Utah Biannual HIV Needs Assessment Report

Utah Department of Health
Division of Disease Control & Prevention
Bureau of Epidemiology

Treatment and Care Services Program
Ryan White Part B Program

2013

For more information, contact:

Ryan White Part B Program
Treatment and Care Services Program
Bureau of Epidemiology
Division of Disease Control and Prevention
Utah Department of Health
Box 142104
Salt Lake City, UT 84114-2104
Phone: (801) 538-6191
Fax: (801) 536-0978
E-mail: RWP@utah.gov
Web Site: http://health.utah.gov/epi/treatment/index.html

Prepared for: **Ryan White Part B Program**
Treatment and Care Services Program

Submitted by: Utah Department of Health
Division of Disease Control and Prevention
Bureau of Epidemiology
Treatment and Care Services Program
Ryan White Part B Program
288 North 1460 West (84116)
Box 142104
Salt Lake City, UT 84114-2104

Prepared By: Miriam Cariello, Brigham Young University, MPH (c)

Primary Contact: Marcee Mortensen, Ryan White Part B Program
Telephone: 801.538.6042
Fax: 801.536.0978
Email: marceemortensen@utah.gov

Special Thanks: Evan Done, Tyler Fisher & Duane Abplanalp, Utah AIDS Foundation
Peter Danzig, Clinic 1A at the University of Utah
Treatment and Care Services Program, Utah Department of Health
Michelle Interdonato, Veteran's Administration
Colleen Guymon, Utah State Prison
Toni Johnson, People with AIDS Coalition of Utah
Danielle Watters, Utah Pride Center
Utah HIV Planning Group

Table of Contents

List of Tables……...……9

Introduction ……...……..……11

HIV Background……11

National and Utah HIV Rates……11

Most Affected HIV Populations……11

Risk and Protective Factors……...…12

Statement of the Problem……..……..…12

Background and Need……..……13

Best Practice Strategies……..….13

Purpose of the Project……..……...15

Research Questions……..……...16

Methods……16

Research Design……..……16

Study Setting……..……16

Sampling and Participants……..……17

Sample Selection & Eligibility Criteria……..……17

Sampling Methods/Recruitment……..……...17

Sampling Frame……..……19

Intervention and Materials……..……20

Instrumentation……..……20

Survey Development……..……20

Constructs and Variables……..……..21

Informed Consent……..……..22

Pilot Test……..……..….23

Survey Printing…….…….25

Data Collection…….…….26

Data Collection Preparation…….……..…26

Survey Distribution…….……...……26

Survey Incentive…….……...……29

Data Entry…….…….29

Data Cleaning…….……30

Data Analysis…….……30

Results……31

Participant Demographic Information……...31

Primary Demographic Information…….……...31

AIDS.…….……34

LGBT Community…….……35

Significant Other…….……...35

Pregnancy…….……..36

Dependents…….……36

Time in Utah…….…….37

Working Situation…….…….……38

Refugee…….…….39

Prison…….……39

Living Arrangement…….……..40

Languages…….……41

HIV Diagnosis & Cause…….……42

Co-infections…….……44

Tuberculosis …….……45

Medical Treatment and Medical Care Needs of PLWHA in Utah…….……...46

Medical Care Place & Timing…….……..46

HIV Medications…….……...48

Medical Care Payment…….……..49

Indicators of Care . …….……...50

Health Care Provider Treatment……54

Medical Care Gaps…….……55

Medical Treatment and Medical Care Service Ratings…….56

Barriers to Care of PLWHA in Utah……..60

Support Service Needs of PLWHA in Utah……..61

Case Management…….……61

Others that Connect to Services…….……64

Support Service Ratings…….……65

Services in English…….……72

HIV Preventive Behaviors of PLWHA in Utah…….73

Injection Drug Use…….……73

Sex under the Influence…….……75

Sexual Partners…….……..77

Unprotected Sex…….……80

Asking & Disclosing HIV Status……...81

Trading Sex…….……...84

Discussion……..87

Medical Treatment and Medical Care Needs…….……87

Barriers to Medical Care Needs…….……..…..90

Support Service Needs…….……..92

HIV Preventive Behavior Needs……95

Limitations……..……...97

Conclusions……...…….……..99

Time Table for Project Completion……100

References……101

Appendices……...…108

2013 Utah Needs Assessment Survey……..…108

Table 76: Data Cleaning Survey Response Changes……...…123

List of Tables

Table 1: Quota Stratums, Quotas to be Met, Final Survey Response Count, whether Quotas Were Met……..…18

Table 2: Surveys Distributed to Each Participating Organization & Number of Completed Surveys Returned from Each…….....27

Table 3: Primary Demographic Information……...32

Table 4: Black Place of Birth……..……..34

Table 5: Other Races Countries……..……..34

Table 6: Diagnosed with AIDS……35

Table 7: AIDS Diagnosis Year……35

Table 8: Part of LGBT Community……...……..35

Table 9: Significant Other……..……..36

Table 10: Current Pregnancy……...36

Table 11: Dependents Number…….....……..…….....37

Table 12: Time in Utah…….....……..……..37

Table 13: Working Situation…….....…..…….....38

Table 14: Refugee…….....……..……..39

Table 15: Refugee Country of Origin…….....……..……39

Table 16: Currently in Prison…….....……..……39

Table 17: Prison Time……..…….....……40

Table 18: Living Situation…….....…..……41

Table 19: Sexual Activity in Prison…….....……..……..41

Table 20: Languages…….....……..……..42

Table 21: HIV Diagnosis Timing…….....……..……..43

Table 22: Utah HIV Diagnosis…….....……..……..……43

Table 23: Other State for HIV Diagnosis…….....…..……..43

Table 24: Cause of HIV…….....……..……..……...44

Table 25: Co-infections/Diseases…….....……..……..……45

Table 26: TB Testing……...……..…….....……..……45

Table 27: Last TB Test…….....……..……..……46

Table 28: Treatment for TB Positive Test…….....……..……..…….....46

Table 29: Place for HIV Medical Care……..……..…….....……..……..47

Table 30: Seeking Medical Care Timing after Diagnosis.……..… .....……..……..47

Table 31: Taking HIV Medications…….....……..……..……48

Table 32: Skipping/Stopping HIV Medications...……..…… .....……..……..49

Table 33: Payment Methods for Medical Care……...……..…….....……..……..50

Table 34: Lab Tests in the Last Year……..….....……..……51

Table 35: Reason for No Lab Tests in the Last Year.....52

Table 36: Last Lab Tests Results.....53

Table 37: ART Medications Taken.....53

Table 38: Treated Poorly at Health Care Provider's Office.....54

Table 39: Reasons for Poor Treatment at Health Care Provider's Office.....55

Table 40: Ever Not Receive HIV Medical Care.....56

Table 41: Reasons for Gap in Medical Care 56

Table 42: Medical Treatment and Medical Care Need Ratings.....57

Table 43: Medical Treatment and Medical Care Importance Ratings.....58

Table 44: Medical Treatment and Medical Care Satisfaction Ratings.....59

Table 45: Medical Care Top Barriers.....60

Table 46: Have a Case Manager.....62

Table 47: Reasons Not Having a Case Manager.....63

Table 48: Last Contact with Case Manager.....63

Table 49: Improve Case Management.....64

Table 50: Someone Else that Connects to Services.....65

Table 51: Who Else Connects to Services.....65

Table 52: Support Services Need Ratings.....66

Table 53: Support Services Importance Ratings.....68

Table 54: Support Services Satisfaction Ratings.....70

Table 55: Comfort Receiving Services in English.....73

Table 56: IDU & Last Time of Use.....74

Table 57: IDU Drugs.....74

Table 58: Sharing Needles & Last Time of Use.....75

Table 59: Sex under the Influence.....76

Table 60: Sex under the Influence Drugs.....77

Table 61: Sex in Last Year.....78

Table 62: Sex Only with HIV Positive Individuals.....78

Table 63: Sex with One Primary Partner.....78

Table 64: Where Sexual Partners are Found.....78

Table 65: Sex with Partner Types.....79

Table 66: Unprotected Sex with Partner Types.....80

Table 67: Female Sex with MSM & Oral Sex Protection.....81

Table 68: Asking Sex Partner HIV Status.....82

Table 69: Disclosing HIV Status to Sex Partner 83

Table 70: Notify Sex Partner of HIV Status Afterward...84

Table 71: Reasons Did Not Notify Sex Partner of HIV Status84

Table 72: Trading Sex for Money, Drugs or Other Reason85

Table 73: Last Time Traded for Sex86

Table 74: Trading Sex Other Reasons86

Table 75: Timetable of Project Completion101

Table 76: Data Cleaning Survey Response Changes124

Introduction

HIV Background

Human immunodeficiency virus (HIV) is a virus which can develop into acquired immunodeficiency syndrome (AIDS) (CDC, 2013b). Currently, there is no cure for HIV and your body is unable to get rid of the virus. In the U.S., HIV is most commonly transmitted by having unprotected anal or vaginal sex or by sharing intravenous equipment with an infected person (CDC, 2013b). HIV weakens the immune system and the body's ability to fight off other infections and diseases (CDC, 2013b). HIV treatment consists of antiretroviral therapy (ART) which can prolong life and lower infection rate (CDC, 2013b).

