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Older Drug Users: A Life Course Study of Turning Points in Drug Use [in a large Southeastern Metropolitan Area], 2009-2010

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User Guide

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DOCUMENTATION FOR ODUS DATA SETS

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Title

Older Drug Users: A Life Course Study of Turning Points in Drug Use and Injection Trajectories

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Table of Contents	Page
1. Project Description Summary	3
2. Specific Aims	4
3. Background and Significance	4
3.2 The Life Course Perspective	
3.3 Bayesian Networks: A Brief Introduction	
4. Research Design and Methods	7
4.1 Retrospective data collection	
4.2 Recall bias and social desirability bias	
4.3 Self-reported data	
4.4 Sample and sampling procedures	
4.5 Geographic location of data collection and time period covered	
5. Development of the Instruments	11
5.1 Life History Matrix	
5.2 Survey Data Collection Instrument	
6. Variables	13
6.1 Demographics and 30 Day Drug Use Variables	
6.2 Yearly Variables	
6.3 Comment boxes (string variables)	
6.4 Details on constructed and weight variables	
6.5 Details on changes made to survey	
6.6 List of abbreviations, variable names, and descriptions	
6.7 Technical information on files	
6.8 Unit(s) of analysis/observation	
7. Flowchart	16
8. Training	16
8.1 Preparation	
8.2 Interview	
8.3 Post-Interview	

9. Quality Control	19
10. Recoding of the Data	22
10.1 Recode logic	
10.2 Recode list	
10.3 Variable reduction and aggregation	
11. Results	25
12. Data Visualization Images	26
13. Qualitative Data	27
14. Related Publications	27
References	29
Appendices	
Appendix A Timeline	
Appendix B Life History Matrix	
Appendix C Qualitative Interview Guide	
Appendix D Demographic 30-Day Questionnaire	
Appendix E Yearly Questionnaire	
Appendix F Short Qualitative Interview Guide	
Appendix G Flowchart	
Appendix H Data Collection Overview	
Appendix I Legend of Data Visualization Images	

1. Project Description Summary

National trend data show older adults comprise the fastest growing age group of drug users, and there is an alarming increase in HIV/AIDS infection among adults 45 or older, a cohort composed primarily of aging baby boomers (CDC 2008). Yet our understanding of the drug trajectories and knowledge on drug use patterns and risk behaviors among this cohort as older adults is limited. The goal of this study was to provide in-depth life history data on the drug trajectories of older drug users, specific turning points in drug use patterns, and drug-related health risks over their life course. In this mixed-methods study we used quantitative methods to collect numerical data on relevant variables regarding drug use patterns, social events and HIV risk behaviors for every year of life, as well as qualitative in-depth interviews to further examine the life histories.

The Older Drug User Study (ODUS) employed a retrospective longitudinal design. The community-based sample consisted of 100 respondents who were age 45 to 65, including both active users and former users of heroin, cocaine, crack and/or methamphetamine. The inclusion of former users allowed for an investigation of life events and social circumstances surrounding cessation.

Both quantitative and qualitative data were collected simultaneously, employing a novel mixed-methods research methodology. The quantitative data provided in this archive includes two data sets: the DEMOGRAPHICS 30 DAY data set and the YEARLY data set. The DEMOGRAPHICS 30 DAY drug use data set comprises 246 variables, including basic demographic data, drug use in the last 30 days, routes of administration, and HIV, AIDS and HCV status. The YEARLY data set provides responses to 308 variables for every year of the respondent's life, including specific drug use, social variables, and sexual behaviors. The unit of analysis in the yearly data set is PERSON-YEAR. This results in over 1,500,000 data points in the YEARLY data and 25,000 in the DEMOGRAPHICS 30 DAY data. Longitudinal data like ODUS existing in long format is also known as person period data used for event history analysis.

The study was collaboratively conceptualized by a sociologist ethnographer and a mathematician. Informed by these diverse disciplines, the combined knowledge, experience, and skills of the investigators produced a complex and innovative methodology. We collected data using a computer assisted personal interview program (CAPI) on netbooks with the SNAP survey software program. The survey consisted of questions on events and changes in the life of the respondent in terms of residence, family, work, relationships, health, education, and criminal justice involvement over the entire life course from birth. Drug use by type of drug, frequency of use, route of administration and drug treatment were collected for every year. Also collected were the demographics of the respondents, their HIV/AIDS and HCV status, and past 30-day drug use. The quality control of the data during and after the data collection was central to the data collection and is described more fully below.

The ODUS provides a wealth of retrospective longitudinal data for

secondary data analysis of drug use trajectories, social context, cultural influences on drug use over the life course, and turning points in drug use and risk behaviors for HIV/AIDS and other infectious diseases. Retrospective life histories of older adult drug users also allow an in-depth exploration of how the risk factors and turning points identified by statistical analysis are embedded in social context, influenced by the social roles over the life course, and affected by social policy over time. The diverse sample provides ample data on health disparities by race, gender, age, geographic location, and social economic status. Using the entire life history, the complex data collected in this study can be used for analyses to inform the development of prevention, intervention and treatment programs, as well as for future research hypotheses on drug policy, risk reduction, and health care services for drug users of all ages. For example, the mathematical and statistical models generated from the data analyses can be used to target treatment strategies on specific turning points in drug use trajectories and behavioral changes.

2. Specific Aims

The ODUS had three specific aims:

- To identify turning points in the onset, continuation, and cessation of drug
 use throughout the life course of a sample of older users; specifically how
 social roles, race, gender, age, social contexts, policies and historical
 events influence changes in drug use patterns and drug-related HIV risk
 behaviors.
- 2. To thoroughly explore these turning points and transitions over the life course, specifically changes in drug availability, risk behaviors, routes of administration, social roles, networks, social support, policies, settings, and geographic locations,
- **3.** To build Dynamic Bayesian Networks (DBN) that best model the static and dynamic aspects found in our quantitative and qualitative data. In so doing we are able to identify not only statistical relationships between the variables but also the influence and progression of these through time.

3. Background and Significance

The US Census defines the baby boomer cohort as those born from 1946 to 1964. Baby boomers comprise the largest portion of the current older drug using population (Blow, Oslin and Barry 2002; Gfoerer et al. 2003). Predictions that today's adults will become more accepting of illicit drugs as they age than were previous elderly cohorts are supported by epidemiological data and ethnographic reports (Johnson and Sterk 2003; Kwiatkowski and Booth 2003; Levy and Anderson 2005; Menninger 2002; Patterson and Jeste 1999). While the "maturing out" theory proposed that most drug users stop using drugs by age 35 (Winick 1962), new research suggests that the pattern may be changing to "maturing in" (Allen and Landis 1997). However, this older age cohort of drug users has been a largely hidden population comprised of both early-onset and late-onset users (Boeri, Sterk and Elifson 2008; Schensul et al. 2002). Due to the lack of statistical data on this age group, some call the aging of drug users an

"invisible epidemic" (Blow 1998). The impact of this epidemic is already overwhelming substance abuse health services, and a better understanding of older drug use patterns is essential for the development of interventions and treatment for older users (Blow, Oslin and Barry 2002; NIDA 2007).

3.1. HIV Risk Behaviors of Older Drug Users

In the U.S. new HIV/AIDS cases due to injection use increased 42% from 1998 to 2003, and injecting drug use was one the most frequently cited mode of transmission of HIV worldwide (UNODC 2007). Epidemiological and prevention studies consistently show that the older drug-using population is at high risk for HIV transmission (CDC 2008; Levy 1998). A special publication by the Journal of Acquired Immune Deficiency Syndromes (JAIDS) on "The Graying of the AIDS Epidemic" reported an increase in the number of older drug addicts identified with HIV/AIDS and highlighted the need for further exploration into older drug-using adults and their multiple risk behaviors (Levy, Ory and Crystal 2003). A study on narcotic addicts found aging addicts had abnormally high rates of infectious diseases (Hser et al. 2004). The risk of drug-related AIDS transmission is greater among the socially vulnerable, minority groups, and women; aging adds an increased risk for these vulnerable groups (Altschuler, Katz and Tynan 2004; Anderson and Levy 2003; Murray and Adam 2001; Neundorfer et al. 2005; Nokes and Emlet 2006; Orel, Wright and Wagner 2004; Theall et al. 2003).

Adults age 50 and older living with AIDS increased 17% from 2001 to 2005 (CDC 2008). The increasing rates of HIV/AIDS among older adult drug users expose the need for a more in-depth understanding of risk behaviors among this population (Korper and Raskin 2002). We know that social support for people with HIV/AIDS diminishes with age (Kwiatkowski and Booth 2003), and older drug users with AIDS are significantly less likely than younger users to have emotional support and employment (Crystal et al. 2003). More knowledge is needed regarding how social role changes influence risk behaviors among older drug-using adults (Coon, Lipman and Ory 2003; Levy, Ory and Crystal 2003). In order to address the increase of HIV/AIDS among older drug users we need to understand how transitions in life affect their drug use patterns. Recently, NIH "articulated the need for research that is specific to older persons but also embeds that discussion in a broader life course perspective" (Auerbach 2003). Our study is specifically on life course transitions.

3.2 The Life Course Perspective

Life course focuses our attention on transitions and turning points across an individual's life history (Baltes and Brim 1982; Giele and Elder 1998). Turning points are times or events that take a person in a different direction or trajectory (Laub and Sampson 1993). A life history interview is used to distinguish transitions and turning points throughout life (Bruckner and Mayer 1998; Clausen 1998). Historical events, individual life events, social roles and transitions in social roles have an impact on individual choices. Historical trends in social exclusion and poverty also affect individual agency within a cohort, and

differences related to race and gender can impact drug use transitions over the life course (Dewilde 2003; Schensul et al. 2002).

Transitions in the life course are linked to changes in social roles. Social roles are the behaviors, responsibilities, activities and privileges belonging to a particular social status (Gecas 1986). Roles are used to organize personal activities, provide guidelines for behavior and act as a point of reference. Research overwhelmingly confirms that drug use trajectories are influenced by social roles (Agar, 1973; Akers 1998; Boeri 2004; Faupel 1991; Sterk 1999). The concept of role acquisition and role loss provides an additional tool for understanding turning points in drug use for older drug users (Stryker and Serpe 1994; Thornton and Nardi 1975; Turner 1962). We know that problematic use of drugs is associated with a loss of social roles (Anderson and Bondi 1998; Stephens 1991); as adults lose mainstream roles (e.g. work and parenting roles), they acquire new ones or return to previously held roles—a process known as role transition. Examining the role transitions among current and former older drug users throughout their life course provides insights into the social influences on drug use patterns and identifies specific turning points, which also can be used to inform research on younger users.

3.3. Bayesian Networks: A Brief Introduction

Mathematical analysis is a significant component of this study. Bayesian methods, born in the 1950s, have recently been employed in social science research. For example, Bayesian methods have been used in research to capture nonlinear relationships, distinguish age, period and cohort effects, provide predictive estimates of random effects, and create decision-making models for medical settings (Berk et al. 1992; Cohen et al. 1998; Grant et al. 2006; Lewis and Raftery 1999; Tallberg 2005; Yang 2006).

