertising to “make it more known that they're not going to have any kind of trouble by using it [the SEP].”

Marvin (PI 5) suggests an attempt at reducing both the general stigma attributed to injection drug use, and the police related concerns PWID have with using the SEP, as means of increasing SEP participation:

in order for them to trust a program like this I think the social taboo of drug use would have to be lifted, there would have to be a more believable promise that you would be protected against the law.

He also goes on to suggest opening additional SEPs in nearby counties as a means of increasing harm reduction among PWID who live outside of Scott County:

People in other counties don't know anything about it [the SEP]. I think people in Jackson County...they're not in Scott County so they don't know much about it, so they're sort of sketched out about it. I think if you put a needle exchange in Jackson County then it would be easier people to learn about it, then they would be more inclined to use it.

Summary

Participants in the study reported several concerns directly and indirectly involved with their experiences with the SEP. Elicited concerns centered around negative outcomes associated with implementing and using the SEP, as well as barriers to accessing the SEP. These barriers include police related barriers and nonuse related to stigma and fear of exposing status as PWID. Additionally, suggestions for improving the SEP were gathered. Many of these responses discussed methods for improving SEP access among PWID in the community.

Four concerns were raised regarding negative outcomes as a result of implementing the SEP. Many of the participants reported concerns regarding the legality of carrying syringes after the implementation of the SEP. While participation in the SEP does protect participants carrying unused syringes from criminal charges, many still reported feeling unsure of the exact parameters of this protection. These discussions of the law's limitations centered upon whether trace amounts of residual drug in used syringes would violate the law, and how this protection only applied within county limits. The second concern raised by participants was an increase in police harassment resulting from their participation in the SEP. Many of them described instances in which they experienced harassment such as increased police searches and increased police patrolling

as a result of their participation in the SEP. The third concern raised by a minority of participants was that the SEP would result in an increased number of syringes left on the streets of the community. In response, a couple participants explained that PWID may quickly discard of a syringe improperly if presented with the threat of being stopped by the police with a syringe that may have trace amounts of residual drug left within it. The last concern raised by a minority of participants was that the availability of syringes offered by the SEP enables and promotes injection drug use among PWID.

Participants also discussed different barriers to accessing the SEP. The vast majority of these barriers were police related concerns. Potential areas of concern centered upon two aspects of police related barriers: the SEP's close proximity to the police station, and the fear of increased police surveillance and harassment as a result of using the SEP. The SEP's proximity to the police station was discussed among all of the focus groups and many of the private interviews. The SEP and police station in Scott County occupy neighboring buildings, separated by a small alley and some parking space, on the same side of the street. Most of the participants reported either no concerns or limited concerns toward the SEP's close proximity to the police station. However, a couple participants did report avoiding the SEP's physical location due to this close proximity. These participants did not report whether they utilized the outreach van as an alternative method. Fears of increased police surveillance and harassment was a second reported police related barrier. Many of the respondents reported police harassment as a result of their status as a person who injects drugs as a barrier to accessing the SEP. Participants reported both descriptions of events that happened to them as well as related fears of possibility of harassment as a result of SEP participation. Many who commented

did believe the police were keeping a closer watch on them since the implementation of the SEP, and some even voiced suspicion that the SEP itself was being operated by the police.

Two additional concerns regarding barriers to using the SEP were discussed among participants. Some participants said the stigma PWID face acted as a barrier to their participation in the SEP. Such participants reported trying to protect this status from the public, members of their family, or their employers out of concern of the consequences of their status becoming known. The second concern, vocalized by a minority of participants, was the fear that SEP participation could cause an intervention with Child Protective Services (CPS) that could result in the parent losing their children.

At the conclusion of the focus groups and private interviews, participants were asked for ways they felt the SEP could improve. The responses reported upon in these findings cover three topics. Addressing police concerns among PWID was the first suggestion. A couple participants suggested police provide warnings to SEP participants who may have residual drug left within used syringes, and a couple others suggested a large fence be built between the police station and the SEP to reduce these concerns. The second suggestion, offered by a minority of participants, was that the SEP could help reduce the number of improperly disposed syringes in the community by increasing their educational efforts regarding proper syringe disposal. The last suggestion, offered by a minority of participants, concerned how the SEP could increase the number of PWID in the community who are utilizing its services. Responses within this suggestion include increased advertisement of hours and efforts to reduce the stigma associated with injection drug use.