National and Utah HIV Rates

Over the past decade approximately 50,000 people each year have been infected with HIV in the U.S. (CDC, 2013b). Nationally, it is estimated that 1.1 million people are living with HIV, although an estimated 18% do not know they are infected. While HIV affects a small percentage of the U.S. population, some groups are affected more than others, such as gay males and people of color (CDC, 2013b). In Utah, the rate of people living with HIV/AIDS (PLWHA) has been increasing over the past several years (UDOH, 2001a). In 2009, 2,614 people in Utah were reportedly living with HIV, increasing to 2,734 in 2011 and 2,782 by 2012 (UDOH, 2011a).

Most Affected HIV Populations

Nationally, the percentage of people living with HIV/AIDS (PLWHA) is higher in urban areas, with the greatest percentage living in metropolitan areas with 500,000 people or more (CDC, 2013b). Black Americans and gay and bisexual men of all races and ethnicities in the U.S., especially youth, have increasing new infection rates (CDC, 2013b). In the U.S., HIV also

affects increasing proportions of women and continues to affect racial and ethnic minorities disproportionately (Morris, Kurth, Hamilton, Moody & Wakefield, 2009). A frequently reported risk among men nationally has been intravenous drug use (Morris, et al., 2009).

Risk and Protective Factors

The most significant risk factors associated with contracting and spreading HIV/AIDS are lack of knowledge about HIV prevention, risky behaviors related to sex and drugs, lack of skills to refuse unsafe sex, injection drug use involving needle sharing, and alcohol or drug use (Dowshen et al., 2011; Diaz, M., 2012; WHO, 2004). Men who have sex with men (MSM) are considerably more likely to have multiple partners than men reporting sex with only female partners. (Choi et al., 1999). Various precautions can be taken to decrease the likelihood of contracting HIV such as not participating in high-risk behaviors (e.g. unprotected sex and sharing intravenous needles). Protective and preventive factors for HIV/AIDS include community involvement, strong family support and values, condom use, knowledge of HIV prevention, and HIV testing (NIDA, 2008; WHO, 2004; Choi et al., 1999). HIV testing in particular often leads to HIV treatment and care and decreased HIV transmission to others (Gardner et al., 2011).

Statement of the Problem

Since the early 1980s, the spread of HIV/AIDS has become a serious public health concern (Chin & Mann, 1988). It continues to be a problem in Utah as rates of people living with HIV/AIDS and new infections continue to increase (UDOH, 2011a). Some of the most significant HIV challenges today in the U.S., and in Utah specifically, are inadequate engagement, linkage, and retention of HIV-positive individuals within the HIV care system (Gardner et al., 2011 & Cheever, 2007). For this reason, it is important to conduct research and

implement methods to identify unmet needs and barriers to HIV services so that HIV organizations can respond accordingly. Addressing unmet needs will likely lead to improved engagement, linkage, and retention of HIV-infected individuals in care and decrease the incidence of HIV infection in the future in Utah.

Background and Need

Best Practice Strategies

In times of economic constraint and large-scale systems change, as is occurring in the U.S. health care system, evidence-based decision making is a preferred approach to maximize limited resources. "For a public health professional, evidence is some form of data-including epidemiologic (quantitative) data, results of program or policy evaluations, and qualitative data—for uses in making judgments or decisions," (Brownson, Fielding & Maylahn, 2009, p.177). For years, public health practitioners have regarded needs assessments as key in these decision-making processes. In this regard, the Utah Department of Health (UDOH) has effectively conducted targeted needs assessment processes in the HIV/AIDS field.

Screening, physical examination, diagnostic, ART, and behavioral interventions are all best practices for HIV treatment and care (Aberg et al., 2004). Once HIV-infected individuals are diagnosed, it is highly recommended that they quickly receive care and continue in care (Branson et al., 2006). Utilizing ART as part of comprehensive prevention requires that HIV-positive individuals receive and adhere to treatment to maintain viral suppression (Grassly et al., 2001). Furthermore, ART also reduces the risk of HIV transmission (Donnell, 2010). Behavioral interventions include general messages regarding risk reduction and should be provided at all clinical encounters, regardless of risk behaviors or the health care provider's perceived risk (Aberg et al., 2004).

Engagement of HIV-infected individuals in receiving HIV medical care is critical for individual health and the prevention of HIV transmission to others (Gardner et al., 2011). HIV-infected individuals who are engaged in HIV medical care have three main barriers to successful treatment with ART: 1) delay or failure to initiate therapy, 2) poor adherence to therapy, and 3) viral resistance to ART (Gardner et al., 2011). Despite these barriers, best practices have been established to engage HIV-positive individuals in regular HIV medical care and improve adherence to treatment (Gardner et al., 2011). A more recent best practice strategy addresses HIV treatment as prevention for HIV transmission through test-and-treat strategies (Gardner et al., 2011). Test-and-treat strategies for HIV prevention involve communities implementing expanded testing and earlier and better treatment coverage to markedly decrease ongoing HIV incidence and transmission, stemming the HIV epidemic (Das, 2010). However, incomplete engagement in HIV medical care is common in the U.S. and accounts for the largest proportion of HIV-infected individuals with detectable viral loads (Gardner et al., 2011). Improvements in the entire continuum of engagement in HIV medical care are required for test-and-treat strategies to substantially increase the proportion of HIV persons with undetectable viral loads (Gardner et al., 2011).

Case-management interventions are widely accepted as best practice and the current standard to increase initial linkage to HIV medical care (Gardner et al., 2011). The Health Resources and Services Administration (HRSA) identified case management as a priority for interventions designed to improve retention in HIV medical care (Tobias et al., 2007). Outreach activities are another best practice for engaging and retaining out-of-care persons in HIV medical care (Bradford, 2007). Outreach interventions exemplify strategies that simultaneously address several barriers to medical care of HIV-positive individuals (Gardner et al., 2011). Outreach

activities include mental health services, substance abuse treatment, transportation assistance, and housing assistance (Conviser & Pounds, 2002). The majority of HIV-infected individuals have a need for at least one support service (Katz et al., 2000). Increased case management contact is highly connected with lowering many unmet needs such as for home health care and emotional counseling (Katz et al., 2000). Such holistic approaches provide the best current hope for comprehensive management (Gardner et al., 2011).

Purpose of the Project

The purpose of this project is to conduct a needs assessment for people living with HIV/AIDS (PLWHA) to address unmet needs for the UDOH Ryan White Part B Program in Utah. Research and reporting of unmet needs in treatment and support care are performed by the program through a biannual needs assessment which is a requirement to receive federal funding from HRSA. This needs assessment will provide insight into how current services are being provided as well as determine unmet needs and barriers to HIV treatment, medical care, and support services for PLWHA in Utah. This information will assist HIV service agencies in making evidence-based decisions to improve health care and support services that impact the adoption of positive health behaviors among HIV-positive individuals and ultimately decrease the HIV infection rate in Utah. The improved program changes will hopefully lead to improved engagement, linkage, and retention of HIV individuals in medical care. This needs assessment report will serve as a resource to nonprofit and governmental organizations working with PLWHA as well as researchers, students, health care providers, and others who seek information regarding the needs of PLWHA in Utah. The report will be made available on the UDOH website.

Research Questions

Four main research questions will be analyzed in this needs assessment:

1. What are the medical treatments and care service needs of PLWHA in Utah?

2. What are the barriers to HIV medical care of PLWHA in Utah?

3. What are the support service needs (services which provide coordination for access to medical care and services that help meet basic or special HIV needs) of PLWHA in Utah?

4. What HIV-preventive behaviors of PLWHA in Utah require greater attention?

Methods

Research Design

This research used a pilot tested needs assessment survey to identify needs of adults living with HIV/AIDS in Utah. A convenience sample was obtained by distributing surveys through five HIV-related organizations and survey participants were offered a gift card as an incentive. The research design included a descriptive study design involving cross tabulations and frequencies. There were no exposure and outcome variables, control group, null and alternative hypotheses, or power considerations.

Study Setting

The research setting was limited to Utah. Although the majority of the organizations that distributed the survey are located within Salt Lake County, representation from various health districts and Utah counties was achieved and is presented in the participant demographic information section.