A Bayesian network is a probabilistic graphical model that is generated from empirical data and *a priori* knowledge. Bayesian network analysis helps to solve problems of inference and provide predictive models when many variables asserting varying influences are involved (Chang and Maskowitz 2003; Heckerman 1996). Bayesian networks also have been used to provide relationship models that do not require the distribution assumptions of statistical models such as multivariate regression and structural equation modeling (Kim, Imoto and Miyono 2003).

Since 1988, Bayesian networks have had rapid success both in theoretical and practical applications (in the data mining and diagnosis fields, for example). Advantages of Bayesian networks include: (1) the possibility of non-distribution (non-parametric) statistics; (2) the ability to handle more variables than standard approaches; and (3) the incorporation of both data and non-data knowledge, such as the experience and intuition of an expert in the field. Dynamic Bayesian Networks (DBNs) have the advantage of modeling both static and dynamic relations between variables.

4. Research Design and Methods

This exploratory study did not start with a hypothesis, but numerous hypotheses can be generated from examination of the data. Embedded in a life course perspective, ODUS was designed to collect the both quantitative and qualitative in-depth data that provided minute detail on complex social and behavioral changes over the course of 45 to 65 years in the lives of older drug users. The consistent collection of the same variables for every year of life allows for a thorough examination of changes over time and the social influences on transitions in drug use and risk behaviors.

4.1 Retrospective Data Collection

The ODUS research used a mixed-methods design to collect retrospective longitudinal data. While not included in this archive, the addition of qualitative methods allows researchers to gain a deeper understanding of the meanings and motivation of drug use and risk behaviors from the users' perspective, as well as identify the complexity of drug use patterns (Bluthenthal and Watters 1995; Denzin and Lincoln 1994; Lofland et al. 2006). Previous research findings show that drug users tend to report valid information in qualitative interviews since validity issues regarding the truthfulness of the data are less likely to occur in face-to-face qualitative interviews than in survey interviews (Anglin, Hser and Chou 1993; Ball 1967). In the ODUS, qualitative data added richness and a more complex view of the longitudinal quantitative data collected.

Life course research implies using either prospective or retrospective longitudinal designs in order to collect data on events and processes that occur over time. The prospective longitudinal design is when respondents (or cohorts) are interviewed at repeated intervals (Deren et al. 2003). The retrospective longitudinal design collects historical data on the same individual or cohort.

4.2. Recall Bias and Social Desirability Bias

Challenges to the reliability and validity of longitudinal data include two forms of biases: recall accuracy and social desirability (Guest, Bunce and Johnson 2007). Respondents are typically more likely to report illegal activities of the past than those that are current and may be self-incriminating; therefore, retrospective data collection of illegal behaviors reduces social desirability bias (Murphy et al. 2010). While retrospective designs reduce social desirability bias, recall bias is increased.

To reduce recall bias, we used a number of strategies, such as incorporating historical events to trigger the memory and employing cues such as timelines and memory aids targeted for each individual (Agar 1980; Becker 1998; Darke 1998; Fontana and Frey 1998; Lambert 1990; Nurco et al. 1975; Shaw 2005; Sobell et al. 1988). The ethnographers and interviewers who collected the data were trained on how to develop rapport with respondents to reduce social desirability bias. Substantial research shows that retrospective designs can provide reliable and valid data on self-reported behaviors when these strategies employed (Anglin, Hser and Chou 1993; Weatherby et al.

1994).

In addition, a timeline with historical reference points was used to assist the respondents in remembering time periods of drug use and other social variables, providing a context in which respondents could place events in their lives that coincided with drug use (see Appendix A). We modified the timelines based on the respondents' age, gender, and race, finding that these influenced recall of historical events. The life history matrix and timeline facilitated the recall of the specific events and specific time periods regarding drug use and social environment over the life course. Inconsistencies and gaps in the respondents' stories could be quickly and easily caught and clarified by interviewers, thus enhancing the reliability and validity of the survey data as well.

As discussed above, social desirability is a greater problem when data is collected from individuals with stigmatized or illegal behaviors, such as using and selling drugs (Johnson and Ritcher 2004). Strategies for reducing social desirability potentially reduce this bias (Shaw 2005). Compared to prospective designs, retrospective longitudinal data collection provides some advantageous in reducing social desirability bias. Establishing rapport with the respondents in the study helps to reduce embarrassment regarding sensitive questions and lessens the tendency to give socially desirable responses (Fontana and Frey 1998). Similar strategies were used to reduce the problems inherent in self-reported data.

4.3 Self-reported Data

Reliability and validity are necessarily questioned in self-reported data. The primary problems with validity were in studies with samples drawn from prison and treatment programs. However, studies using community drawn samples, and those using a life history and ethnographic research conducted in conjunction with survey collection methods, were found to increase overall validity of the study results since the interviewers and respondents were provided with a form of self-checking (Fendrich et al. 1997).

As discussed above, establishing rapport also increases the validity of self-reports, and this is more easily accomplished in the community than in an institutional setting (Fontana and Frey 1998). Recruitment strategies such as adaptive sampling (Thompson and Collins 2002) and theoretical sampling (Glaser and Strauss 1967) have been shown to increase the validity of findings on hidden populations. Extensive research finds that self-reported data can be reliable when proper data collection strategies are used (Anglin et al. 1993; Murphy et al. 2010; Weatherby et al. 1994).

Mixed methods research is gaining interest in much social science and health research (Lieber 2009). Johnson and Ritcher (2004) propose that using mixed methods is particularly important when conducting research on drug use in order to avoid the problems associated with social desirability. Typically this is accomplished using a quantitative survey with a large probability sample followed by a purposive sampling for qualitative data collection, or vice versa. However, the ODUS mixed methods study used an integrated design (Deren et al. 2003;

Lieber 2009; Teddlie and Yu 2007). According to Ragin (2008), "the middle path between qualitative and quantitative research should consist of methods for building general knowledge from case-oriented knowledge" (p. 5). In other words, mixed methods should build broad knowledge and not isolate effects into independent variables.

4.4. Sample and Sampling Procedures

The study sample was recruited in a large southeastern metropolitan area using a combination of ethnographic mapping, snowball sampling and targeted sampling methods (Biernacki and Waldorf 1981; Watters and Biernacki 1989). Ethnographic mapping started in "natural settings" of drug use (Agar 1980; Spradley 1980), such as street corners, bars and single room occupancy (SRO) hotels. The Principal Investigator (PI) already had contacts in a number of social settings known as drug-using environments. She had spent considerable time conducting research in the inner city neighborhoods known for its heroin and crack dealing, as well as in suburban and rural counties when she recruited respondents for methamphetamine studies (Boeri 2012). Her experiences suggested that some drug use networks, such as methamphetamine users, are more hidden than others; therefore, a multi-method approach was used to recruit diverse networks and types of drug users.

Snowball sampling involved asking respondents and interested users who were not eligible to participate to refer others to the project (Biernacki and Waldorf 1981). Former users were recruited in the same way as active users with the exception that some were also drawn from community-based groups, such as after-treatment programs and 12-step groups.

Targeted sampling methods were used to recruit respondents from hidden populations and ensure a diverse sample (Bluthenthal and Watters 1995). Targeted sampling provided a mechanism that adjusts to the target population to obtain systematic information when true random sampling is not feasible and convenience sampling is not rigorous enough.

Community consultants were identified at various times during the study. These were people who were knowledgeable members of the community and who were well informed about the behaviors, drug use patterns, and social practices among local drug-using networks. They were uniquely positioned to access specific population segments, broaden networks of contacts, add to the credibility and legitimacy of research, describe or explain behavioral subtleties and practices, and provide feedback on the validity and gaps in data collection instruments (Page and Singer 2010). The temporary employment of community consultants has been shown to be beneficial and allows access into neighborhoods and networks that might otherwise be closed to outsiders (Lambert, Ashery and Needle 1995).

No identifying material was collected from respondents, such as full names or identification. A <u>Certificate of Confidentiality</u> obtained from NIDA/NIH protected all data and researchers from court subpoena. All researchers and assistants received certification from a course on conducting ethical research with human

subjects. The university's Institutional Review Board (IRB) approved the study protocol. Respondents were read a consent document and gave verbal approval. Interviews lasted between two to five hours on average, and respondents were paid a \$40 stipend for their time. The PI monitored adherence to research protocol to ensure the confidentiality of respondents and safety of all involved throughout the recruitment and interview process.

Based on the literature regarding recruitment of respondents from hidden populations, we designed three levels of recruitment strategies: (1) primary recruitment that was researcher initiated; (2) secondary recruitment from referrals; and (3) tertiary recruitment that resulted from fliers. These recruitment strategies often overlapped.

Primary recruitment involved conducting ethnographic fieldwork with community consultants, often found while out in the field doing ethnography. Ethnographic fieldwork involved walking street, talking to people, sitting in bars and all night restaurants, and hanging out in places where drug users or drug dealing is found. Community consultants already known to the researchers helped identify areas for ethnographic work, and additional community consultants were identified during the study.

Secondary recruitment involved snowball sampling in which a respondent or someone met on the field refers others to the study. Those who refer other users who participate in the study received a small referral fee. A respondent or community consultant could refer only up to six respondents from the same network.

Tertiary recruitment involved hanging up fliers, passing out fliers and leaving small informational cards about ODUS everywhere, such as parking lots, stores, schools, bars, and restaurants, as well as methadone clinics, a needle exchange center, and homeless shelters. Fliers advertised the need for current or former drug users for a paid health study and included the study phone number.

Callers were screened for eligibility on the phone and again before the interview. Screening consisted of asking questions regarding eligibility interspersed with questions that would not disqualify a respondent, such as "do you have children?" This was done so that those who were not eligible would not guess the eligibility requirements.

To be eligible, respondents had to be at least 45 years old at the time of the interview and either active or former users of heroin, cocaine/crack or methamphetamine. These drugs were chosen because they represent the three major drugs of use associated with the most severe consequences (Brecht et al. 2008; Hser et al. 2008). Active use was defined as having used one of these drugs in the past year. Former use was defined as having used at least one of these drugs in the past ten years, for at least six consecutive months, but not used any of these drugs in the past year or longer. One year was chosen as the time period of no drug use since it incorporated any relapse identified within a time period of 12 months (Barrick and Conners 2002). Transition in drug use

from active and inactive was measured in one-year time periods, which we identified to be the smallest period of time with a reliable amount of recall accuracy.

The goal was to collect quantitative and qualitative data on 100 respondents to provide enough cases for correlative analyses (Graves 2002). The sample was purposely designed to include about half former (inactive) users and half active users of the drug of choice (heroin, cocaine, crack or methamphetamine). Polydrug use was the norm among our sample, as is found in contemporary studies (Boeri et al. 2008; Halkitis, Mukherjee and Palamar 2007).

4.5 Geographic Location of Data Collection and Time Period Covered

All data were original and collected as part of the ODUS study. Data were collected between August 2009 and October 2010 in the suburbs of a large southeastern metropolitan area.

5. Development of Instruments

We developed an innovative quantitative and qualitative triangulation design to collect life history interviews that provided data with distinguishable transitions throughout the life course (Bruckner and Mayer 1998, Murphy et al. 2010). The life histories of older adults provide rich retrospective longitudinal data on the diversity of paths taken throughout the life course and changes that occur over time (Baltes and Brim 1982; Elder 1985; Hser, Longshore and Anglin 2007; Laub and Sampson 1993; Scott and Alwin 1998). The triangulation design we used gives equal emphasis to both types of data, which were collected together in one setting and informing each other, also called a convergence model (Creswell and Clark 2007).