CHAPTER 5: DISCUSSION

The purpose of this thesis was to understand and examine the experiences, successes, and challenges of PWID with the first legal SEP in Indiana. This was achieved through analyzing existing data set from a qualitative exploratory study conducted shortly after the HIV outbreak in Austin, Indiana, following the implementation of the SEP. This thesis is one of the few studies that examines a rural SEP and as such fills a gap in our general understanding of SEP experiences that may affect SEP access and usage. Findings may be particularly informative when implementing SEPs in similar geographic areas.

The findings of this thesis indicate many of the interviewed PWID have positive attitudes toward the SEP, and specifically noted positive outcomes with the SEP services (e.g. an increase in access to sterile syringes), SEP staff, outreach van, and its impact on containing the HIV outbreak. Several of these findings corroborate the larger body of literature. The observation that the SEP contained the spread of HIV is supported by the large evidence base of more formal, larger scale SEP evaluations (Aspinall et al. 2014; Des Jarlais 2009; Heimer 1998; Wodak and Cooney 2006; Vlahov et al. 2010). Additionally, many participants reported positive relationships developed with the SEP staff. The literature suggests this can lead to increased SEP visitations (McNeil and Small 2014); and as well as other positive health outcomes such as referrals to physicians and care coordination, and to opioid dependency treatment (Macneil and Pualy 2011). Positive, judgment-free, relationships are an important, yet potentially overlooked, aspect of SEPs. Qualitative interview evidence suggests that doctors and medical providers in more formal healthcare settings, such as a hospital, can hold stereotypes and negative

opinions of PWID (Henderson, Stacey, and Dohan 2008). The harm reduction philosophy SEPs embrace rests in contrast to this approach.

These findings indicate some concern regarding SEP operations among a minority of participants. Specifically, the SEP's reduction in hours of operation at the permanent location was not well received among a small number of participants. A few offered scenarios in which these reduced hours could be inconvenient and confusion about the new hours because they had not been informed of the change in hours. However, the SEP's limited capacity can be problematic in providing operating hours satisfactory to all SEP participants. The SEP's limited capacity is a situation that finds resonance with much of the literature on rural healthcare infrastructure both overall, and as it relates to service provision to vulnerable populations (Bradshaw 2007; Edwards et al. 2009). The current lack of rural SEP literature, and the literature documenting the lack of substance abuse treatment facilities in rural counties in Indiana (Kooreman and Green 2016), may also be construed as an indicator of the limited capacity rural areas have to extend harm reduction services to PWID.

One notable finding can be found in participant opinions of the SEP's harm reduction equipment, particularly the cookers used to prepare the drug solution. It is worth highlighting that, although participants reported generally positive experiences with the harm reduction equipment, the findings indicate the vast majority of participants held unfavorable opinions of the cookers the SEP distributes. The most common critique was that the cookers were too small. Consequently, they did not always hold enough volume to contain the drug solution, and they often burned the individual holding it during drug preparation.

No literature on SEP participant opinions and experiences with cookers was found over the course of this study. However, the ease of transmitting HCV relative to HIV especially denotes the need for sterile, single use cookers that are functional for the injection practices of PWID in this community. Additionally, many of the PWID interviewed report using the bottom of a soda can as a cooker. The method PWID use to convert a soda can into a cooker presents the opportunity for harm. Blood from a cut on the edge of the soda can bottom has the potential to infect the surface with HCV given both the high HCV infection rate among PWID in general (Suryaprasad et al. 2014), as well as the high incidence of chronic HCV in Scott County relative to the Indiana state average (402.7/100,000 people vs. 105.8/100,000) (ISDH 2017).