Sampling and Participants

Sample Selection & Eligibility Criteria

The target population for the study was PLWHA in Utah, 18 years of age or older. This included people of various races/ethnicities, refugees, pregnant women, mentally disabled people, economically and educationally disadvantaged people, and incarcerated people. The needs assessment survey was only available in English or Spanish so nonproficiency in these languages was an exclusion criteria. With a confidence level of 95% and a confidence interval (margin of error of plus or minus 5 percentage points) on a population of 2,614 PLWHA in Utah (based on the most recent data), a sample size of 335 was calculated as the target sample size for this needs assessment.

Sampling Methods/Recruitment

Originally, quota sampling, or nonprobability sampling, was selected as the sampling strategy. Quota sampling predetermines the number of participants desired (n=335) and then a nonrandom selection mechanism is utilized until the desired number of completed surveys is obtained. Quota sampling was initially designed so that the survey sample would represent the general population of PLWHA in Utah by gender, risk category, and race: males, females, MSM, injecting drug users (IDU), and whites. Quota sampling ensures the sample approximates the distribution of HIV cases in Utah by setting a target number of completed questionnaires with specific subgroups of the population of interest. The Communicable Disease Prevention Program (CDPP) at the UDOH raised concerns about not including any other race besides whites in the quota sampling strategy even though it would be difficult to obtain quotas for many races. Accordingly, it was decided to group the minority races together and add it as a quota stratum.

Stratified or random sampling was not used due to the short time frame to collect data, difficulty recruiting adequate participants, and inadequate access to all known HIV cases in Utah.

Although 335 participants was the goal for the sample, this level could not be reached during data collection. After five months of data collection, the survey was concluded with 284 responses. Therefore, purposeful convenience sampling was conducted similar to what has been done with all past needs assessments from the UDOH Ryan White Part B Program. A breakdown of the quotas that were planned as well as the amounts that were met is outlined in Table 1. Although quota sampling could not be achieved, four out of the six quota strata were met and the last two quotas were close to being met.

Table 1: Quota Stratums, Quotas to be Met, Final Survey Response Count, whether Quotas Were Met

Quota Stratums	Quotas to be Met (based on 335 total surveys originally planned):	Final Survey Response Count (based on 284 returned surveys)	Whether Quotas Were Met
Males	(86%): n=288	(85%): n=239	Didn't meet quota by 1%
Females	(14%): n=47	(15%): n=43	Met quota
Men who have sex with men (MSM)	(55% of males): Of the 288 males surveyed, 158 MSM	MSM (64%): n=174	Exceeded quota
Injecting Drug Users	(11%): Of the 288 males surveyed, 32 IDU. Of the 42 females surveyed, 5 IDU	IDU (12%): n=33	Met quota
Whites	(65%): n=218	(77%): n=216	Exceeded quota
Minorities	(35%): n=117	(26%): n=76	Didn't meet quota by 9%

Since human subjects were involved, researchers complied with Health and Human Service (HHS) requirements for the protection of human subjects. Risks to subjects were minimal in relation to anticipated benefits and the selection of subjects was equitable.

Researchers monitored data collection to ensure the safety of subjects. Safeguards were taken to protect the vulnerable population to protect the privacy of subjects and to maintain the confidentiality of data kept. Survey data could not be linked or traced back to a name or any other identifying information. All subject information was anonymous and confidential. Everyone involved in the research received the UDOH Health Insurance Portability and Accountability Act (HIPAA) training and followed HIPAA protocol. Institutional Review Board (IRB) approval was received from the UDOH at the beginning of August 2013. A Brigham Young University (BYU) IRB application was unnecessary since no data were collected from the BYU community or public schools. Therefore, the BYU IRB office deferred their review to the UDOH IRB with an authorization agreement. UDOH IRB approval documents were sent to and found to be acceptable by the BYU Office of Research & Creative Activities (ORCA) office.

Sampling Frame

Two-hundred and eighty-four individuals completed the needs assessment survey. Of the 284 responses, 281were used in the final data analysis. Three surveys were excluded from analysis because the question on age was not answered and therefore it couldn't be verified that they met the inclusion criteria of being at least 18 years of age. Four additional surveys did not include a response on the age question but were included in the final analysis because each of those respondents answered a different question in the survey indicating they lived in Utah for more than 18 years. Therefore, it was inferred that those respondents met the age inclusion criterion. In addition, three respondents did not answer the question related to whether they had HIV or AIDS which is also part of the inclusion criteria. However, these surveys were included in the final data analysis because each of those respondents answered a different question about how they acquired HIV.

Intervention and Materials

This study did not involve any physical measurements, measurements on biological samples, investigational treatments, interventions, outcomes, or adverse reactions to an intervention.

Instrumentation

Survey Development

There was no established questionnaire in the published literature for a needs assessment for PLWHA. A sample needs assessment survey found in the Ryan White HRSA Center for AIDS Research and Education (CARE) Act Needs Assessment Guide has been adapted over the years for each needs assessment conducted by the Ryan White Part B program. Therefore, a survey instrument was developed based on HRSA federal grant reporting requirements and constructs and the most recent 2011 needs assessment survey used by the Ryan White Part B Program. Survey modifications were also made based on feedback from partner agencies such as the CDPP at the UDOH including data they wanted to gather (e.g., some National HIV Prevention Program Monitoring and Evaluation [NHME] data variables about risk behaviors). Furthermore, the Hands United Program conducted a survey analysis on the 2011 needs assessment survey. Important survey improvement suggestions described in the analysis were applied while developing the current 2013 needs assessment survey instrument. As a result of the substantial number of changes and revisions made to the 2011 needs assessment survey, the final 2013 needs assessment survey reflected significant improvements making it more appropriate for current data needs. The 2013 Utah HIV/AIDS Needs Assessment Survey was a 15-page pamphlet containing 122 questions. It consisted of 114 multiple-choice/Likert scale questions and eight open-ended questions. Half of the open-ended questions simply asked for a numerical

response. In addition, 18 multiple-choice questions had possible open-ended follow-up questions depending on the question response. The broad topics included in the survey were medical care, case management, HIV risk behaviors, barriers to medical care; and client service importance, satisfaction, and need.

The survey went through several revisions following input from various UDOH employees. The survey and research methods expertise of Dr. Rosemary Thackeray, an Associate Professor at BYU, were also used to answer survey development questions. The survey was also translated into Spanish and revised by two Spanish-speaking UDOH employees to ensure accurate translation. Revisions were also made based on their edits.

Constructs and Variables

A construct is a label assigned to a group of behaviors or attributes that are not directly observable or measurable. The constructs defined for the needs assessment survey were medical care, case management, HIV risk behaviors, barriers to medical care, support services, and service need. First, medical care is defined as HIV medical help including help with medications, doctor visits, and lab tests. Case management is defined as timely coordination of medical care and support services including offering assistance with the Ryan White Part B Program semiannual recertification requirement, inclusive of AIDS Drug Assistance Program (ADAP) recertification. HIV risk behaviors include unprotected anal or vaginal sex and sharing intravenous equipment with an infected person. Barriers to medical care are the effects of structural, cognitive, physical, mental, and financial environments that keep PLWHA from obtaining care. Support services in this research study are defined as services which provide coordination for access to primary medical care as well as services that help HIV-positive residents meet basic needs and special needs related to HIV status (non-medical needs). These

services include support groups, case management, psychological counseling, women's health, inpatient/outpatient substance abuse treatment, food bank, transportation assistance, housing assistance, dental care, and help paying for insurance. Service need is defined as the extent to which HIV-positive individuals require a medical care or support service that is lacking or wanted.

The survey variables or items on the data collection instrument were medical care, case management, HIV risk behaviors, barriers to medical care; and client service importance, satisfaction, and need. Medical care and case management questions were asked through multiple-choice questions. Participants were also asked a series of behavioral questions to measure their involvement in certain risk behaviors through multiple-choice questions. Client satisfaction, need, and importance of HIV treatment and support services were assessed by participants rating each of the services on a Likert scale. The scale rating used for level of service need from highest to lowest was "need, sometimes need, do not need, and not applicable." The scale rating used for level of service importance from highest to lowest was "very important, important, neutral, not important, not very important, and not applicable." The scale rating used for level of service satisfaction from highest to lowest was "very satisfied, satisfied, neutral, dissatisfied, very dissatisfied, and not applicable." Treatment, medical care and support service categories that were rated include medical care, substance abuse services, case management, mental health services, food services, transportation, financial assistance, health education, housing, and dental care.

Informed Consent

Since no personally identifiable information was collected or written on the needs assessment survey and given the minimal risks to participants, the use of implied consent was

distributed with the survey instrument. The consent statement that appeared at the beginning of each survey reads, “This survey does not ask for your name, address, or other personal information that can identify you. You do not have to answer any question you do not want to. Any information you give will be kept confidential. By beginning the survey, you acknowledge that you have read this information and consent to participate, with the knowledge that you can end the survey at any time without penalty. There are no risks to participation in this study. If you would prefer to have someone read the survey to you, ask a survey administrator. If you have any questions about the survey, please contact the Utah Ryan White Part B Program at 801-538-6191 or RWP@utah.gov.”