5.1. Life History Matrix

Three sources of direct data were collected: a Life History Matrix (Appendix B); an in-depth digitally recorded life-history interview for the collection of qualitative data (see semi-structured qualitative interview guide Appendix C); and a survey instrument for the collection of quantitative data (Appendix D & E). These are explained in more detail below.

The life history matrix was used to set the stage for the social context, risk behaviors, and major social roles throughout the life course (Appendix B). This was collected face-to-face by the interviewer using paper and pencil. The life history matrix facilitated the recall of the specific events and specific time periods regarding drug use and social context over the life course. Respondents were free to expand on any areas of their life, and the interviewer used constant probing questions to obtain more in-depth description where needed. A timeline with historical reference points was used to assist the respondent in remembering time periods of drug use and other social variables (see Appendix A). The life history matrix helped guide the in-depth interview and the collection of detailed survey data on every year of the respondents' life.

The in-depth interview was conducted simultaneously with the life history

matrix or immediately after the life history matrix was completed, although the digital recorder was on for the entire process, and the respondent could elaborate at any time during the matrix data collection. The questions on the qualitative interview instrument were developed to explore relationships between drug use and social context, relationships, and behaviors that change over time, with a specific focus on turning points in initiation, progression, cessation, and relapse of drug use. Risk behaviors such as injection, sex work and involvement with the criminal justice system were also explored more thoroughly. A long version of the qualitative instrument (Appendix C) had been read and memorized by the interviewers, and only a shorter version was used during the interview (Appendix F).

5.2. Survey Data Collection Instrument

The survey data was collected by the interviewer using an ultra- mobile computer (netbook) loaded with the SNAP survey software program that could easily export the data to SPSS or other data management software. The life history matrix assisted the collection of the retrospective longitudinal data by providing a guide and an additional source of validity and reliability during the data collection.

The survey questionnaire was developed by the PIs and uploaded in SNAP software (see Appendix D & E). First the basic demographics (e.g., age, race, gender), HIV and HCV status, and drug use in the last 30 days were collected. Next the data for every year of the respondent's life were collected year-by-year. All questions were created by the PIs except four questions that were obtained from the Diagnostic Statistical Manual (DSM) IV.

A codebook was generated by SPSS from the final quality controlled and re-coded data sets (see Appendices H & I). The text used to name the variables was shortened and edited to best reflect the question asked. The codebook names and variables appear different than the questionnaire since most questions on the questionnaire were multiple choice, while the survey used primarily dichotomous variables with "yes or no" responses, or not applicable.

All respondents were asked every question unless the respondent already indicated that the question did not apply. For example, if a respondent said he/she did not use heroin in a specific year, the accompanying questions regarding frequency, route of administration, and treatment questions for heroin were skipped and a not applicable (NA=9, 99, 999, or 999) was applied. The flow chart seen in Appendix G for the DEMOGRAPHIC 30-DAY data set and the YEARLY data set show the skip patterns for not applicable.

There were no missing data. Each respondent was asked every question and the computer did not allow the next question to be asked if the respondent did not provide an answer. In a few incidents, a "don't know" (DK=98) was used when the respondent could not remember an answer accurately. In case ID 2, questions on problematic use were not asked since an early version of the survey was used. All other not applicable (N/A) data due to skip patterns are represented by 9, 99, 999, or 9999, depending on the value limit of the corresponding variable.

Respondents were asked to estimate specific data that occurred in the past,

such as number of sex partners with the help of timelines and other cues discussed above. Some respondents gave a range rather than choose one number. We recoded "ranges" that were entered for the number of sex partners (i.e., 30-40) and used the mean of the range for the new value (rounded to the highest number). This only affected the data for three respondents who consistently reported number of sex partners as a range instead of a single number.

6. Variables

The survey consisted of questions regarding residence, family, work, relationships, health, education, and criminal justice involvement and drug use for the last 30 days and for every year. The DEMOGRAPHIC 30-DAY drug use questions were collected in one survey. The interview number assigned in the original data collection was interviewer specific for the purpose of providing interviewers a set of ID numbers. Each interview was assigned a list of 100 consecutive ID numbers. Not only did this allow interviewers to know which number to use next but it also allowed us to know who conducted the survey during the quality control process. This number was later re-coded to be consecutive starting from number 1, as is explained in the re-coding details. In the DEMOGRAPHIC 30-DAY data set, the ID number is the respondent (person). In the YEARLY data set, the case is the ID number combined with the year or PERSON-YEAR; the year starts with the year of birth. After two screening variables that established if the respondent is active or former (inactive in the last year), the variables in this survey were grouped into the categories described in the next two sections.

6.1. Demographics and 30-Day Drug Use Variables

Variables in this data set included gender; race/ethnicity; HIV, AIDS, HCV status; ever injected; date of interview; current age; education; year of birth; drug use in the last 30 days for each drug, including: tobacco (TOB); marijuana (MAR); alcohol (ALC); hallucinogens (HAL); cocaine (COC); crack cocaine (CRK); heroin (HRN); amphetamine (AMP); methamphetamine (MET) and prescription pill misuse (PRP). The route of administration and treatment was also collected for each drug used in the past 30 days, and the respondent's known HIV and AIDS status.

6.2. Yearly Variables

The YEARLY data set included the same variables regarding drug use that were in the DEMOGRAPHIC 30-DAY data set with the addition of problematic and dependence variables for each year. These were asked only if the respondent indicated drug use occurred in that year.

The other additional variables in the yearly data set were grouped into sections that include: social variables (residence, family, work, and incarceration) and sexual variables (sexual partners, type of partners, frequency of sex and condom use).

At the end of each year, the survey ended, and a new survey began anew for the next year. This continued until the year of the interview. Designing the survey to stop at the end of each year allowed a completed and inclusive survey for each year and enabled skipped years if nothing changed. This also made what could be a very long interview process much shorter, for some. The skipped years were later cloned from the identical years, so no years were missing from a respondent's life.

6.3. String Variables (comments and other)

String variables were used for "other" categories such as race. For example, the five race responses included in the survey were African American, White, Hispanic/Latino, Asian and Other. The "Other" value includes string variables in the data sets. The only other open-ended responses in the quantitative data set are the comments. These comments were used during the quality control process to check for consistency and accuracy. These comments boxes are shown as variables in the SPSS and .csv data sets and appear immediately after the related questions on drug use. For example, a comment box was added after the questions regarding frequency of drug use to explain any changes in frequency during the year.

6.4. Details on Constructed and Weighted Variables

We do not have any weighted variables in this data set.

Based on the literature and our knowledge of drug use behavior, we created two variables to indicate what is known as "problematic" drug use. These two questions are not used in any literature that we are aware of, and they were not tested as a scale for dependence. We were attempting to capture *problematic drug use* in contrast to dependence or addiction, which are contested terms (Keane, Moore and Fraser 2011). Further statistical analysis should be conducted on these variables. The two questions are:

During this year, had there been a period when you spent a great deal of time using drugs, getting drugs or getting over its effects?

Response choices: Never; Sometimes; Often; Always

During this year did you feel that your drug use caused problems in your life?

Response choices: Never; Sometimes; Often; Always

In addition, we used four of the seven Diagnostic Statistical Manual (DSM-IV) questions that are widely used in the literature to measure drug dependence (O'Brien 2011). Much debate exists in the literature regarding the expediency of the DSM-IV questions for assessing problematic drug use or addiction, and various modified versions of the DSM-IV questions have been used (Forney, Lombardo and Toro 2007; Keane, Moore and Fraser 2011). Dependence and addiction have been called "troublesome" concepts that may indicate a range of compulsive use as well as functional use (Akers 1991; Fraser and Valentine 2008; Granfield 2004; Lende et al. 2007; Morgan and Zimmer 1997; Sharp et al.

1991; Weinberg 2000). Since the DSM-IV questions were cumbersome for our respondents to answer in pilot interviews and found to be redundant, we used four of the seven criteria questions for dependence that were mutually exclusive. In addition, based on pilot interviews designed to collect user definitions of problematic use, we developed two questions that referred to drug use causing problems and being out of control, as described above. The respondent was asked to list drug(s) to which the problem use or dependence responses referred. Further validity and reliability testing on these sets of questions is needed.

6.5. Details on Changes Made to Survey

During the ongoing quality control of the data that started with the first interview, minor changes were made to the survey data collection and instrument to increase the validity and consistency of the data. All previous respondents' data were updated with the correct information based on the triangulated data sources. Typically a response to a variable was added since one or more respondents mentioned that specific answer in a comment box. The comments and the qualitative interviews allowed us to complete any added variables. No changes were made to the survey after the first ten interviews were collected.

6.6. List of Abbreviations, Variable Names, and Descriptions

A list of variable names and labels for the data sets is found in the codebooks for the DEMOGRAPHIC 30-DAY and YEARLY, along with summary description of the variable and values (Appendices H & I). These summary codebooks were produced by SPSS software. For ease of use, we provided a name and description as a list in an excel spreadsheet (Appendices J & K). Variable names were given that conveyed information about the variable as unambiguously as possible. The variable labels were drawn from the original questions in the questionnaire (see Appendix D & E) and were modified in this list and in the data sets to make it easier for the users of the data sets to understand each variable referent. For example, in the questionnaire, if the question asked: "During this year, did you use any of the following drugs?" a list of drugs followed. Since each drug represented a variable with yes/no responses, we changed the question on each variable label (description) to show which drug was used, for example "During this year, did you use heroin?" instead of asking "this drug." We preserved as much of the original questionnaire as possible in any renaming process (further details in the re-coding section below).

6.7. Technical information on files

The two data sets (DEMOGRAPHIC 30-DAY and YEARLY) are provided in both SPSS and .csv formats. The DEMOGRAPHIC 30-DAY data set is a cross sectional flat file. The YEARLY data set is retrospective longitudinal file. The respondent ID links the data for each year. The ID number also links the two data sets.

6.8. Unit(s) of analysis/observation

The unit of analysis is the respondent (ID) in the Demo_30 Day drug use

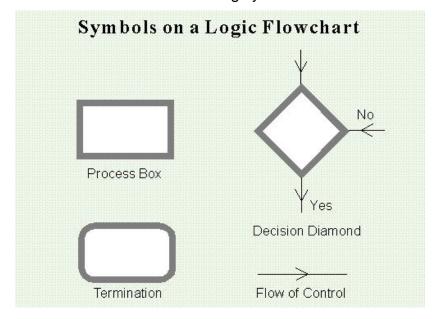
data set. The unit of analysis in the Yearly data set is PERSON-YEAR, which includes the person ID for each year in the respondent's life.

7. Flowchart

A graphical guide to the data collection skip patterns illustrating how various items link to each other is shown in Appendix G. In this flowchart, the logical structure of the variables and their values are mapped out in several diagrams. These diagrams exhibit:

- 1) The "semantic" relationship between the variables.
- 2) The Q&A structure of the survey. This can help the user understand the relationships between the variables and the logical structure of the data.
 - 3) The logic of the skip patterns.