There were a couple of concerns raised regarding the SEP. Many SEP participants reported unfamiliarity with the exact parameters of their legal protection from possessing syringes, especially used syringes that may have drug residual. At one point, in two of the four focus groups, participants engaged in verbal dispute in an attempt to clarify the limits of their protection. Several reports appeared to be intertwined with an overall attitude of distrust toward law enforcement which could then have influenced the extent of the participants' strong attitudes of concern with their legal protection when enrolled in the SEP. Many participants reported instances of police harassment, being stopped and searched, and fears of police harassment related to SEP enrollment. These findings fall in line with findings from a 2010 national survey of SEP program managers in which 31% reported at least monthly confiscation of client syringes, and 12% reported at least monthly client arrests while en route to the SEP (Beletsky et al. 2011).

Concern and distrust of the police was a general theme that ran through much of the findings and touched on three areas: (1) reports of concern with the police station's close proximity to the SEP, (2) reports of increased police harassment resulting from SEP participation, and (3) reports of forgoing participation in the SEP as a result of police harassment.

Several participants reported concern with the SEP's close proximity with the proximity to the police station. Although none reported this prevented them from accessing the SEP, some did report knowing individuals for whom this did prevent visiting at least the SEP's physical location. The Scott County Health Department SEP's close proximity to the police station appears to be an anomaly in relation to SEPs discussed in the literature, much of which does not seem to specify how a SEP's location relates to that of the nearest police station. However, the location of the SEP does reflect a suggested practice within the rare literature base on rural SEPs which recommends implementing a SEP in an area where higher concentrations of PWID live or congregate (Parker et al. 2012). Both the police station and SEP are located in a small area within the town that is locally known for its relatively high amount of drug activity. This recommendation, however, may not be contextually relevant given the SEP's close proximity to the police station and attitudes of distrust and concern toward the police among PWID.

Negative experiences with law enforcement was both commonly reported among PWID in the findings and in the literature. Some participants reported increased harassment and surveillance after the SEP was implemented. The survey conducted by Beletsky and colleagues (2011) reports 43% of SEP program managers report SEP

participants experience police harassment on monthly or more frequently. This suggests police harassment is common among SEP participants generally. However, this does not substantiate the claim that police surveillance and harassment increased after the SEP's implementation; because this is self-reported data, this phenomena could be more perception than reality. Literature examining police activity pre and post SEP implementation provides loose support for the perception of the PWID in this study; a study of an urban SEP suggests sterile syringe distribution may be associated with an increase in police activity (Wood et al. 2013).

A relatively small number reported police harassment influenced either themselves or people they knew, to avoid using the SEP. Police harassment has been observed as a barrier and a means of reducing SEP access and utilization (Blumenthal et al. 1997; McNeil and Small 2014). Many of the participants reported police harassment and negative police experiences reported a sense of fear from using the SEP or possessing syringes. Participants did not comment as to whether this decreased their use of sterile syringes, as they may have still secured syringes from other sources.

Participants reported other negative effects of police harassment. Unsafe syringe disposal (e.g. throwing the syringe on the ground) was one such effect. Additionally, one participant indicated reusing syringes to reduce his frequency of visits to the SEP to avoid the police harassment encountered en route. Both outcomes have been observed in the literature as a potential negative effect of police surveillance (Cooper et al. 2005; Small et al. 2006). An unwillingness to carry syringes as result of police activity and the fear of harassment was observed in both the findings and literature (Small et al. 2006). As indicated earlier, the findings suggest some participants were unwilling to carry syringes

in public as a result of perceived ambiguity or potential for entrapment under the current protections participation in the SEP entails.

The findings also examine SEP nonuse either directly or indirectly. This can be observed in three different areas: (1) police harassment (as indicated earlier), (2) concerns with having children taken away by CPS as a result of using the SEP (reported by two participants), and (3) the desire to protect the identity as PWID due to stigma. The stigma PWID face was particularly prevalent as a reason cited for not using the SEP among those who did not want to their identity as PWID disclosed to the public. Noted reasons include the desire to keep their identity from being common knowledge in a small town, keeping their identity a secret from family or friends, and not wanting to be caught by work partners, with the latter of these two reasons observed in larger scale quantitative research (Pokrajac et al. 2016). While the stigma PWID face influenced a minority of participants in the findings to refrain from using the SEP, the same study indicates stigma and discrimination was the primary reason PWID in the sample did not utilize harm reduction resources (Pokrajac et al. 2016).