Pilot Test

Once the survey was reviewed and finalized, the survey was pilot tested at the Utah AIDS Foundation (UAF) Food Bank (n=10) at the end of August 2013 for one week with about three visits to the food bank. Cognitive interviewing with set protocol was conducted with HIV-positive individuals at the food bank who voluntarily participated. Cognitive interviewing is a method to evaluate sources of response error in survey questionnaires (Willis, 1999). It is a common approach for identifying and correcting problems with survey questions (Beatty & Willis, 2007). Cognitive interviewing focused on the cognitive processes that respondents used to answer survey questions involving the comprehension, recall, decision, or response processes necessary to adequately answer survey questions. A draft survey was administered while additional verbal information about the survey responses was collected. This information was used to determine the quality of responses and to determine if survey questions were generating the information envisioned. There are two major types of cognitive interviewing methods, referred to as think-aloud interviewing and verbal probing (Willis, 1999). Think-aloud

motivational interviewing was selected to be used as part of the pilot test procedure. Subjects were asked to openly "think aloud" as they answered the survey questions. Interjections were only made occasionally to say "tell me what you're thinking" when the subject paused. Comments and notes were written up for each completed interview. Advantages of the think-aloud technique included minimal interviewer training requirements, an open-ended format, and no interviewer-imposed bias (Willis, 1999).

With the assistance of UAF service providers, ten volunteer subjects from the HIV target population were recruited and individually interviewed face-to-face in a private room at the end of August. Subjects were trained on what the think-aloud procedure was and how to perform it. The interviewer explained the importance of the subject thinking out loud as much as possible, voicing how they arrived at their answers, and voicing the problems they encountered in order for the interviewer to identify poor questions. This training involved careful practice at the start of the interviews to understand flow of verbalization and expression. Training included, "Try to visualize the place where you live, and think about how many windows there are in that place. As you count up the windows, tell me what you are seeing and thinking about" (Willis, 1999). Further training was unnecessary since everyone responded well to the training exercise. Once the interview with the draft survey began, interviewees were encouraged to provide specifics about what he/she was thinking. If the subject had difficulty thinking aloud, the interviewer would give prompts like, “Tell me what you’re thinking or what are you thinking about right now?” In addition, it was stressed to the interviewee that testing the questionnaire was the primary interest by identifying questions that were difficult to understand, hard to answer, or that made little sense (Willis, 1999).

Once interviews were completed and interviewer notes were compiled, the findings were discussed with the Ryan White Part B Program staff (Willis, 1999). An important beneficial result of cognitive interviewing involved detecting structural or logical problems like erroneous skip patterns, unclear layout, and other elements. Survey questions were modified when at least 50% of those interviewed voiced confusion or misunderstanding or if the interviewer sensed confusion or misunderstanding from the survey respondent. After convening with Ryan White Part B Program staff, it was decided that 50% would be an appropriate cut off because it represented at least half of the majority of pilot test participants. Thus, it was assumed that those survey elements would also be confusing for most of the HIV population. In addition to going through the survey, each person was asked if they thought the survey was too long given the gift card incentive. Eighty percent said the length of the survey was acceptable since they believed all the questions to be necessary. According to the cognitive interviews, it was estimated that the survey would take 30 minutes (on average) to complete. No questions were added or removed as a result of the pilot test but various changes were made to survey instructions, the wording of questions, and response options that created a clearer refined survey instrument.

Survey Printing

After survey revisions were made from the pilot test, the questionnaire was sent to the Utah Correction Industries (UCI) print shop for printing and preparation for mailing. Each envelope included the needs assessment survey, a postage paid return envelope, and a gift card slip for respondents to write their name and address for gift card remittance. The Ryan White Part B Program funded the needs assessment including printing costs and incentives. The needs assessment survey print order was delayed by the Ryan White Part B Program staff until November 2013 due to several grant application deadlines and the implementation of the Patient

Protection and Affordable Care Act. Once surveys were printed and envelopes were received in December 2013, they were ready to be distributed to the target population (n=335). About 1,100 English and 400 Spanish (1,500 total) surveys were ordered.

Data Collection

Data Collection Preparation

Before data collection began, organizations distributing the survey were informed about an upcoming needs assessment research in a presentation given at the Utah HIV Planning Group (UHPG) meeting in mid-November 2013 where various HIV stakeholders were present including Clinic 1A at the University of Utah, People with AIDS Coalition of Utah, Utah AIDS Foundation, Veterans Administration Clinic, and Northern Utah Coalition. Two weeks later, these organizations were reminded again about the needs assessment through email and asked to distribute the survey to their clients. One of these organizations, Clinic 1A at the University of Utah, had concerns about collaboration, the length and design of the survey, survey timing, and clinic space. For example, because of limited space for clients in the clinic to fill out a survey and the potential impact on patient care and workflow, it was agreed that clinics would distribute surveys and ask participants to finish the survey at home and return it via mail. With concerns resolved, clinic managers were ready to distribute the survey.

Survey Distribution

The Utah HIV/AIDS Needs Assessment was administered through the mail and in person through HIV agencies. First, the needs assessment survey was mailed to former and current clients of the Ryan White Part B Program. Contact information was obtained through a database records search. Two-hundred thirty six survey responses were collected in this manner. Since it is important to hear the needs of PLWHA that are both in and out of HIV medical care, mailing

surveys to all past and present clients allowed for representation from HIV individuals currently receiving HIV treatment and medical care as well as those who have missed appointments or dropped out.

Second, the needs assessment survey was administered to HIV clients/patients through the following partner agencies of the Ryan White Part B Program:

- Clinic 1A at the University of Utah Hospital
- People With AIDS Coalition of Utah (PWACU)
- Utah AIDS Foundation (UAF)
- Utah State Prison
- Utah Pride Center (UPC)
- Veterans Administration Clinic (VA)

Table 2 below shows the number of surveys given to each organization in both English and Spanish for survey distribution.

Table 2: Surveys
Distributed to Each Participating Organization & Number of Completed Surveys Returned from Each Organization

Distributing Organization	Surveys for Distribution in English	Surveys for Distribution in Spanish	Completed Surveys Returned
Ryan White Part B Program (mailed)	700	150	236
Veteran's Administration	50	0	0
People with AIDS Coalition of Utah	30	0	3
State Prison	19	1	7
Utah AIDS Foundation	90	15	22
Clinic 1A	200	100	16
Utah Pride Center	30	0	0
HIV specialty doctors	143	11	0

Each partner agency was given a document with instructions necessary to distribute the needs assessment survey including information about inclusion criteria for clients who could take the questionnaire, survey confidentiality, the quota sampling strategy, how to return completed surveys, and researcher contact information. Case managers and other HIV-related service providers within these agencies distributed the surveys to individuals with HIV who were receiving primary health care including a nurse at the state prison who distributed surveys to HIV-positive prisoners during their clinic time. Case managers and other HIV-related service providers from the various participating organizations mailed completed surveys to the Ryan White Part B Program or hand-delivered them to a Ryan White employee.

After four months of data collection, HIV specialty doctors and clinics throughout the state were recruited to reach more PLWHA with private insurance (and to represent those who likely have higher incomes) who were not enrolled in the Ryan White Part B Program and were not attending services of its partner agencies. Four HIV specialty doctors were recruited and provided surveys to distribute. However since data collection was terminated early, no surveys were returned in time to be included in the final data analysis. The Northern Utah Coalition and Planned Parenthood were contacted to assist with survey distribution but no response was received from them.

The first several hundred surveys that were mailed and distributed were not numbered beforehand due to clerical error by UDOH Ryan White Part B staff. Therefore, the origin of the distributing organization of these surveys is unknown. This likely led to an overestimation of surveys from this program and underestimation of surveys received from the other participating organizations. Once the mistake was realized, the rest of the surveys were numbered before being distributed to the remaining agencies. Thus, an assumption was made that the unnumbered

returned surveys were from the Ryan White Part B Program client database. This assumption was based upon the fact that several hundred surveys were sent from the client database and the other participating organizations likely did not return any completed surveys.

Survey Incentive

Since participants were asked to take a substantial amount of time to complete the survey, respondents were given a $10 Smith's gift card incentive for returning a completed survey. Only the state prisoners were not allowed to be given gift cards. All other survey participants who returned a survey were offered the Smith's gift card, regardless of the amount of survey completion. Since no identifiable information was collected on the survey, in order to distribute the gift card, the survey respondent wrote their name and address on a gift card slip distributed with each survey. The slips were not linked to or associated with survey responses. All of the slips with the mailing information were returned to the UDOH Ryan White Part B Program and respondents were mailed a gift card at the address provided.