The flowchart uses the following symbols:



8. Training

The complexity of this data collection design required extensive and focused training for the research team members. The success of the outcomes and the validity and reliability of the data were substantially dependent on this training.

Each interview was conducted by two highly trained interviewers; one collecting the quantitative data and the other collecting primarily the qualitative data and ensuring quality control. The semi-structured interview guide (Appendix C) was referred to when needed. Most of this life history was reported during the collection of the life history matrix, and the interviewers used probes to ensure all areas were captured in the narrative. The qualitative interview (not included in

this archive) focused on the interaction processes throughout the life course between drug use and social roles and the complex social factors surrounding drug use. Trained transcribers listened to the interview and transcribed those sections that were not collected by the survey data collection process, resulting in a transcription of the narrative. Field notes were written to supplement the other data sources. All transcripts and notes were saved in Word documents.

The interviewers were trained in the following specific protocol required for each interview:

8.1. Preparation

Folder should always be ready with the following documents:

- 1. Consent forms (at least 2)
- 2. Money received forms (at least 2)
- 3. Response cards
- 4. Life History (Turning Points) Matrix
- 5. Qualitative Interview Guide
- 6. Historical Timeline
- 7. Local Library List (for rooms to interview in private)
- 8. NIDA HIV/AIDS INFO Sheet (given to ALL respondents)
- 9. Treatment resources (given only to those who ask)
- 10. A copy of the Certificate of Confidentiality to have on hand if needed
- 11. Reimbursement and food money
- 12. Pens, pencils and a notepad for notes
- 13. Netbook
- 14. Digital recorders

8.2. Interview Training

There was a "lead" interviewer on each interview. This person was responsible to have the respondent's phone number, the netbook, at least one digital recorder and batteries, and the reimbursement money. The lead interviewer should know the meeting place and leads the process from start to finish. The following instructions were provided for all research team members.

- 1. Start with the consent form. Give one copy to respondent to read and read aloud the major areas. If respondent consents to all, write" respondent read and agreed" sign your name and date. Write interview number in top right hand corner. Give a copy to the respondent to keep. Put your signed consent in your folder. Do not put the respondent's name on this form.
- 2. Turn the digital recorder on to record after explaining the consent and record again that you asked if they read and agreed to the interview (you

- do not have to turn it on until you finish explaining the process). Keep the digital recorder on after this point.
- 3. One interviewer should be assigned to do the survey (survey interviewer) and the other takes care of the life history matrix, notes, the recorder, and qualitative interview questioning (lead interviewer).
- 4. Go over the turning points matrix being sure to get the major dates for each area on the matrix that indicates a transition (e.g., started or ceased drug use; left home; moved out of city or state; children born, gained or lost employment, etc.). The lead interviewer should keep the matrix updated with changes and new turning points emerging from the narrative during the interview.
- 5. The person conducting the survey should be setting up the netbook during this time, taking notes, keeping interviewer and respondent informed of historical timeline events, and be ready to start when the life history interview and turning points matrix is finished.
- **6.** The lead interview should be the one asking questions such as "can you talk about that little more?" The survey person makes sure the survey is taken care of.
- 7. If nothing changes or there is very little change in the respondent's life from one year to the next, these years can be skipped and filled in later by copying a previous year in the survey. The skipped year that is copied is hereafter called a "cloned" year. Both team members can write which years were skipped and if any changes need to be added to the cloned year. Compare notes later. Only up to three years should be skipped, except in childhood years before drug use started; and, in some cases, for former users who stopped the primary drug for more than three years.
- 8. The lead interviewer should keep the interview moving. Both team members can question the respondent if data seems inconsistent with previous data reported elsewhere in the interview process—keep aware!
- Both interviewers need to take good notes.
- 10. When interview is completed, pay the respondent and get the signed money received form; Pay the referral fee *only* to the person who gave the referral. Do not put the respondent's ID number on these forms.
- 11. Offer the respondent food during a break, before, or after the interview.

8.3. Post-Interview

 The team members should stay together after the interview to record the survey changes and the cloned surveys on the netbook. The notes should state specifically where interview years need to be cloned and if any further changes are needed in these years. These notes are called the "cloning notes" since we will be creating person-years based on these specific notes.

- 2. Once again, no cloning notes should be made for more than three years unless it is in childhood BEFORE drug use started.
- 3. Save the survey and the digital recording on a USB drive.
- 4. Both team members will write field and interview notes and send them to the project manager within 24 hours. Use the template for interview notes and include any issues that were raised
- 5. Notes will be used in the quality control processes.
- 6. As soon as the interview is transcribed, the life history interviewer is responsible to listen to the recording, reading along with the transcript and inserting any corrections, additions, comments etc. This should be done within a week of receiving the transcript.
- 7. All team members are responsible to show up at weekly meetings to conduct quality control of the survey data.
- 8. Give all interview paperwork materials (consent, signed forms) and USB data (survey, digital recordings) to the project manager.
- 9. Once all the e-files are archived, the interviewers should delete all interview data from the netbooks and USB drives.
- 10. Restock any paperwork and materials needed for the interview folder.
- 11. Periodic quality control of data by the team will be performed.

9. Quality Control

Validity and reliability are closely linked to quality control. The triangulation of the field observation notes, drug history matrix, the recording and transcription of the interview and the survey data helped address concerns of validity and reliability. The replication of patterns across disparate sources of data also added to the validity in this multi-method study (Ball 1967). The quality control of the ODUS data was a mix of known quality control strategies, including those described in the literature above, and strategies we developed over the course of quality control of the data after it was collected.

One of the most important strategies used in the quality control process was the assessment of reliable data. Reliability issues are concerned primarily with inconsistencies. As mentioned previously, the problems that arise in traditional survey data, such as inconsistencies in time and frequency of use, are reduced when collecting data from multiple methods simultaneously. Also described above, the interviewers were trained to clarify any inconsistency issues while collecting data during the interview to avoid future problems with reliability during the analysis. The interview data collection and quality control process is summarized and visually shown in Appendix H.

9.1 During the Data Collection

A number of interview tools were developed to assist the interview process

and to integrate the data collection of both qualitative and quantitative data in a parsimonious manner. These included a timeline (Appendix A) and a life history matrix (Appendix B), and an innovative structured process for combining data collection methodologies. In addition, the entire interview process was recorded for future quality control.

During the preliminary data collection on the matrix, the interviewer asked the respondent to expound on turning points and specific events. These sections of the recording were transcribed verbatim. During subsequent quality control, the data was triangulated using the various data sources (e.g., survey, matrices, notes, recordings) and any inconsistencies and gaps found were clarified or corrected.

9.2. Post Data Collection

Within a week after each interview, the whole team of researchers met in a conference room with all the data sources available. This included the two interviewers who conducted the interview, the PI, the project manager (and in some incidences a part-time interviewer/consultant). The data sources used for this quality control process included the following:

- 1. Completed life history matrix (often more than one are used to capture all the years)
- 2. Survey data in SNAP and in SPSS
- 3. Interviewer notes from two interviewers
- 4. Cloning notes
- Digital recording
- 6. Transcripts

Using an overhead projector, the entire team looked at every year on a SPSS data set and compared years visually, trying to identify any inconsistencies or unusual patterns (see page 2 in Appendix H). We looked at the SPSS data and made sure that it matched what we saw in the matrices, interviewer notes, and cloning notes. We typically relied on the matrix, the original surveys and the cloning notes to determine authenticity. We occasionally turned to the interviewer notes for clarification. When a discrepancy arose that could not be corrected with the notes, we very often listened to the recording, skipping to the section we believed contained the answer. As recordings were transcribed, we included the transcript as an additional quality control resource.

After quality control of the first five interviews, we implemented the strategy of "cloning" identical or similar years to save time during the survey interview process. Cloning involved replicating the responses for the entire year in the SPSS data set and then manually entering any needed data changes. This was done when all or most of the responses were identical over many years. The interviewers took detailed notes on which years to clone and if there were any changes to make in the cloned year, which we called *cloning notes*. Although the cloning process created some additional problems, we found the detailed notes usually resolved these during quality control team meetings. Based on these meeting outcomes, we eventually established a rule that unless the

circumstances were very particular, we would only clone up to three years consecutively.

During quality control meetings we looked for gaps and inconsistencies across years. When we came to a year or a group of years that did not seem to fit the other patterns in this person's life, we used all sources of data to make sure this was not a mistaken entry by the interviewer while the survey was being conducted. Such entry mistakes usually concerned an incorrect route of administration, two frequencies checked when only one should have been, a missed family role or drug role, and so on.

Other quality control checks were not case specific. These were typically "logic checks." For example, if treatment was selected for a drug, then a type of treatment must also be given, so we checked to make sure that in every case where the answer about drug treatment was yes, an answer was given for the next question on treatment type. Similarly, we crosschecked to make sure that the "any treatment during this year" (treatany) variable had an answer other than no.

When inconsistencies between the triangulated data were found during quality control of already collected data, the research team discussed the inconsistencies and returned to all sources of data until consensus was found. Consensual validity was reached through negotiated validity, wherein consensus was achieved through persuasive and supported argument by team members.

The co-investigator, a mathematician, conducted quality control on blocks of the data after it was collected. The data visualization images of the trajectories he created helped us find consistent mistakes that were occurring early in the data collection process and correct these. The SNAP computer software allowed us to program the survey so that all questions were answered and any questions that did not apply were skipped. This ensured that there would be no missing data in this data set since the computer assisted program would not allow the interviewer to proceed to the next question, or the next series of questions, without providing a response.

Some of the quality control required the interviewers or researchers with expert knowledge of the data and sample to respond to specific concerns regarding the data, such as an unusually large number or outlier. For example, one question raised during quality control regarded the hundreds of partners (strangers) reported by one respondent for one year. Discussion with the interviewers revealed that the respondent was a sex worker who was particularly active in one year. Other concerns regarding unusually large numbers involved respondents who used crack or methamphetamine with extensive drug networks. In other cases, specific and unusual life events made the data appear to be incorrect until triangulated notes were consulted. For example, a woman reported having sex with one "steady partner" instead of "spouse" during a year she was married. The notes for this interview showed that she and her husband divorced during the year but she had sex with him after the divorce. Therefore, she had a "spouse" role in that year (for at least part of the year) but list him as a "steady

partner" in response to the sex questions, since she was not married to him for the part of the year when they had sexual relations.

Other areas of quality control were less complex. This included quality control of the in-depth interview transcripts and final quality control of the quantitative data using statistical analysis, explained in more detail below.

The quality control process did more than address the quality of the data and reliability and validity issues; it also contributed to the training of the interviewers, strengthened the team bonding, and protected the investment of time, energy and money in each interview. The team members all developed a personal responsibility for the validity of the data as well as honestly representing to the best of their ability the story of the person they had interviewed, and with whom they often had became emotionally involved for a few hours. The quality control of each interview resulted in the interviewers reliving the interview session again and remembering the feelings of the interview experience. These relived moments added to the assessment of the validity and reliability of the data.

10. Recoding of the Data

After all the survey data were collected and quality controlled, we re-coded some of the variable responses and re-worded names and descriptions for ease of use by eventual users of this data set. These were often performed and verified through statistical analysis of the data.