The findings indicate a very small minority of participants believed the SEP was producing negative outcomes. One of the vocalized concerns was that the SEP has led to an increase in the amount of syringes discarded in the community's streets and yards. However, the implementation of a SEP should result in a decrease in the number of syringes unsafely discarded throughout the community, if law enforcement surveillance and harassment does not increase and syringes are exchanged at the intended one to one ratio. Determining whether this concern holds truth would require a community level study and no data existed pre-SEP for Scott County. However, it is important to properly

address this concern as claims such as this can be over-inflated by SEP critics, who may, as evidenced by the findings above, occasionally be PWID themselves sometimes. While SEPs should lead to a decrease in the number of syringes discarded throughout the community when there are no barriers to proper syringe disposal, the findings indicate there may be barriers for such with the Scott County SEP. The findings indicate police harassment, the fear of harassment, or even police presence may prompt some PWID to quickly and unsafely discard their syringes to reduce any of chance of infringing upon the law. These findings have been echoed across several other studies which document increases in improper syringe disposal during periods of police crackdowns (Small et al. 2006), or as a result of increased police searches (Cooper et al. 2005).

The findings also show a couple of participants held concerns that the SEP enabled and legitimized injection drug use among PWID, as if to imply the presence of the SEP would make it easier for PWID to continue injecting drugs and more difficult to quit injecting drugs. This is a common concern among SEP critics, despite the overwhelming scientific evidence supporting the effectiveness of SEPs in terms of not increasing drug use. These attitudes can be harbored by law makers as well, as observed in Indiana's reluctance to legalize SEPs in the wake of a public health state of emergency. Additionally, no data were gathered on this study's behalf to determine whether some PWID had reduced their injection drug use or were referred to substance abuse treatment services. However, literature on the topic provides strong evidence that SEPs do not lead to an increase in injection drug use (e.g. Wodak and Cooney 2005).

Lessons Learned and Recommendations

Recent research endeavors have demonstrated considerable progress in documenting public health challenges in rural areas. Studies have examined the silent growth of HCV cases in rural areas, as it nears epidemic proportions (Suryaprasad et al. 2014; Zibbell et al. 2015). Researchers, spurred by the rapid HIV outbreak in Scott County, Indiana, have conducted a nationwide assessment of county level vulnerability to rapid HIV or HCV outbreak, to reveal the most vulnerable counties to be rural (Van Handel et al. 2016). In conjunction with the vulnerability many rural areas face, access to harm reduction interventions, such as SEPs, is still lacking for many (Des Jarlais et al. 2015). This study offers some recommendations for communities seeking to implement a SEP in rural settings that may optimize their use and effectiveness.

1. Place SEPs in areas where PWID can walk to, and decrease police visibility from the SEP

Research by Parker and colleagues (2012) about rural SEPs suggests placing a SEPs in rural communities in areas of high injection drug use activity. This placement of a SEP will help bridge transportation gaps for PWID in the community who do not have reliable access to transportation, and it will increase access by making the SEP more walkable for a larger group of PWID than if the SEP were placed in a random location. Placing a SEP in an area that is convenient for PWID may help increase connection to harm reduction among PWID.

This suggestion may not be contextually relevant for Scott County, as the SEP is located in close proximity to the police station. In smaller rural communities this may be unavoidable to a certain extent. The findings detail the concerns many participants held

toward the SEP's close proximity and visibility from the police station. This proximity even influenced some to avoid visiting the SEP's physical location, although the findings do not indicate this had any bearing on the utilization of the outreach van. Creating physical modifications to create greater privacy and anonymity could help alleviate the concerns PWID experience. For instance, the SEP in Scott County could only be accessed by a side entrance facing away from the police station. The findings also suggest constructing a fence between the police station and SEP to reduce the visibility of PWID from the police station. Simple barriers such as these may help reduce the fear PWID have about visiting a SEP in close proximity to the police station.