Data Entry

An undergraduate public health intern from the University of Utah conducted data entry for every returned survey. A Qualtrics online version of the survey was developed to expedite data entry and decrease error while entering data. The intern used the Qualtrics survey link to enter data from each returned survey. A log of the names of individuals who completed the survey was also kept to ensure there was no respondent duplication. Data were collected from December 2013-May 19, 2014 and data were entered from January 16, 2014-May 19, 2014. During data collection, only research team members had access to raw data. During the data entry and analysis, the data were stored on locked computers until the report was complete. After the needs assessment report is complete, completed surveys will be shredded.

Data Cleaning

After data collection, data were cleaned, analyzed, and interpreted from May-June 2014. Once data entry was complete, the data in Qualtrics were exported into Excel for data cleaning. While reviewing the exported data file, several responses were checked by referring back to the original completed surveys. Data entry errors were found and corrected through this method. In addition, when the data were exported from Qualtrics into Excel, all of the questions with missing answers or those that were legitimately skipped, were blank slots in Excel. So data cleaning also included ensuring all blank question responses were given a value of 99. If open response questions had multiple responses, the categories were each added as a new column in Excel so every slot had only one possible response. The last part of data cleaning included excluding the three surveys that could not be verified for meeting the inclusion criteria.

Data Analysis

A total of 284 surveys were returned and entered into Qualtrics, and of those, 281 surveys were entered into IBM SPSS Statistics, Version 22 for data analysis. The 10 responses collected during the pilot test were included in the final analysis. The research study included a descriptive study design involving cross tabulations and frequencies according to target sub-populations (women, men, whites, minorities, IDU, MSM, heterosexuals, urban, and nonurban) and for the entire sample. The subcategories were chosen because they are at-risk groups of PLWHA of interest in Utah. These subcategories have also been researched in past needs assessments. This research involved both quantitative and qualitative data analysis. Qualitative data are meant to provide context and give further insight into the concerns of PLWHA. Twenty-one survey questions had open response options where respondents could express their feedback to improve services. Qualitative data from open response questions were changed into categories or ranges

for easier data analysis. Seven survey questions required a numerical response which was later changed into categories with ranges of numbers for easier data analysis. Each survey question, original survey responses, and modified categories are displayed in Table 50 in the Appendix. No power calculations were computed since there was not a quantitative effect for post-hoc analysis to test. In addition, there are no exposure and outcome variables, a control group for comparison, or null and alternative hypothesis. The survey results cannot be generalized because the research methodology did not include randomization.

Results

The results of each research question are presented here and are organized by section and subsections. The most significant results from each table are highlighted in the text. Tables provide results from the entire sample or by subcategory including women, men, whites, minorities, IDU, MSM, heterosexuals, urban, and nonurban.

Participant Demographic Information

Several survey questions asked demographic questions that describe the sample. Therefore, this section is divided into fifteen subsections: Primary Demographic Information, AIDS, LGBT Community, Significant Other, Pregnancy, Dependents, Time in Utah, Working Situation, Refugee, Prison, Living Arrangement, Languages, HIV Diagnosis & Cause, Co-infections, and TB.

Primary Demographic Information

Primary demographic information results displayed in Table 3 include: gender, age, race and ethnicity, exposure category, income, education level, county, and rural/urban. Tables 4 and 5 ask where black survey respondents were born and the specific country. For the race/ethnicity question, respondents could list more than one answer. All percentages represent the percentage

of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The vast majority of respondents were male (84.3%) and white (76.5%). Of black respondents, most were born in the United States (5%). The sample included 28.3% of minorities. The sample had an average age of 46 with the majority between the ages of 40 and 59 (57.6%). For exposure category, 61.2% were MSM and 11.7% were IDU. Although most of the sample had some college education (43.4%), most also had incomes below $17,236 (31.7%). Most of the sample lived in Salt Lake County (74%) and in an urban area (87.2%).

Table 3: Primary Demographic Information

Demographic Category	Demographic Subcategory	Number	Percent	Min	Max	Mean
Gender	Males	237	84.3%			
	Females	42	14.9%			
	Transgender	1*	.4%			
Age	Average Age	277	-	24	88	46
	Ages 18-29	22	7.8%			
	Ages 30-39	67	23.8%			
	Ages 40-49	81	28.8%			
	Ages 50-59	81	28.8%			
	Ages 60-69	28	10%			
	Ages 70-79	1*	.4%			
	Ages 80-89	1*	.4%			
Race and Ethnicity	American Indian or Alaska Native	3*	1.1%			
	Asian	2*	.7%			
	Native Hawaiian or Pacific Islander	10	3.6%			
	Black	21	7.5%			
	Hispanic or Latino	39	13.9%			
	White/Caucasian	215	76.5%			
	Other	4*	1.4%			
Exposure Category	Injecting Drug User (IDU)	33	11.7%			

	Homosexual-Gay: Men who have Sex with Men (MSM)	172	61.2%			
	Homosexual-Lesbian	2*	.7%			
	Heterosexuals	61	21.7%			
	Bisexuals	37	13.2%			
Income Level	$1 to $11,490	117	41.6%			
	$11,491 to $17,235	50	17.8%			
	$17, 236 to $22,980	39	13.9%			
	$22,981 to $28,725	31	11%			
	$28,726 to $34,470	18	6.4%			
	$34,471 to $40,215	8	2.8%			
	$40,216 to $45,960	4*	1.4%			
	$45,961 and above	9	3.2%			
Education Level	Never attended school (Only kindergarten)	1*	.4%			
	Grades 1-8 (Elementary)	12	4.3%			
	Grades 9-12 but did not graduate	20	7.1%			
	Grade 12 or GED (High school graduate)	58	20.6%			
	College 1-3 years (Some college/technical school)	122	43.4%			
	College 4 years (College graduate)	42	14.9%			
	Post-graduate education	23	8.2%			
Counties	Salt Lake County (mostly urban)	208	74%			
	Utah County (mostly urban)	14	5%			
	Washington County (mostly urban)	6	2.1%			
	Davis County (mostly urban)	13	4.6%			
	Weber County (mostly urban)	16	5.7%			
	Sevier County	1*	.4%			
	Tooele County	5	1.8%			
	Box Elder County	3*	1.1%			
	Kane County	1*	.4%			
	Cache County	1*	.4%			
	Grand County	2*	.7%			

	Summit County	4*	1.4%			
	Duchesne County	1*	.4%			
	County outside of Utah (CA and NV)	2*	.7%			
Urban/Rural	Urbanized Area	245	87.2%			
	Non-urbanized Area	15	5.3%			
	Inconclusive/don't know	21	7.5%			

*Cell size less than 5

Table 4: Black Place of Birth

If black, where were you born? (n=19)		
	Number	Percent
United States	14	5.0%
African country	2*	.7%
Other country	3*	1.1%

*Cell size less than 5

Table 5: Other Races Countries

Other (please specify) (n=3)		
	Number	Percent
Middle East	2*	.7%
Haitian	1*	.4%

*Cell size less than 5

AIDS

Survey respondents were asked if they had been diagnosed with AIDS (the most advanced stage of HIV) by a doctor. For those who answered yes, a follow-up question asked about the year of diagnosis. Results are displayed in Tables 6 and 7. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The majority of respondents did not have AIDS. Of the 31.3% that did, most were diagnosed in the last 14 years (20.6%).

Table 6: Diagnosed with AIDS

Has your doctor told you that you have AIDS? (n=273)		
	Number	Percent
Yes	88	31.3%
No	185	65.8%

Table 7: AIDS Diagnosis Year

Yes- what year? (n=80)		
	Number	Percent
2010-2014	24	8.5%
2005-2009	20	7.1%
2000-2004	14	5.0%
1995-1999	12	4.3%
1998-1994	4*	1.4%
1993-1989	3*	1.1%
1988-1984	3*	1.1%

*Cell size less than 5

LGBT Community

Survey respondents who were not heterosexual were asked if they felt part of a cohesive lesbian, gay, bisexual, transgender (LGBT) community. Results are displayed in Table 8. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Most respondents answered no (38.4%) or sometimes (20.3%).

Table 8: Part of LGBT Community

Do you feel part of a cohesive/unified LGBT community? (n=215)		
	Number	Percent
Yes	50	17.8%
No	108	38.4%
Sometimes	57	20.3%

Significant Other

Survey respondents were asked if they had a partner, spouse or significant other. Results are displayed in Table 9. All percentages represent the percentage of the entire sample.

Percentages might not add up to 100% due to the exclusion of nonresponses. The results were fairly evenly distributed between yes and no responses but most respondents answered no (54.1%).

Table 9: Significant Other

Do you have a partner, spouse or significant other? (n=279)		
	Number	Percent
Yes	127	45.2%
No	152	54.1%

Pregnancy

Survey respondents were asked if they were currently pregnant. Results are displayed in Table 10. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. No respondents were pregnant but all answered not applicable to me or no.