10.1. Recode logic

In consultation with the PIs, the project manager who helped to develop the quality control strategies and program the SNAP survey tool made the following changes to how the skipped questions were downloaded by SNAP into SPSS. He first looked at each variable which looked like missing data with "missing" values (that is, "." cells) and determined in values should replace the "." Typically, this was a standard numerical value that represents "not applicable" (9, 99, 999, 9999). For those variables with more complicated missing data, he ensured that the response was due to the respondent not knowing the answer and then replaced these with 98, 998, 9998 ("don't know"). All missing values were re-coded for both the DEMOGRAPHIC 30-DAY and the YEARLY data sets. This was accomplished using the SPSS "Recode into Same Variables" function, with appropriate conditions, to do all of the recoding. This process is consistent with the ICPSR's best practices manual (2009):

Missing data codes should match the content of the field. If the field is numeric, the codes should be numeric, and if the field is alphanumeric, the codes may be numeric or alphanumeric. Most researchers use codes for missing data that are above the maximum valid value for the variable (e.g., 97, 98, 99). ... Missing data codes should be standardized such that the same code is used for each type of missing data for all variables in a data file, or across the entire collection if the study consists of multiple data files. (p. 17).

After a training session on the data instrument with the PIs, a consultant with expertise in SPSS and longitudinal data analysis ran statistical analyses on the data sets to identify variables and responses that appeared inconsistent or otherwise questionable. These ostensible errors were typically explained sufficiently by the PIs, who had access to the qualitative data and field notes that could validate unusual occurrences and responses. For example, one respondent, a transgender male/female, was a sex worker for many years. The number of sexual partners reported in some years appeared to be troublesome outliers; however, consultation with the interviewers confirmed that the number was probably accurate as much as can be estimated. All other questionable data was verified in this manner. In a few cases, a response that was out of the range was found to be data entry error and corrected. In cases where a range was reported instead of a single number, the average was used. These were rare incidents.

All other changes made during the final quality control of the data set were made for ease of use by future analysts and did not change the original content of the raw data. These include the recodes found in the next section.

10.2. Recode List

Recoded data include the following:

- Removed unneeded variables: id.format, id.completed, id.enddate, id.time, id.end, and id.date. Kept dateint.
- Changed value for "Year of Birth" variable from 1-25 to 1940-1964. NOTE: the original value was an artifact of using SNAP, which input it this way. RECODE birthyr (1=1940) (2=1941) (3=1942) (4=1943) (5=1944) (6=1945) (7=1946) (8=1947) (9=1948) (10=1949) (11=1950) (12=1951) (13=1952) (14=1953) (15=1954) (16=1955) (17=1956) (18=1957) (19=1958) (20=1959) (21=1960) (22=1961) (23=1962) (24=1963) (25=1964).

Year of Birth	Current Value	New Value
1940	1	1940
1941	2	1941
1942	3	1942
1943	4	1943
1944	5	1944
1945	6	1945
1953	14	1953
1954	15	1954
1955	16	1955
1956	17	1956
•		
1964	25	1964

- Changed 9s to 0s for Use of "specific drug" within past 30 days. If a person responded "no" to the general question asking if they used any of the listed drugs within the past 30 days, then a 0 should be entered (not a 9) for drug use for each specific type of drug.
- Spot checked all contingency questions.
 - o If a person did not use a specific drug (i.e., heroin) in the past 30 days, then the person gets a 0 for use of that drug (i.e., heroin) and then is coded 9 for all remaining questions relating to that drug (i.e., heroin) (route of entry, frequency, treatment, type of treatment, etc).
 - o If a person did use that specific drug (i.e., heroin), then a 0 or 1 is entered for all contingency questions related to that drug EXCEPT, however, if the person indicated that they did not receive any treatment for that drug. In these cases, the type of treatment questions is coded 9 if they did not receive treatment for that drug.
- Spot checked HIV/AIDS/HEP C Diagnosis and Year of Diagnosis
 Variables. If they were not diagnosed with the illness (i.e., HIV), then the
 year of diagnosis is coded 9999. In some cases, the person indicated that
 he/she was diagnosed, but they must not have given a year (or didn't
 know it) and year of diagnosis is coded 9998 for these cases.
- Recoded 2s to 0s (no) for the following variables: useactv, useform, hivdiag, aidsdiag, hepcdiag, injever. Original version inputted a yes response as 1 and no response as 2.
- Recoded 2s to 0s for any30day drug30day_1 drug30day_2 drug30day_3 drug30day_4 drug30day_5 drug30day_6 drug30day_7 drug30day_8 drug30day_9 drug30day_10 (2=0). Original version inputted a yes response as 1 and no response as 2.Changed value labels accordingly.
- Changed value labels for HOW person used tobacco and HOW frequently. Added 0=no, did not use by [smoking/injecting/etc]. Specified that 9= N/A; did not use that particular drug.
- Changed 2s to 0s for tobtreat30 and tobtrtyp30_1-6. RECODE tobtreat30 tobtrtyp30_1 tobtrtyp30_2 tobtrtyp30_3 tobtrtyp30_4 tobtrtyp30_5 tobtrtyp30_6 (2=0). Original version inputted a yes response as 1 and no response as 2.
- Recode 2s to 0s for alcohol treatment. RECODE alctreat30 alctrtyp30_1 alctrtyp30_2 alctrtyp30_3 alctrtyp30_4 alctrtyp30_5 alctrtyp30_6 (2=0). Changed labels accordingly. Original version inputted a yes response as 1 and no response as 2.
- Recode 2s to 0s for marijuana treatment and type of treatment RECODE martreat30 martrtyp30_1 martrtyp30_2 martrtyp30_3 martrtyp30_4 martrtyp30_5 martrtyp30_6 (2=0). Original version inputted a yes response as 1 and no response as 2.Edit value labels accordingly.
- Recode 2s to 0s for treatment and treatment type for remaining variables. Original version inputted yes response as 1 and no response as 2.
- Edited labels for marijuana use and route of use to reflect meaning of question. Edited labels for prescription pills AND remaining drugs.

 For confidentiality we deleted the state from the Yearly data set. If the user would like to have more detailed information on geographic location, the Principal Investigator may be contacted.

10.3. Variable reduction and aggregation

Although we did not produce a data set that included any variable reductions, we suggest a few ways the many dichotomous variables can be reduced or aggregated.

- 1. One variable reduction scheme is to aggregate the many dichotomous variables with yes/no response into one variable with multiple choices into one. If the multiple choices are exclusive, this is a straight-forward process to aggregate these into one categorical variable.
- 2. The multiple choices of non-exclusive choices are more difficult to merge. In some cases it makes sense to merge some of the choices if they are similar, such as the merging of 11 categories into 2 categories.
- 3. In the case of drug use frequencies, we can aggregate non-singular answers while attempting to respect the underlying scale variable. For example, by considering the borders of the intervals defining our scaled (ordinal) responses, the mean can be used as the value for that response. The result preserves not only the ordinal information but also estimated scale and ratio information if appropriate.

11. Results

A total of 100 respondents were enrolled in the study. After quality control was performed (described above) 8 respondents' data were eliminated from the quantitative data sets. The data (cases) eliminated from the quantitative data set were due to the following reasons: too many inconsistencies were found in the quantitative data; inconsistencies were found between the quantitative responses and the other sources of data (in-depth interview, field notes); or the research team determined the respondent not to be reliable with recalling past history in enough detail to be included in the quantitative data set.

After quality control of the data, the final sample that remained in the quantitative data set included 92 respondents. Among these, 56 (60.9%) were active users of methamphetamine, cocaine/crack or heroin, and 36 were inactive in the last year. Demographic characteristics of this sample show that 54 (58.7%) were male, 37 (40.2%) female and 1 transgender; 46 (50%) were African American, 42 (45.7%) were White, 2 were Hispanic/Latino and 2 identified as other races. Ages ranged from 45 to 65 years old.

While the DEMOGRAPHIC 30-DAY data set has 92 cases; the YEARLY data set resulted in almost 5,000 person-year cases. The rich and comprehensive data for every year of life provides innumerable analysis possibilities, and the two data sets can be merged in various ways. Smaller data sets can be developed from the entire data sample depending on the research

questions examined and the goals of the analysis. For example, data can be analyzed by person periods, historical periods, initiation periods, cessation periods, as well as by specific drugs, risk behaviors, social context and other influential factors, and appropriate smaller data sets can be created from the larger data set for each specific research goal.

The amount of interrelated data in this study makes it difficult to easily capture some of the basic information it provides. Because of the extensive amount of variables for every year of the respondents' lives, we created unique data visualizations for ease of initial use. For example, the simple sequences of on/off drug use of the respondents, along with selected social variables, can be easily viewed as a sequence of white and black data visualization images that illustrate the entire life of each respondent.

12. Data Visualization Images

The data visualization images (DVI) exhibit binary or binarized variables, including drug use, control, role, sexual activity and other social variables collected on each respondent. The data is imaged as a color-coded matrix, with a column representing a given year of the respondent's life and a row representing a trajectory for a given variable over the life of the individual. For a given agevariable cell, the two possible values of the binary variable are color-encoded as a light and dark color. For example, in the case of drug use variables, a dark shaded cell represents active use and light cell represents non-active for a given year.

The legend for the DVI is found in Appendix I. Most of the variable values were simplified to provide a succinct image of the respondents' life over time and the potential relationships between the selected variables. Here we abridge this information provided by the data set into a single binary variable for each year. The primary foci are the drug use trajectories. These provide a good example of how and why the values were abridged (re-coded as binary values) in the visualization image.

This simplification has several advantages: (1) it enables a more parsimonious description and discussion of the measures we developed; (2) it attends to issues regarding the validity of self-reported data (i.e., recall of use and non-use each year over many years is plausibly more valid than recall of frequency of use for every year over the life course); (3) the transitions between use to non-use are probably more noteworthy than any other transition between two drug use levels and likely reflect a major change in the user's drug career; (4) analyzing such binary trajectories complements the existing growth models perspective since the latter cannot really be applied to binary trajectories as is without taking care of adapting the usual definitions and interpretations (for example, what would a "steadily increasing" drug use trajectory be if use were to only be captured by a binary variable?); (5) the difference between growth aspects and discontinuity aspects of trajectories is not so clear when considering multiple use levels of drug use trajectories.

The point of the DVI is to be able to view as much data as possible, aligned by year. We tried to strike a balance between presenting a lot of data without overloading the view. Actually making inferences will require using the appropriate statistics. Yet presenting the data this way helps the analyst to decide what to look for, hypothesize, and infer.

The re-coded values for the variables in the DVI are shown in the legend in Appendix I. In addition to the drug use variables, other variables shown were chosen to be represented in the DVI because they are known to be influential on drug trajectories or conversely influenced by drug use. Any variables in the data set may be added, but using all variables would make the image unwieldy. Looking at the images helps the researcher to form hypothesis that can be tested using the data. Measures of transition, relapse and remission derived from the visualization images can be found in our publication, "Drug Use Trajectory Patterns among Older Drug Users." If a user is interested in seeing other variables inserted into the images, the Principal Investigators may be contacted.