2. The SEP's outreach van provides a crucial service to PWID in the area.

Residents of rural communities can face a variety of unique barriers to accessing healthcare in relation to urban communities. Common themes from the findings suggests PWID faced the following barriers to accessing the SEP: access to transportation, real or perceived police harassment, stigma and the fear of community members learning of their identities as PWID, and potentially inconvenient operating hours at the physical location. To highlight a common contextual difference in rural communities; the findings suggest participants concerned with their identity being discovered felt that if they were discovered attending the SEP, they faced a high probability of this information being conveyed to family or friends, or even the community at large. Going to the SEP's physical location can be identifying in a small community, and the outreach van can help protect an individual's anonymity relative to the SEP's physical location, where an encounter with someone who knows the other's family or friends is not unexpected. Additionally, many rural communities have limited or no public transportation those

without access to transportation can utilize; even with the option to use the outreach van, a minority of participants reported walking relatively long distances to the SEP's physical location.

The outreach van offers reprieve from many of the concerns and barriers highlighted in the findings and that are more likely to be present in rural communities. The findings indicate overwhelmingly positive experiences with the outreach van and especially the van staff. Participants concerned with protecting their identities as PWID praised the outreach van for improving the odds of this protection, although a small minority did report that even some community members may recognize the outreach van in a person's driveway. The outreach van proved itself valuable to participants in this study. It may be a necessary component for the success of rural SEPs.

3. Provide ongoing education to law enforcement and PWID on the exact parameters of protections offered by having a SEP card with regard to carrying syringes.

The findings provide a detailed account on the range of perception participants had toward their right to carry syringes. While many knew they could carry sterile syringes within the county while they had their SEP membership card in their possession, many still felt fear of deviating from these requirements and being convicted for possessing a syringe. Many PWID report previously serving jail and prison sentences for possessing a syringe, and harboring fear of police harassment. Some participants indicated improperly disposing of syringes (e.g. by throwing them on the ground) out of fear of uncertainty of whether they'd be protected by the law or not. A minority of participants reported using the SEP less frequently as a result. These negative outcomes rest in direct opposition to the purpose of a SEP. It is important that law enforcement be

aware of the effect a high police presence can have through creating awareness of this and building buy-in on the benefits a SEP can have.

Given the inconsistencies in the way participants perceived their legal rights, an additional suggestion is to provide an increase in educational activity to improve the knowledge PWID have about their rights. A structural way to deal with this challenge is to amend the SEP laws to specifically identify what is safe to carry and decriminalize possession of a previously used syringe when enrolled in the SEP. A more immediate term solution would be to have SEP staff and law enforcement agree on a policy and then communicate this to participants when enrolling in the SEP, for example both verbally and with fliers or information packets that participants receive when first enrolling. Additionally these materials could be displayed for attendees to obtain as they are waiting for syringes and additional harm reduction equipment.

4. Incorporate feedback from PWID into the design, implementation, and ongoing maintenance of the SEP.

While the findings above may not capture the voices of all PWID in Scott County, they offer rich, detailed descriptions, of the accounts of many SEP users, and a few nonusers. This study captured feedback through a more intentional and systemic approach than would be gathered through informal conversations with PWID as they would arise through more typical interactions. As a result, the findings from this study exposed several praises, concerns, and barriers many of the participants face. Gathering this feedback and these perspectives is the first step in creating an actionable, user-focused, plan toward continuous improvement. For example, another useful piece of feedback was with the SEP provider cookers not being very useful in the context of

Opana ER use and learning that folks were using homemade soda pop can cookers. SEPs in this case might identify ways to better serve their particular populations better in this regards. What works for harm reduction with heroin injection, for example, may not work well for injecting certain pills. This would not be discovered without talking to the PWID themselves. Utilizing qualitative research methods through private interviews and focus groups to systemically gather and assimilate feedback into a SEP's program design will aid improvements in the SEP.

Limitations

These findings should be interpreted while bearing several limitations in mind. Because this is a qualitative study designed to gather rich, detailed descriptions around experiences with the SEP in a particular social context, the extent to which these findings generalize are limited relative to a larger, probabilistic, sample. Not only is this a rural community but the type of drug primarily injected, Opana ER, may lead to unique findings to this particular community. As a result, the findings are not intended to generalize to all PWID in a rural community, or even to all PWID in Scott County. Many of the participants were recruited using location based convenience sampling. The primary recruitment location was in a small area of the town in which key informants deemed as having a high concentration of PWID. While this offered an in depth account from the perspectives of many within a particular area of the town, and of those in their network, it is unlikely this captured the voices of all PWID in the community. As is characteristic of many rural areas, there is the possibility that many PWID live farther outside of Austin, Indiana's city limits. While the findings do have some representation among those living miles outside of the town, it is clear many of the participants live

closer to the city's limits. Furthermore, the geographical distribution of PWID living outside the city's limits is unknown.