Table 10: Current Pregnancy

Are you pregnant now? (n=274)		
	Number	Percent
Not applicable to me	177	63.0%
No	97	34.5%

Dependents

Survey respondents were asked to write down the number of dependents they claim when filing taxes (whether they file taxes or not). Results are displayed in Table 11. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the

exclusion of nonresponses. The vast majority of respondents had one dependent (60.5%). The second most common answer was no dependents (16.4%).

Table 11: Dependents Number

Write the number of dependents you claim when filing taxes. (n=264)		
	Number	Percent
0	46	16.4%
1	170	60.5%
2	25	8.9%
3	12	4.3%
4	6	2.1%
5	3*	1.1%
8	1*	.4%
9	1*	.4%

*Cell size less than 5

Time in Utah

Survey respondents were asked how long they have lived in Utah. Results are displayed in Table 12. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The most common answer was between 0-10 years (23.1%) with the second most common answer being 11-20 years (19.6%).

Table 12: Time in Utah

How long have you lived in Utah? (n=273)		
	Number	Percent
0-10 years	65	23.1%
11-20 years	55	19.6%
21-30 years	48	17.1%
31-40 years	51	18.1%
41-50 years	29	10.3%
51-60 years	21	7.5%
61-70 years	3*	1.1%
71-80 years	1*	.4%

*Cell size less than 5

Working Situation

Survey respondents were asked about their current working situation. Respondents could list more than one answer. Results are displayed in Table 13. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The three most common answers were that they were unable to work/on disability (30.2%), they work full time or 40 hours a week (25.3%), and they work part time or less than 40 hours a week (21.7%). The least common answer was being a homemaker (5.7%).

Table 13: Working Situation

Which best describes you?			
		Number	Percent
I work full time (40 hours/week) (n=199)	Yes	71	25.3%
	No	128	45.6%
I work part time (<40 hours/week) (n=185)	Yes	61	21.7%
	No	124	44.1%
I am self-employed (n=176)	Yes	34	12.1%
	No	142	50.5%
I am out of work for more than 1 year (n=177)	Yes	54	19.2%
	No	123	43.8%
I am out of work for less than 1 year (n=163)	Yes	25	8.9%
	No	138	49.1%
I am unable to work/on disability (n=195)	Yes	85	30.2%
	No	110	39.1%
I am a homemaker (n=164)	Yes	16	5.7%
	No	148	52.7%
I am a student (n=164)	Yes	20	7.1%
	No	144	51.2%
I am retired (n=165)	Yes	19	6.8%
	No	146	52.0%

Refugee

Survey respondents were asked if they were a refugee. For those who answered yes, a follow-up question asked for their country of origin. Results are displayed in Tables 14 and 15. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Only two respondents (.7%) answered they were a refugee and only one reported their country of origin which was Conga (.4%).

Table 14: Refugee

Are you a refugee? (n=279)		
	Number	Percent
Yes	2*	.7%
No	277	98.6%

*Cell size less than 5

Table 15: Refugee Country of Origin

If yes, what country of origin?		
	Number	Percent
Conga	1*	.4%

*Cell size less than 5

Prison

Survey respondents were asked if they were currently in prison or jail. For those who answered yes, a follow-up question asked for their length of time in prison or jail. Results are displayed in Tables 16 and 17. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Seven respondents (2.5%) answered they were in prison. Most had been there for 1-5 years (1.1%)

Table 16: Currently in Prison

Are you currently in prison or jail?(n=276)		
	Number	Percent
Yes	7	2.5%
No	269	95.7%

Table 17: Prison Time

If yes, for how long? (n=7)		
	Number	Percent
0-12 months	1*	.4%
1-5 years	3*	1.1%
11-20 years	1*	.4%
21-30 years	2*	.7%

*Cell size less than 5

Living Arrangement

Survey respondents were asked to describe their living arrangement during the last 12 months. For those who answered they had been in prison or jail in the last 12 months, a follow-up question asked if they were sexually active while there. Respondents could list more than one answer. Results are displayed in Tables 18 and 19. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The majority of respondents have rented a home (57.7%) or lived with friends or family (34.5%) in the last year. The least common responses included: lived in a halfway house (1.8%) and lived in a drug treatment center (2.8%). Women had the highest percentage of renting a home (71.42%) and the lowest percentage of living in a drug treatment center (0%). Minorities had the highest percentage of living in a halfway house (7.14%). IDU had the lowest percentage of owning a home (6.89%) and the highest percentages for living in a hotel or motel (16.66%), being homeless or living in a shelter (29.03%), and for being in prison or jail (26.66%). Nonurban respondents had the highest percentage of owning a home (36.36%), living with friends or family (77.77%), and the lowest percentage of being homeless or living in a shelter (1.25%). Of those who responded they were in prison or jail in the past 12 months, the majority were sexually active while there (14.6%).

Table 18: Living Situation

In the past 12 months, have you...								
	Owned a home? (%) (n=240)	Rented a home? (%) (n=259)	Lived in a hotel or motel? (%) (n=230)	Lived with friends or family? (%) (n=241)	Lived in a drug treatment center? (%) (n=228)	Been homeless or lived in a shelter? (%) (n=230)	Lived in a halfway house? (%) (n=228)	Been in prison or jail? (%) (n=229)
Entire Sample	20.3%	57.7%	3.6%	34.5%	2.8%	6%	1.8%	8.2%
Women	20.58%	71.42%	3.33%	50%	0%	9.37%	0%	6.45%
Men	24.39%	61.43%	4.52%	38.94%	4.06%	7.10%	2.53%	10.65%
Whites	25%	61.16%	3.24%	37.69%	3.27%	7.06%	.54%	8.19%
Minorities	19.35%	64.17%	7.14%	49.20%	5.35%	7.01%	7.14%	15.78%
IDU	6.89%	65.62%	16.66%	67.74%	13.33%	29.03%	3.33%	26.66%
MSM	25.33%	61.96%	3.40%	35.52%	2.75%	3.44%	.68%	7.58%
Heterosexuals	20.40%	69.09%	6.38%	50%	2.12%	8.16%	4.2%	6.38%
Urban	22.64%	64.78%	2.91%	37.38%	2.94%	6.8%	1.47%	9.75%
Nonurban	36.36%	54.54%	12.5%	77.77%	12.5%	1.25%	0%	12.5%

Table 19: Sexual Activity in Prison

If you were in prison or jail in the past 12 months, were you sexually active while there? (n=44)		
	Number	Percent
Not applicable, I was not in prison or jail	3*	1.1%
Yes	41	14.6%

*Cell size less than 5

Languages

Survey respondents were asked if they spoke English, Spanish or another language. For those who spoke another language besides English or Spanish, respondents could list other languages. Results are displayed in Table 20. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The majority of respondents spoke English (93.6%). Nearly 19% spoke Spanish and about 8% spoke another language.

Table 20: Languages

What languages do you speak?			
		Number	Percent
English (n=267)	Yes	263	93.6%
	No	4*	1.4%
Spanish (n=202)	Yes	52	18.5%
	No	150	53.4%
Other (n=33)	Yes	21	7.5%
	No	12	4.3%
Other specified (n=25)	European language (French, German, Italian, Portuguese)	18	6.4%
	Asian language (Thai, Japanese, Chinese, Burmese)	4*	1.4%
	Creole	1*	.4%
	African language (Afrikaans, Lingala, Kiwanda, Swahili)	2*	.7%

*Cell size less than 5

HIV Diagnosis & Cause

Survey respondents were asked how long it had been since they learned they were HIV positive, whether they were diagnosed with HIV in Utah, and how they contracted HIV. Respondents could list more than one answer for the question asking how they acquired HIV. For those who were diagnosed with HIV outside of Utah, respondents could write what state they were diagnosed. Results are displayed in Tables 21, 22, 23, and 24. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Nearly half (49.8%) of respondents learned they were HIV-positive 10 or more years ago followed by 26% who found out 5-9 years ago. Almost 71% were diagnosed in Utah and most respondents got HIV by having sex with a man (63.3%). Sixteen percent did not know how they got HIV. Of those who were diagnosed with HIV outside of Utah, most were diagnosed in California (10%).