13. Qualitative Data

Transcribed in-depth interviews, field notes, interviewer notes, and scanned penciled in matrices were all part of the qualitative data collected and stored in password protected computer files. These are not included in the archive due to the sensitivity of this data, as well as the time and work needed to de-sensitize these documents to protect confidentiality. The quantitative data accompanied by qualitative transcripts can provide invaluable additional information on every phase of drug use, social context, and influences on turning points identified in the quantitative analyses. If a user is interested in having access to this qualitative data, the Principal Investigator may be contacted for this inquiry.

14. Related Publications

Boeri, Miriam, Thor Whalen, Benjamin Tyndall and Ellen Ballard. 2011. "Drug Use Trajectory Patterns among Older Drug Users" *Substance Abuse and Rehabilitation* 2:89-102.

Abstract: To better understand patterns of drug use trajectories over time, it is essential to have standard measures of change. Our goal here is to introduce measures we developed to quantify change in drug use behaviors. A secondary goal is to provide effective visualizations of these trajectories for applied use. We analyzed data from a sample of 92 older drug users (ages 45 to 65) to identify transition patterns in drug use trajectories across the life course. Data were collected for every year since birth using a mixed methods design. The community-drawn sample of active and former users were 40% female, 50% African American, and 60% reporting some college or greater. Their life histories provided retrospective longitudinal data on the diversity of paths taken throughout the life course

and changes in drug use patterns that occurred over time. Bayesian analysis was used to model drug trajectories displayed by innovative computer graphics. The mathematical techniques and visualizations presented here provide the foundation for future models using Bayesian analysis. In this paper we introduce the concepts of transition counts, transition rates and relapse/remission rates, and we describe how these measures can help us better understand drug use trajectories. Depicted through these visual tools, measurements of discontinuous patterns provide a succinct view of individual drug use trajectories. The measures we use on drug use data will be further developed to incorporate contextual influences on the drug trajectory and build predictive models that inform rehabilitation efforts for drug users. Although the measures developed here were conceived to better examine drug use trajectories, the applications of these measures can be used with other longitudinal data sets.

Boeri, Miriam W. and Benjamin D. Tyndall. 2012. "A Contextual Comparison of Risk Behaviors Among Older Adult Drug Users and Harm Reduction in Suburban Versus Inner-City Social Environments." *Journal of Applied Social Science* 6(1): 72-91.

Abstract: Recent epidemiological data show that older adults comprise a growing age group of drug users and new AIDS cases in the United States. Prevention and intervention studies show that risk behaviors leading to HIV infection are increasing among older users, particularly among the socially vulnerable. Yet older adults remain an underresearched population of drug users and little is known about their risk behaviors. Our aim is to address this gap in knowledge on older users by comparing contextual factors that influence risk behaviors and harm reduction strategies practiced by older drug users living in different communities. This study is based on ethnographic fieldwork in suburban and inner-city neighborhoods in a large metropolitan area in the southeastern USA. Interviewers conducted face-to-face, in-depth, lifehistory interviews with 69 older adults (age 45 and older) who used heroin, cocaine, and/or methamphetamine. Findings show that while risk behaviors were similar among older adult drug users living in suburban and inner-city environments, the provision of harm reduction education and paraphernalia varied widely. The results show the need for the expansion of harm reduction services focused on older adult drug users who are homeless, uninsured, or socially isolated. This applicationoriented research will inform healthcare and treatment providers and generate new directions for future collaborative harm reduction services aimed to decrease the spread of HIV and other infectious diseases associated with drug use.

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Appendix A: Timeline

Timeline 1982-Compact Discs introduced 1950-1st credit card 1983-Microsoft Word released; Reagan signs MLK holiday; Japan releases Nintendo 1951-1st Color TV, H bomb 1984-Mac APPLE invented; Michael Jackson wins 1952-1st Sex change operation 8 grammies 1953-First H bomb; and first Play Boy Mag 1985-Reagan ramps up War on Drugs 1954-1st Transistor Radio 1986-Iran Contra, Challenger explosion 1955-Montgomery Bus boycott 1987-Michael Jackson releases BAD; Black 1956-Montgomery Bus boycott Monday on stock market 1957-Wham-o first Frisbee; Sputnik 1 launched 1988-First genetically engineered animal, worldwide computer virus, & conviction based on 1958-RCA introduces stereo LPs DNA 1959-Hawaii becomes a state 1989-Fall of Berlin Wall 1960- Summer Olympics in Rome 1990-Hubble telescope launched 1961-Yuri Gagarin first human in space, Berlin 1991-debut of world wide web Wall built 1992-Clinton defeats Bush 1962-USA enters Vietnam 1993-World Trade Center bombing 1963- President Kennedy Assassinated 1994-first web search engine Yahoo.com 1964-Gulf of Tonkin fabrication 1995-Waco, TX, DVD introduced, 1st exo-solar 1965- Malcolm X assassinated; Bloody Sunday AL planet discovered 1966-Charles Whitman kills 13 at U Texas 1996-Atlanta Olympics, Depp Blue beats Gary 1967-Oil Embargo, 1st Super Bowl Kasparov in chess 1968-RFK and MLK Assassinated 1997-Princess Diana dies 1968- Doors released first album 1998-Ebay founded, Google founded, Clinton 1969-First moonwalk, Nixon declares war on drugs impeached 1999-Windows 98 released; Napster invented 1970-Appollo 13 launched 2000-W2K scare: Bush defeats Gore 1971-VCR introduced 2001-9/11 1972-War on Drugs starts 2002-No Child Left Behind Act signed 1973-USA leaves Vietnam 2003-Crash of shuttle Columbia 1974-Nixon resigns 2004-Mass legalizes same sex marriage; Reagan 1975-McDonalds opens first drive through dies 1976-Jimmy Carter elected 2005-North Korea announces nuclear weapons 1977-Voyager launched 2006-Saddam Hussein sentenced to death 1978-Jamestown Suicides, USA abandons Gold 2008-Obama Elected standard 2009-outbreak of the Swine Flu 1979-3 Mile Island 1980-John Lennon killed

1981-first reported cases of AIDS in USA, MTV

Appendix B: Life History Matrix

Life History and Turning Points Matrix #_ Age:_ Race: Sex_ Age DATE Substance Use Drug Roles Treatment History Residence Family roles Work Roles Law Involvement Partners

Appendix C: Qualitative Interview Guide

ODUS Study

Qualitative Guide
PARTICIPANT ID #:
Age: Gender: Race/ethnicity: Active/Former:
Interviewer initials: Location of interview:
Date of Interview://
Start time::a.m./p.m.

I. Personal Life Issues

(Interviewer: first go over the matrix and summarize the life history in terms of geographic location, family context, employment history, and changes in drug history.)

- 1. What do you consider the most important influences on you in general? Tell me the most memorable experiences of your entire life. Why are they memorable? (If only positive experiences are reported, ask about memorable negative experiences and vice versa.) How did these influence your drug use?
- 2. How do you feel about where you are in life right now? Explain?
- 3. Who are the significant others in your life right now? Are these people with you while you are using drugs? Do they know about your use? (Ask the same questions for five years ago and ten years ago.)
- 4. How religious or spiritual are you? How did this change over time? How does this affect your drug use? How does this impact what drug use means to you?
- 5. Talk about your work? (Use matrix to pinpoint work history). How does work impact your current drug use? How did it impact your drug use over the life course? How did drug use impact your work?
- 6. How did education impact your drug use over the life course? How did drug use impact your education?
- 7. What is your financial situation in terms of comfortable, struggling, etc.?
- 8. Do you think there is any shame or stigma attached to drug use? If so, how do/did you deal with this?

II. Influence of Social Context on Drug Use Trajectories

(Interviewer: go over each drug used but focus on cocaine, methamphetamine and/or heroin.)

- 1. Let's go over each drug you mentioned on the matrix. Why did you start using each drug? What was your drug of choice? How did this change over time?
- 2. What was the general pattern of use in terms of frequency? How did these patterns change over time? By route of administration?
- 3. What are the different settings where you used drugs? How do your patterns of use change by setting?
- 4. What are the differences in how you use drugs in private versus public settings? Known versus unknown settings? Settings in which you are a stranger? As an insider? As an outsider? Alone?
- 5. When or where are you in any social settings where you really want to use? Explain. Where are the setting that you really do **not** want to use? Explain.
- 6. Let's go over each social role you mentioned on the matrix? For each role, what does this role mean to you? How much time do you spend in this role? How important is this role to you? How committed are you to this role?
- 7. How did you acquire each role? What roles are you in the process of acquiring now? What roles do you desire to acquire? What is holding back the acquisition of these roles for you? What steps are you taking to achieve these roles?
- 8. What roles have you lost in the last ten years? Why? What roles have been lost since drug use began? How were they lost (if any)? What roles have been gained? How were they gained (if any)? How was role loss or gain affected by your drug use? How did it affect your drug use?
- 9. How does commitment to each social role affect your risk behaviors related to drug use? Affect your risk behaviors related to sexual activities? (For example, do you not use drugs because your partner disapproves? Because you are concerned about your role as a parent?)
- 10. Have you been involved in criminal activity? With the criminal justice system? If so, how? When? Why?
- 11. What was happening in your life at the time you increased use of (specific drug)?
- 12. What was happening in your life at the time you decreased use of (specific drug)?
- 13. What was happening in your life at the time you stopped use of (specific drug)?
- 14. What was happening in your life at any relapse of use?
- 15. How does aging affect your drug use?

Show the participant the typology of drug users by control and social roles and ask where they fit

on the typology now? Why? Where they fit at other points in their lives and why?

III. Interactions Between Drug Use, Social Bonds And Social Network Across the Life Course (Interviewer: If participant already discussed this, probe deeper. Ask about race, gender, age and class influences if applicable.)

- 1. How did you come to know about each drug you used? What was your first impression when you learned about the drug? When you first tried the drug? After you used for years? When you stopped use?
- 2. Who is the person you first used drug with for each drug used? Why? When? Who do you use drugs with now? Why? When?
- 3. How did your views on drug use change over time? When did they change? Why did they change?
- 4. What do you remember in your childhood regarding drug use? Was drug use discussed in your family while growing up? If so, explain how you felt about this. If not, what do you think about discussing drug use with family members as children are growing up?
- 5. Were drugs part of your social life in any way while growing up? If so, how?
- 6. What were the norms (attitudes, unwritten rules, etc) regarding drugs when you were growing up? How did this change over time? How did this impact your drug use? In what way does this impact your current use?
- 7. Did anyone in your family use drugs when you were growing up? Father? Mother? Sibling? Cousin? Grandparents? Uncles? Aunts?
- 8. Did friends use drugs when you were growing up? Who? When? Where?
- 9. How does drug use affect your relationship with others? Parent? Siblings? Friends? Colleagues at work or school? Bosses or others in authority positions? How has this changed over time?
- 10. What activities other than drug use do you engage in regularly? What activities are done irregularly? When? Why? (For example, running, tennis, church, etc.) How did this change over the life course? How was it affected by drug use? Affect drug use?

IV. Turning Points in Trajectories: Route of Administration (Interviewer: Use matrix to pinpoint routes for each drug used.)