The findings may also suggest PWID in the community who also sell drugs, or work as sex workers, may not be adequately represented within the sample. Only one participant in the study reported engaging in sex work and only two reported ever engaging in dealing drugs. The small amount of data examined within the data set used for this study provides possible indication these individuals may be more likely to avoid the using the SEP. PWID are traditionally a difficult group to reach. Both PWID living outside of the town's limits, and PWID who may sell drugs or engage in sex work, can be an even more difficult subsection of PWID to reach. The sampling methodology of this study forgoes external validity in favor of rich, detailed experiences and attitudes toward the SEP.

Another limitation stems from the misalignment between the aims of this study and the original exploratory study from which this study's findings exclusively rely upon. The original exploratory study was designed to obtain information about risk perceptions and behaviors, preventative and health care service utilization, and additional emergent topics pertaining to the outbreak investigation. These findings should be interpreted in consideration of these original aims. Consequently, the findings from this study may not address this thesis's aims as strongly as an original study with research questions and interview guide constructed for this purpose. In contrast, the data utilized in this study does offer some advantages. Although the data set utilized in this study is a small section from a much larger, comprehensive study, the breadth of this data may be greater than what this researcher could have gathered for the scope of a master's thesis. The original

exploratory study contained 25 private interviews, and four focus groups (n=31), for a total of 56 participants. The exploratory study was designed in conjunction with a large public university, the Indiana State Department of Health, and the Centers for Disease Control and Prevention. Furthermore, a team of several experienced researchers served as research instruments throughout the duration of this study. While it may be a limitation that the data was not gathered with this thesis's intent in mind, it is clearly of a higher quality than what could be gathered from one Master's student.

This study's unique departure in terms of scope and locality from the literature represent another limitation. The lack of literature examining both the experiences of PWID using a SEP, and the lack of representation of rural SEPs in the literature, presents difficulty in putting the findings into perspective. General experiences with a SEP from the user perspective does not appear to be a priority within much of the literature. Several aspects of these findings indicate positive experiences, whereas much of the literature examined for this study reserved publication space for more negative experiences such as concerns, and barriers to identify areas of need and strategies to address them or positive harm reduction behavioral outcomes such as reduction in high risk injecting behaviors. While the aspects of this thesis's findings covering concerns and barriers was situated into a larger literature base, much of this literature base studied larger, urban areas. It is certainly important to consider that SEPs in rural areas are not prominent in numbers or in the literature. This presents limitations for the extent to which the findings can be assessed when existing related literature may be present. This study does not quite bridge a small gap in the literature. Rather, it plots a point in relative isolation. The severity of

opioid and infectious disease epidemics many rural communities face justifies the execution of this study in light of a minimal foundation of literature.

There are several opportunities for future research on rural SEPs. Future research would do well to employ both quantitative and qualitative studies to assess SEPs in rural communities. The need to address concerns raised by SEP critics remains and adding more qualitative studies can help address these concerns. As SEPs grow in numbers and spread to new areas these concerns may be reinvigorated. Future research on SEPs in rural communities would be remiss to not examine factors such as: (1) the syringe exchange ratio and its underlying factors, (2) negative police interactions with PWID as it relates to SEP use, (3) total syringe distribution over time and its various determinants, (4) pre and post testing on the transmission of HIV and HCV, and (5) the impact of the SEP on user referrals to care coordination and substance abuse treatment, to continue to demonstrate the need they fulfill. The context of rural communities also presents unique opportunities for future research. One of the primary differences in this rural community, as indicated by the findings, was the lack of access to reliable transportation in relation to urban communities. For some participants living farther distances from the SEP's physical location, the outreach van was a critical component of connecting the individual to harm reduction measures. Additional research on this topic can investigate the extent to which outreach vans can create access to harm reduction among those lacking reliable access to transportation specifically among PWID living too far away from the SEP to walk. This is just one direction in which research can examine SEPs located in rural communities.