Table 21: HIV Diagnosis Timing

How long ago did you learn you were HIV-positive? (n=279)		
	Number	Percent
Less than 12 months	15	5.3%
1-4 years	47	16.7%
5-9 years	73	26.0%
10 years or more	140	49.8%
I do not remember	4*	1.4%

*Cell size less than 5

Table 22: Utah HIV Diagnosis

Were you diagnosed with HIV in Utah? (n=270)		
	Number	Percent
Yes	198	70.5%
No	72	25.6%

Table 23: Other State for HIV Diagnosis

If no, in what state? (n=63)		
	Number	Percent
California	28	10.0%
New York	4	1.4%
Texas	1*	.4%
Nevada	5	1.8%
London	1*	.4%
Florida	2*	.7%
Indiana	1*	.4%
Arizona	6	2.1%
Pennsylvania	2*	.7%
Washington	4*	1.4%
Colorado	2*	.7%
Puerto Rico	1*	.4%
New Jersey	1*	.4%
Oregon	1*	.4%
Africa	1*	.4%
Georgia	1*	.4%
Illinois	1*	.4%
Virginia	1*	.4%

*Cell size less than 5

Table 24: Cause of HIV

How did you get HIV?			
		Number	Percent
I do not know (n=68)	Yes	45	16.0%
	No	22	7.8%
	Maybe	1*	.4%
Having sex with a man (n=228)	Yes	178	63.3%
	No	18	6.4%
	Maybe	32	11.4%
Having sex with a woman (n=149)	Yes	12	4.3%
	No	130	46.3%
	Maybe	7	2.5%
Needles or tattoo (n=144)	Yes	18	6.4%
	No	106	37.7%
	Maybe	20	7.1%
Transfusion/blood products (n=143)	Yes	5	1.8%
	No	132	47.0%
	Maybe	6	2.1%
Perinatal-mother to infant during birth (n=139	No	138	49.1%
	Maybe	1*	.4%

*Cell size less than 5

Co-Infections

Since people living with HIV/AIDS can have co-infections with other infectious diseases, survey respondents were asked to indicate whether or not they had ever tested positive for any of the following diseases: hepatitis C, hepatitis B, chlamydia, gonorrhea, syphilis, HPV/genital warts, and herpes. Respondents could select more than one answer. Results are displayed in Table 25. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 26% of respondents reported testing positive for gonorrhea, nearly 23% reported testing positive for herpes, and about 22% reported testing positive for chlamydia. IDU had the highest percentages across all infectious diseases except herpes where women had the highest percentage (35.13%).

Table 25: Co-infections/Diseases

Have you ever tested positive for any of the following diseases?							
	Hepatitis C (n=263)	Hepatitis B (n=261)	Chlamydia (n=260)	Gonorrhea (n=257)	Syphilis (n=256)	HPV/Genital Warts (n=255)	Herpes (n=259)
	Yes (%)	Yes (%)	Yes (%)	Yes (%)	Yes (%)	Yes (%)	Yes (%)
Entire Sample	19.60%	14.60%	22.10%	25.60%	21.70%	19.90%	23.10%
Women	23.68%	2.7%	21.05%	10.81%	0%	21.62%	35.13%
Men	20.08%	17.48%	23.98%	30.59%	27.39%	21.65%	23.07%
Whites	19.41%	17.07%	25.98%	30.34%	23.88%	24%	26.60%
Minorities	20%	13.04%	17.14%	21.73%	22.05%	16.17%	26.47%
IDU	42.42%	19.35%	46.87%	38.70%	38.70%	36.66%	33.33%
MSM	17.57%	19.51%	28.83%	36.02%	30.06%	23.60%	27.16%
Heterosexuals	30.35%	10.34%	10.71%	5.55%	5.66%	14.28%	23.21%
Urban	21.30%	15.85%	24.66%	29.33%	25.44%	21.26%	23.66%
Non-urban	7.14%	13.33%	7.14%	21.42%	14.28%	26.66%	26.66%

Tuberculosis (TB)

Survey respondents were asked if they had been tested for TB. For those who answered yes, they were asked a follow-up question of the last time they were tested. For those who answered they had tested positive for TB, they were asked whether they were treated for active TB (contagious TB disease). Results are displayed in Tables 26, 27, and 28. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Approximately 85% of respondents answered they had been tested for TB and of those, nearly half had been tested within the last year. For those who had been tested, about 63% were not positive.

Table 26: TB Testing

Have you been tested for tuberculosis (TB)? (n=280)		
	Number	Percent
Yes	239	85.1%
No	27	9.6%
Don't know	14	5.0%

Table 27: Last TB Test

When was the last time you were tested for TB? (n=236)		
	Number	Percent
Within the last year	140	49.8%
1-4 years ago	71	25.3%
5-10 years ago	14	5.0%
10+ years ago	11	3.9%

Table 28: Treatment for TB Positive Test

If you tested positive for TB, were you treated for active TB? (n=220)		
	Number	Percent
My test results were not positive	178	63.3%
Yes	17	6.0%
No	25	8.9%

Medical Treatment and Medical Care Needs of PLWHA in Utah

Several survey questions addressed the first research question related to HIV medical treatment and medical care needs of PLWHA in Utah. Therefore, this section is divided into five subsections: Medical Care Place and Timing, HIV Medications, Medical Care Payment, Lab Tests, Health Care Provider Treatment, Medical Care Gaps, and Medical Treatment and Medical Care Service Ratings.

Medical Care Place and Timing

Survey respondents were asked whether they have a place where they receive medical care. Medical care was defined as receiving a doctor visit, lab tests, and treatment. The results are displayed in Table 29 by subcategory. Ninety-six percent of respondents reported a medical home with little variation between demographic subgroups. Only one respondent responded he/she didn’t have medical care (.4%). When comparing subgroups, the lowest percentage was MSM (95.88%) and the highest percentage was heterosexuals (98.36%).

Table 29: Place for HIV Medical Care

Do you have one place you go for HIV medical care? (n=279)		
	Yes (%)	No (%)
Entire Sample (n=279)	95.70%	3.60%
Women (n=42)	97.61%	2.38%
Men (n=235)	96.17%	3.82%
Whites (n=213)	96.29%	3.70%
Minorities (n=79)	96.20%	3.79%
IDU (n=33)	96.29%	3.70%
MSM (n=170)	95.88%	4.11%
Heterosexuals (n=61)	98.36%	1.63%
Urban (n=245)	95.91%	4.08%
Nonurban (n=14)	100%	0%

In addition, participants were asked how quickly they received medical care after being diagnosed with HIV. Results are displayed in Table 30. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The majority of respondents sought medical care within two weeks of learning they were HIV-positive (76.9%) and almost 15% of respondents received medical care between six months and a year after receiving their HIV-positive result.

Table 30: Seeking Medical Care Timing after Diagnosis

When you learned you were HIV positive, how soon did you seek medical care? (n=274)		
	Number	Percent
Within 1 week	55	19.60%
Within 2 weeks	161	57.30%
Within 3 months	16	5.70%
Within 6 months	11	3.90%
Within a year	30	10.70%
I have not had medical care	1*	0.40%

*Cell size less than 5

HIV Medications

Survey respondents were asked whether they are currently taking HIV medications. The results are displayed in Table 31 by subcategory. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of non-responses. With one exception, all subcategories reported high levels for current intake of HIV medications. When comparing subgroups, the highest percentage not taking medications was IDU (12.12%) followed by nonurban (7.14%). The lowest percentages were heterosexuals (100%) followed by women (97.61%).

Table 31: Taking HIV Medications

Are you taking HIV medications now? (n=279)		
	Yes (%)	No (%)
Entire sample (n=279)	94.30%	5.00%
Women (n=42)	97.61%	2.38%
Men (n=235)	94.89%	5.10%
Whites (n=213)	94.83%	5.16%
Minorities (n=79)	96.20%	3.79%
IDU (n=33)	87.87%	12.12%
MSM (n=170)	94.70%	5.29%
Heterosexuals (n=61)	100%	0%
Urban (n=245)	94.69%	5.30%
Nonurban (n=14)	92.85%	7.14%

The survey respondents who are taking HIV medications were asked how often they miss doses or stop taking their HIV medications (up to four) whether intentionally or not. The results are displayed in Table 32 by subcategory. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. A total of

28.1% of respondents skip medications at least once a year. All IDU who responded to the question (100%) reported skipping/stopping medications. With regard to frequency of missed medications, most IDU skip taking an HIV medication every week (42.85%) or every month (32.14%). Women had the highest percentage of never skipping or stopping medications (19.44%). Almost 12% of minorities skipped a medication every day while almost 31% of nonurban Utah residents skipped every other month and about 38% skipped once a year.