- 1. Which route of administration was used most frequently for each drug? Explain why. What route or routes of administration may not be typical but you have done in the past? Describe changes in methods of administration. How were these methods learned? What are the behaviors associated with each method?
- 2. How did the form of drugs affect your choice of administering the drug, for example, pill, powder, rock, liquid, etc.?
- 3. How did the purity of the drug affect your choice of administration?
- 4. *(For IDUs)* Describe your typical injection behavior. Your atypical behavior. Explain any changes in injection patterns over time. By setting. Describe your first injection setting. Your last.
- 5. What was happening in your life at this point of initiation of injection practices? Of stopping injection practices? Of any relapse in injection practices?
- 6. What are your views on injection? How were these views formed? How did they change over time? If you never injected a drug, explain why not.
- 7. What behaviors are associated with HIV transmission? Do you participate in any of these behaviors? If so, under what circumstances? With whom do you engage in these behaviors? Why do you engage in them? When do you engage in them? (Be sure to include both sexual and drug-using behaviors.)
- **8.** What do you know about HIV/AIDS? What do you know about HIV risk reduction? How does this influence your use habits?

V. Turning Points in Cessation, Relapse and Treatment

(Interviewer: This applies to any users who have stopped use for at least a year.)

- 1. How did you stop use of each drug (refer to matrix)? Why did you stop?
- 2. What was going on in your life at that point? How did you life change after you stopped?
- 3. How did you relapse (refer to matrix)?
- 4. What was going on in your life at that point? How did you life change after you relapsed?
- 5. Have you ever been in any type of drug treatment? (*If mentioned already above, ask probing questions.*) Please explain. What do you think of the treatment? How has the treatment experience affected your drug use patterns? Your sexual behaviors?
- 6. Are you still in any type of treatment including 12-step programs? If so, why? How has your involvement in treatment changed over time?
- 7. How does your family (partners, parents, siblings, children) affect your involvement in treatment? In relapse?
- 8. How does work affect your involvement in treatment? In relapse?
- 9. What type of treatment program would you like if you could have any treatment? What kind would you design for others? Why? What kind of treatment would fit the "reality" of your life? (Probe for positive and negative aspects of treatment in terms of how it fits with the rest of one's life.)

VI. Health and Drug Use

(Interviewer: if these questions were already answered above, repeat the answer and explain that you want to go into this area more deeply.)

- 1. How has each drug affected your health? Explain in terms of price, purity and form, for example, powder versus rock cocaine.
- 2. How has each route of administration affected your health? (Probe for safe injection factors: acquiring new needles, sharing needles with others, injection paraphernalia, smoking paraphernalia; straws, etc...)
- 3. How has each drug used influenced your sexual behaviors? (Probe for unsafe sexual factors: condom use in terms of frequency and with whom, number of partners; types of sex...)
- 4. How has your treatment experiences/cessation of drug use affected your health? (*Probe for changes in health since treatment or cessation*).
- 5. How have your relationships affected your health? (Probe in terms of physical, emotional, mental...)
- 6. How did you find out about transmission of HIV/AIDS? Describe when you first heard of HIV/AIDS and how it is transmitted. When you heard of changes over time in transmission routes. How has knowledge of HIV changed your drug behaviors? Your sexual behaviors?
- 7. What is your HIV status? How do you know this? If positive, explain details of when you found out. How has this changed your drug use habits? Your sexual behaviors? Your life in general?

VII. Structure and Policy

(Interviewer: For each of the following social events, ask the questions that apply. Offer examples of these influences on society if needed. Ask only those questions that are appropriate for the individual.)

- **THE SIXTIES:** The "sex, drug, and rock and roll" or "free love" influence of the sixties. (For example, greater availability of drugs, especially prescription drugs, greater acceptance of drug use among peers, open drug use of teen idols.)
- **THE VIETNAM WAR:** Ask of anyone who was in the war, had family or friends in the war, or were involved in war protests. (For example, having been to Vietnam, used drugs in VN or after returning from VN; having known someone who was in VN who you used drugs with, using drugs with VN protesters.)

- **THE SEVENTIES:** Political scandals rock the nation, while nuclear plant disaster and mass cult suicide infects our social landscape. The War on Drugs begins.
- **THE WAR ON DRUGS:** The criminal justice policies that increased during the eighties and nineties (For example, greater incarceration of drug users, changes in drug availability, changes in drug settings.)
- **THE EIGHTIES:** The increased economic privatization of the eighties, sometimes known as the greedy period. (For example, trying to climb the corporate ladder, stigmatization of drug users by friends and family, losing money on business ventures.)
- THE NINETIES AND NEW MILLENIUM: Changes in social services and public assistance policies in the nineties. (For example, public aid to families with children, supplemental security income and publicly assisted housing programs.)

Questions:

- 1. How did this time period/event affect your life?
- 2. How did it affect your drug use?
- 3. How did it affect your health?
- 4. Were any turning points in your life due to one or more of these events?

OTHER TOPICS

ADD questions on notes you took during the interview. Invite the participant to raise additional topics.

Appendix D: Demographic 30-Day Questionnaire

(released as a separate document available for download)

Appendix E: Yearly Questionnaire

(released as a separate document available for download)

Appendix F: Short Qualitative Interview Guide

Short Qualitative Interview Discussion

I. Personal Life Issues

- 1. What do you consider the most important influences on you in general?
- 2. Who are the significant others in your life right now?

II. Influence of Social Context on Drug Use Trajectories

- 1. How does commitment to each social role affect your risk behaviors related to drug use? Affect your risk behaviors related to sexual activities?
- 2. What was happening in your life at the time you increased use of (specific drug)?
- 3. What was happening in your life at the time you decreased use of (specific drug)?
- 4. What was happening in your life at the time you stopped use of (specific drug)?
- 5. What was happening in your life at any relapse of use?
- 6. How does aging affect your drug use?

III. Interactions Between Drug Use, Social Bonds And Social Network Across the Life Course

- 1. Were drugs part of your social life in any way while growing up? If so, how? What were the norms (attitudes, unwritten rules, etc) regarding drugs when you were growing up?
- 2. Did anyone in your family use drugs when you were growing up? Father? Mother? Sibling? Cousin? Grandparents? Uncles? Aunts?
- 3. Did friends use drugs when you were growing up? Who? When? Where?
- 4. What activities other than drug use do you engage in regularly?

IV. Turning Points in Trajectories: Route of Administration

- 1. What was happening in your life at this point of initiation of injection practices? Of stopping injection practices? Of any relapse in injection practices?
- 2. What are your views on injection? How were these views formed? How did they change over time? If you never injected a drug, explain why not.
- **3.** What do you know about HIV/AIDS? What do you know about HIV risk reduction? How does this influence your use habits?

V. Turning Points in Cessation, Relapse and Treatment

1. Are you still in any type of treatment including 12-step programs? If so, why? How has your involvement in treatment changed over time?

VI. Health and Drug Use

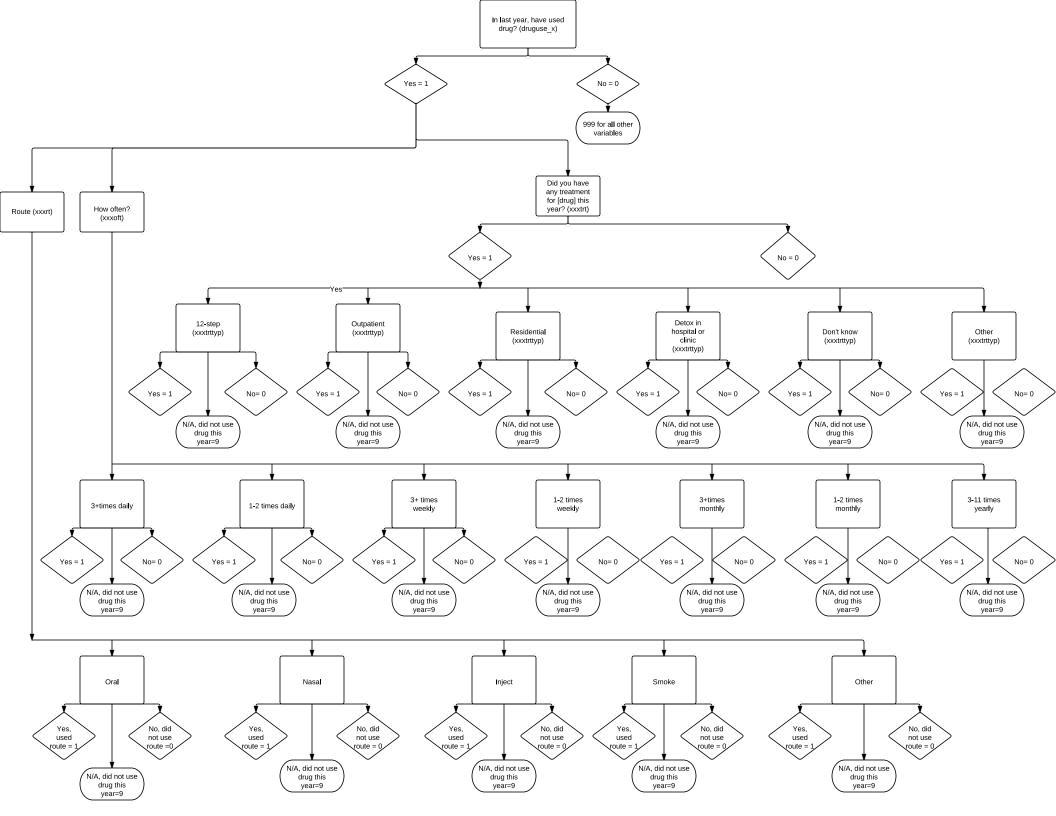
2. How did you find out about transmission of HIV/AIDS? Describe when you first heard of HIV/AIDS and how it is transmitted.

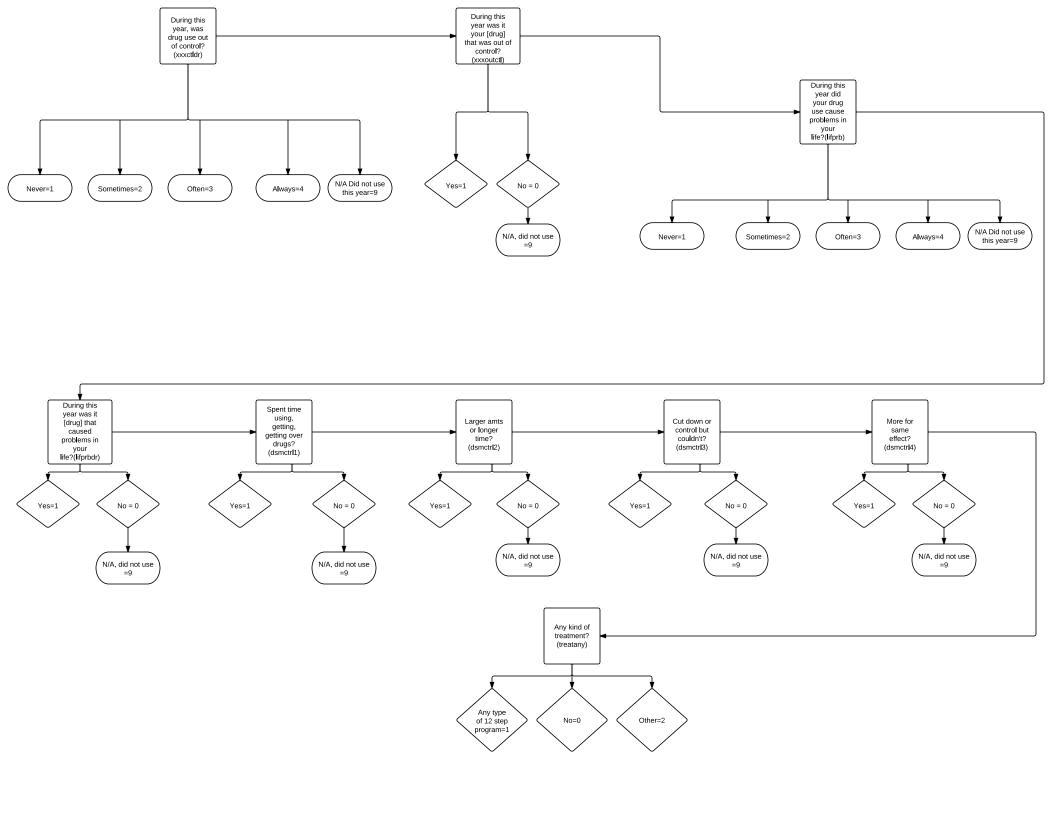
VII. Structure and Policy: Were any turning points in your life due to one or more of these events?