Conclusion

This thesis aimed to provide an evaluation of the Scott County SEP's implementation from the perspectives of PWID in the community through an analysis of the qualitative data obtained from the "HIV in Southeastern Indiana Exploratory Study." The data analyzed for this thesis focuses on the participant experiences with, and perceptions of, the SEP. Components of this include general participant experiences and perceptions of the SEP; and sources of praise, challenge, and barriers to access. Findings helped provide an in-depth understanding of SEPs through the lived experience and authentic voices of PWID, in the context of small, rural community. This study documents positive and negative aspects of those interviewed with the SEP, demonstrates the implications of these experiences, and provides insight into a specific community context in which Indiana's first legal SEP was implemented.

Additionally, the results of this study are of importance because they can serve as a resource for those implementing and operating a rural SEP in other similarly situated vulnerable communities. The literature strongly supports the effectiveness of SEPs in reducing the transmission of HIV and HCV (Des Jarlais 2009; Heimer 1998; Wodak and Cooney 2006). The implementation of SEPs in high risk, high vulnerability communities can offer the practical benefit of reducing HIV transmission. While the qualitative nature of the study provides a more nuanced description of the experiences of PWID in this community, it provides a much needed contribution to the existing SEP literature, which focuses almost exclusively on urban areas and does not often gather qualitative data regarding the experiences of the program participants. The literature on SEPs in urban areas can fail to take into account some of the unique contextual factors of rural

communities and the challenges they face. However, in order to craft an effective approach that will alleviate the emerging challenges and vulnerabilities these communities are facing, a greater understanding of existing efforts is first needed.

APPENDICES

Appendix A: Sample Demographics

	Interview (n=25)	Focus Group (n=31)
Gender, n (%)		
Male	14 (56)	15 (48)
Female	11 (44)	16 (52)
Age, n (%)^a		
18-29	10 (40)	6 (21)
30-39	9 (36)	16 (55)
40-49	4 (16)	5 (17)
50+	2 (8)	2(7)
Race, n (%)		
Non-Hispanic white	25 (100)	29 (100)
Other race	0 (0)	0 (0)
Enrolled in SEP, n (%)^e		
Yes	19 (76)	27 (90)
No	6 (24)	3 (10)
HIV testing, n (%)		
Yes	25 (100)	30 (97)
No	0 (0)	1 (3)
Self-reported hepatitis C status^c n (%)		
Positive	21 (84)	28 (93)
Negative	4 (16)	2 (7)
Self-reported HIV status^c n (%)		
Positive	10 (40)	17 (59)
Negative	15 (60)	12 (41)

^a Information on age was missing for 2 FG participants, ^b Drug injected a first visit for SEP Clients and primary drug injected in previous 12 months for Interview Participants; One Opana user in the PIs injected Opana IR (Instant Release); ^c NA indicates that data on this variable was not collected; ^d 3 interview participants were currently not injecting drugs (range 3-11 months of non-injecting). ^e Two of the participants in the qualitative study were living with insulin dependent diabetes and thus had access to sterile syringes prior to the HIV outbreak. Both had subsequently enrolled in the SEP.

Appendix B: Interview Guides

1. Private Interview Questions

Experiences With Needle Exchange Program

Q1. Can you tell me about your experiences using the needle exchange program? Use? Not used? How are those services working for you? Good? Bad? Do you have any concerns about services?

Probes for “folks who have used”

- Probe about context and content of program (If any are problematic, ask why and what could be done better to meet their needs):
 - o use of COC versus Mobile van
 - o location of the mobile van
 - o type and amount of needles
 - o time it takes to get the needles
 - o hours of operation
 - o people providing the needles
 - o police presence
 - o community perceptions
 - o stigma and discrimination

- Do you give or sell needles to anyone? If yes, can you tell me about that? How does this affect your needle supply?

Probes if “Never used”:

- Why not? What are some reasons? Prompts - Anything to do with?
 - o location
 - o hours of operation
 - o police presence
 - o community perceptions

- What would need to change for you to attend the needle exchange program?

2. Focus Group Questions

Syringe Access Program Evaluation [call it SEP in the group]

Q1. Can you tell us about people’s experiences using the needle exchange program? How is the needle exchange working for them? Good? Bad? Do they have any concerns about using the needle exchange?

Possible Probes:

- Do you know of anyone who started using the service but dropped out? Why?
- Probe about context and content of program (If any are problematic, ask why and what could be done better to meet their needs):
 - o use of COC versus Mobile van versus transition to local health dept.

- *location of the mobile van*
- *type and amount of needles*
- *time it takes to get the needles*
- *hours of operation*
- *people providing the needles*
- *police presence*
- *community perceptions*
- *stigma and discrimination?*
- *Is there anything else that we should know about in terms of what is working and what's not?*
- *Sometimes people bring in used needles that did not come from the SEP? Where do those used needles come from?*

Q2. What about people who have not used the needle exchange program? Please tell me more about them and why you think they have not used it?

Possible Probes:

- *Where are these folks getting their needles?*
- *Are they using their needles more than once?*
- *What could be done to encourage these folks to use SEP services?*
- *Do you know of people who use the SEP and give needles to friends who are not using the program? If so, tell me about that process, how does it work, what happens?*

Q3. Do you have any suggestions about how we can improve the needle exchange program so more people who inject drugs will use it?

Appendix C: Participant Pseudonyms

Private interview

PI number	Code	Gender	Name	Reporting citation
1	CC01	F	Shantel	Shantel, PI 1
2	DB01	F	Scarlett	Scarlett, PI 2
3	DB02	F	Melinda	Melinda, PI 3
4	DB03	M	Jerald	Jerald, PI 4
5	DB04	M	Marvin	Marvin, PI 5
6	DB05	F	Judy	Judy, PI 6
7	DB06	F	Becky	Becky, PI 7
8	DB07	F	Loreta	Loreta, PI 8
9	DB08	F	Diane	Diane, PI 9
10	JD01	F	Karen	Karen, PI 10
11	JD02	M	Ross	Ross, PI 11
12	JD03	M	Issac	Issac, PI 12
13	JD04	M	Andrew	Andrew, PI 13
14	JR01	M	Don	Don, PI 14
15	JR02	F	Sonya	Sonya, PI 15
16	JR03	M	Tim	Tim, PI 16
17	JZ01	F	Shawna	Shawna, PI 17
18	JZ02	M	George	George, PI 18
19	JZ03	M	Eric	Eric, PI 19
20	JZ04	M	Rick	Rick, PI 20
21	JZ05	M	Jeff	Jeff, PI 21
22	JZ06	M	Larry	Larry, PI 22
23	JZ07	M	Todd	Todd, PI 23
24	JZ08	F	Molly	Molly, PI 24
25	JZ09	M	Miles	Miles, PI 25

Focus groups

Group 1	AKA	Numbers	Group 4	AKA	Numbers
1M	Mark	1	1	Jay	24
2M	Joey	2	2	Nancy	25
3F	Carrie	3	3	Frank	26
4M	Sam	4	4	Owen	27
6F	Haley	5	5	Anne	28
9F	Jessie	6	6	Chris	29
10M	Tom	7	7	Sarah	30
Group 2			8	Maria	31
1F	Casey	8			
2F	Alexis	9			
3F	Zoey	10			
5F	Maggie	11			
6F	Tracy	12			
9M	Danny	13			
10F	Lisa	14			
Group 3					
1M	Steven	15			
2M	Mike	16			
3F	Kay	17			
4F	Liz	18			
5M	Brad	19			
6M	Willy	20			
7M	Robert	21			
8M	Colin	22			
9F	Kelly	23			

Appendix D: List of Acronyms

CDC – Centers for Disease Control and Prevention

ISDH – Indiana State Department of Health

IUPUI – Indiana University Purdue University – Indianapolis

HCV – Hepatitis C

HIV – Human Immunodeficiency Virus

PWID – Persons who inject drugs

SEP – Syringe Exchange Program

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Professional Applied Reports

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