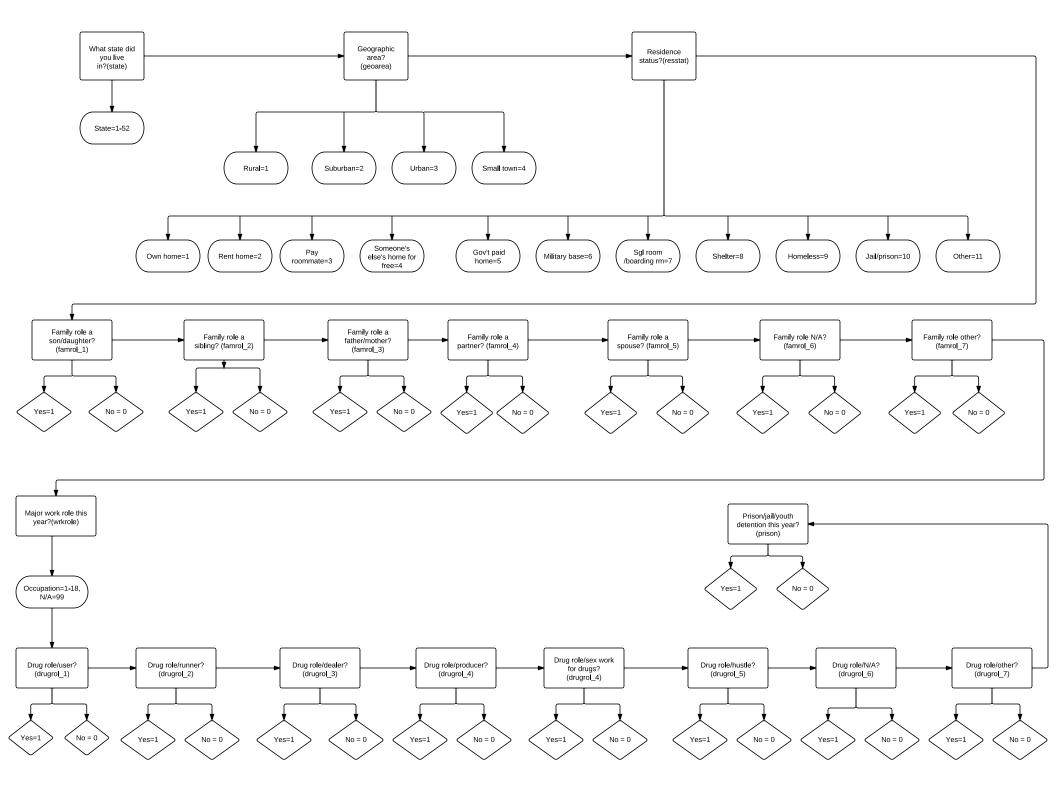
- THE SIXTIES
- THE SEVENTIES
- THE VIETNAM WAR: THE WAR ON DRUGS
- THE NINETIES AND NEW MILLENIUM

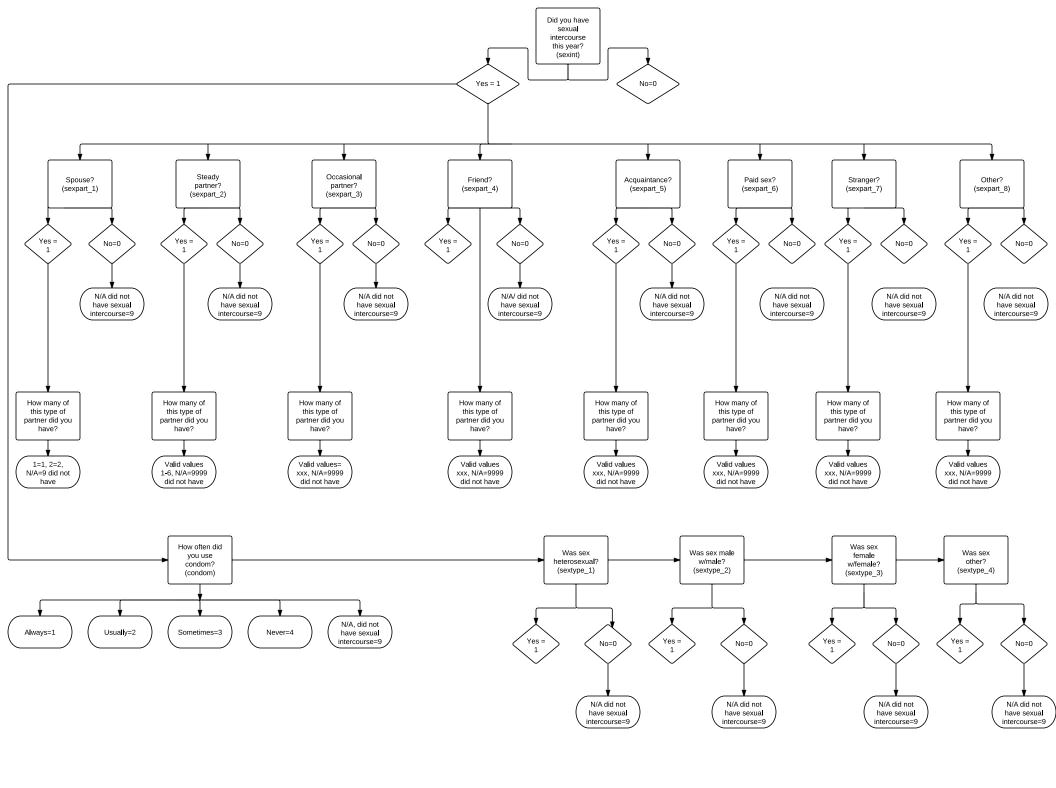
OTHER TOPICS?

Appendix G: Flowchart









Appendix H: Data Collection Overview

Life History Data Collection from Birth:

Technological Advances Integrating Qualitative and Quantitative Methods

Miriam W. Boeri, Thor Whalen, Ben Tyndall, David Paul Gibson, Craig Rafuse; Kennesaw State University

Life History of Older Drug Users

- Long history of drug use allows for observing patterns and turning points over life course
- Lack of current knowledge of on older users who haven't "matured out"

Sample

- 100 adults from a large Southeastern metropolitan area Turning Points Matrix # Age:
- 45 years or older at the time of the interview (oldest was 65)
- About half current users (used in the last year)

Mixed method study

- Qualitative interview
 - In-depth audio recorded narrative interview
 - Focus on drug use turning points
 - Entire life from birth to present
- Quantitative survey
 - Computer survey administered by interviewer using netbook
 - In addition to demographics, records drugs use, social role and risk behavior information for every year of respondent's life

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	Treatment						
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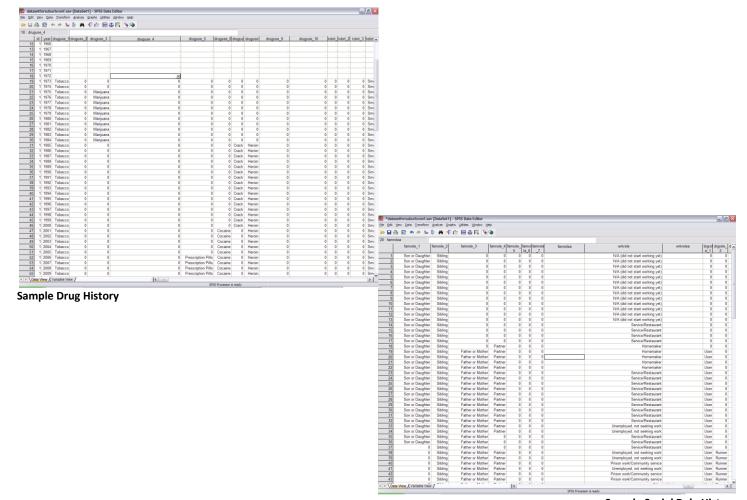
Development of methods

- Interview
 - Guided by Turning Points Matrix (see above)
 - o Interviewers record major events and changes in respondent's life on matrix
 - Interview is open-ended and participant driven, but matrix helps keep interview focused and organized
- Survey
 - o Problems to overcome
 - 45+ years of data x 100 participants x 100+ variables per year = half a million variables
 - Too long to allow R to complete; two interviewers
 - Age and behavioral issues make sitting and focusing on a long interview difficult
 - Needed a concise and efficient computer based survey
 - Solutions for the survey
 - As originally conceived: one survey per respondent, required completion of every year of R's life
 - Too long and difficult to navigate for interviewer
 - Often very little change from year to year
 - Survey and data files were too large for the survey software to handle well
 - Rather than have each respondent as a case, we made each year a case
 - Only requires two short surveys, one that captures demographic data and one that captures data for only one year
 - The demographic survey includes data needed only once
 - The yearly survey includes a variable for the year so that each year needed can be created anew
 - Respondent's ID number links all surveys
 - This allows us to complete similar years after the survey is completed and focus on major years during the interview, keeping it shorter for the respondent

Life History Data Collection from Birth: Technological Advances Integrating Qualitative and Quantitative Methods

Data management and quality control

- Data imported into base survey software and unentered years are entered by two researchers
 - Copious notes taken during interview to complete surveys (what years and responses to enter)
 - Two team members help ensure minimal human error (only able to see one year at a time)
- Completed surveys are quality controlled
 - Survey data is imported into SPSS
 - Two team members view the "big picture" and scan for incongruities and possible mistakes in each survey
 - Any oddities are investigated using data triangulation
 - Interviewer notes(written shortly after interview)
 - Recording (includes both qualitative and quantitative portions of interview)
 - Turning Points Matrix
 - o Quality controlled surveys are ready to go on to mathematician and statistician for analysis
- Qualitative interview is quality controlled concurrently
 - Recordings are sent to transcribers trained to transcribe only the narrative interview leaving out the survey but including any qualitatively interesting quotes said during survey
 - o Transcripts are then sent to researchers who listen along and make corrections as needed
 - Quality controlled interviews are ready for coding



Sample Social Role History

Appendix I: Legend of Data Visualization Images

(this document has been suppressed from this public release)