Table 32: Skipping/Stopping HIV Medications

How often do you miss doses or stop taking HIV meds? (n=247)						
	Every day (%)	Every week (%)	Every month (%)	Every other month (%)	Once a year (%)	Never- I do not skip/stop (%)
Entire Sample (n=247)	3.20%	7.50%	17.80%	18.50%	28.10%	12.80%
Women (n=36)	5.55%	16.66%	11.11%	22.22%	25%	19.44%
Men (n=210)	3.33%	7.14%	21.90%	20.95%	32.85%	13.80%
Whites (n=193)	1.55%	8.80%	20.20%	22.79%	32.12%	14.50%
Minorities (n=68)	11.76%	5.88%	20.58%	16.17%	30.88%	14.70%
IDU (n=28)	3.57%	42.85%	32.14%	3.57%	17.85%	0%
MSM (n=156)	2.56%	5.76%	20.51%	21.79%	35.25%	14.10%
Heterosexuals (n=51)	7.80%	13.72%	13.72%	15.68%	31.37%	17.64%
Urban (n=216)	3.24%	6.94%	21.75%	20.83%	31.94%	15.27%
Non-urban (n=13)	0%	7.69%	15.38%	30.76%	38.46%	7.69%

Medical Care Payment

Survey respondents were asked how they pay for HIV medical care including HIV medications. The results are displayed in Table 33 by subcategory. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Of the six response options to pay for medical care, a majority (66.5%) used the Ryan White Part B Program, including ADAP services. Only 5.3% of respondents used Utah's Comprehensive Health Insurance Pool (HIPUtah); HIPUtah was discontinued December 31,

2013. All IDU and nonurban respondents (100%) reported using some other way to pay for medical care. Every nonurban respondent (100%) also reported using Ryan White Part B. Furthermore, when comparing subcategories, nonurban respondents had the highest percentages of every payment method for medical care except Medicaid, of which heterosexuals were the highest reporting group (53.57%).

Table 33: Payment Methods for Medical Care

In which ways do you pay for HIV medical care?						
	Medicaid (%) (n=130)	Medicare (%) (n=133)	Private/Employer health insurance (%) (n=135)	State High Risk Insurance Program (HIPUtah) (%) (n=111)	Ryan White Program including [ADAP] (%) (n=214)	Other (%) (n=37)
Entire Sample (n=214)	16.00%	17.10%	18.50%	5.30%	66.50%	9.60%
Women	45%	36.36%	18.75%	0%	84.37%	66.66%
Men	33.02%	36.36%	41.52%	15.78%	87.84%	73.33%
Whites	34.90%	38.18%	39.44%	14.28%	85.97%	73.07%
Minorities	31.03%	34.48%	35.29%	8%	90.16%	80%
IDU	27.77%	25%	31.25%	0%	87.50%	100%
MSM	28.04%	34.48%	43.61%	16.43%	88.14%	68.42%
Heterosexuals	53.57%	44%	27.27%	5%	84.44%	60%
Urban	32.77%	35.24%	37.39%	12.62%	86.45%	69.69%
Non-urban	33.33%	66.66%	57.14%	40%	100%	100%

Indicators of Care

Survey respondents were asked if they had a CD4 count, viral load test, or ART within the past 12 months. The results are displayed in Table 34 by subcategory. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. One-hundred percent of IDU and nonurban residents reported receiving a CD4 count in the last year. All nonurban respondents (100%) also reported receiving

a viral load test. Heterosexuals had the lowest percentage of receiving a CD4 count (95%) and viral load test (94.73%). For ART, women had the lowest percentage (90%) while men had the highest percentage (94.27%).

Table 34: Lab Tests in the Last Year

In the past 12 months, have you had any of the following?			
	CD4 Count (white blood cells that fight infection) (%) (n=275)	Viral load test (%) (n=270)	Antiretroviral therapy (ART) (medications to fight HIV) (%) (n=268)
Entire sample (n=275)	95.40%	94.00%	89.00%
Women	97.61%	95%	90%
Men	97.40%	98.25%	94.27%
Whites	98.08%	98.55%	94.14%
Minorities	96.20%	96%	90.78%
IDU	100%	96.87%	90.32%
MSM	98.21%	98.79%	93.33%
Heterosexuals	95%	94.73%	93.10%
Urban	97.09%	97.89%	93.64%
Nonurban	100%	100%	92.85%

Survey respondents were given the opportunity to explain why they had not received a CD4 count, viral load, or ART in the last 12 months. Respondents could list more than one answer. The results are displayed in Table 35. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. No insurance was listed as a reason for not having a CD4 count, viral load count, or ART in the last 12 months (1.2%). The top reasons for not receiving ART were that they were not taking medications/they weren't prescribed any medications (1.1%) followed by they do not like taking medications (.7%).

Table 35: Reason for No Lab Tests in the Last Year

Why have you not had a….? (n=11)			
Open-responses		Number	Percent
CD4 count (n=2)	No insurance	1*	0.40%
	Couldn't afford doctor visits	1*	0.40%
Viral load (n=3*)	No insurance	1*	0.40%
	Don't like taking meds	1*	0.40%
	I'm undetectable	1*	0.40%
Antiretroviral Therapy (ART) (n=9)	No insurance	1*	0.40%
	Don't like taking meds	2*	0.70%
	Counts good/undetectable	1*	0.40%
	Not taking meds/not prescribed	3*	1.10%
	I don't know	1*	0.40%
	In hospice	1*	0.40%

*Cell size less than 5

Survey respondents were specifically asked what their last CD4 count and viral loads were as well as what ART medications they take. For ART medications, respondents could list more than one medication. The results are displayed in Tables 36 and 37. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The most frequently reported CD4 count was 500 or above (40.2%), while 12.8% reported they did not know or did not remember what their CD4 count was. More than half of respondents reported an undetectable viral load (55.2%) and 5.7% responded not knowing their viral load. Of the respondents on ART, the three most commonly prescribed ART medications were Truvada (30.6%), Atripla (21.70%), and Norvir (21%).

Table 36: Last Lab Tests Results

What was your last….?			
		Number	Percent
CD4 count (n=219)	<200	21	7.50%
	200-349	17	6.00%
	350-499	32	11.40%
	500+	113	40.20%
	Don't know/don't remember	36	12.80%
Viral load (n=229)	Detectable	58	20.60%
	Undetectable	155	55.20%
	Don't know/don't remember	16	5.70%

Table 37: ART Medications Taken

Which ART medications do you take? (n=222)		
	Number	Percent
Atripla	61	21.70%
Stribild	12	4.30%
Isentress	42	14.90%
Truvada	86	30.60%
Reyataz	39	13.90%
Norvir	59	21.00%
Epivir	2*	0.70%
Tivicay	4*	1.40%
Epzicom	19	6.80%
Stiruv	3*	1.10%
Prezista	16	5.70%
Intelence	3*	1.10%
Kaletra	12	4.30%
Complera	9	3.20%
Viramune	10	3.60%
Selzentry	1*	0.40%
Sustiva	13	4.60%
Trizivir	2*	0.70%
Prevestatin	1*	0.40%
Combivir	11	3.90%
Ziagen	2*	0.70%
Lamivudine	1*	0.40%
Viread	7	2.50%

Atazanavir	2*	0.70%
Emtriva	2*	0.70%
Ritonavir	2*	0.70%
Tenofovir	2*	0.70%
Abacavir	1*	0.40%
Acyclovir	1*	0.40%
Baraclude	1*	0.40%
Emtricitabine	1*	0.40%
Aptile	1*	0.40%
Don't know/don't remember	5	1.80%

*Cell size less than 5

Health Care Provider Treatment

Survey respondents were asked if they ever felt treated poorly at their health care provider's office. For those who answered yes, a follow-up question asked about the reasons why they felt this way. Under other reasons for feeling mistreated by a health care provider, respondents could list more than one answer. Results are displayed in Tables 38 and 39. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The vast majority of respondents did not feel treated poorly (89%) but about 10% felt they were treated poorly. The top three reasons respondents listed for their poor treatment was their income (3.6%), their sexual attraction (2.8%), or another reason (4.6%) such as a rude/uncompassionate doctor.

Table 38: Treated Poorly at Health Care Provider's Office

Did you ever feel treated poorly at your health care provider's office? (n=279)		
	Number	Percent
Yes	29	10.30%
No	250	89.00%

Table 39: Reasons for Poor Treatment at Health Care Provider's Office

For which reason(s) did you feel treated poorly at your health care provider's office? (n=31)			
		Number	Percent
My race/ ethnicity (n=18)	Yes	3*	1.10%
	No	15	5.30%
My age (n=18)	Yes	5	1.80%
	No	13	4.60%
My gender/sex (n=17)	Yes	1*	0.40%
	No	16	5.70%
My sexual attraction (n=18)	Yes	8	2.80%
	No	10	3.60%
My drug use (n=18)	Yes	4*	1.40%
	No	14	5.00%
My immigration status (n=18)	Yes	3*	1.10%
	No	15	5.30%
My difficulty speaking English (n=18)	Yes	1*	0.40%
	No	17	6.00%
My HIV status (n=19)	Yes	6	2.10%
	No	13	4.60%
My income/ money I make (n=21)	Yes	10	3.60%
	No	11	3.90%
Where I live (n=17)	Yes	5	1.80%
	No	12	4.30%
Other (n=17)	Yes	13	4.60%
	No	4*	1.40%
Other Specified (n=15)	Rude/ uncompassionate doctor	8	2.80%
	My mental/emotional health/status	2*	0.70%
	Being a prisoner	1*	0.40%
	Couldn't keep appointment for being late	1*	0.40%
	Rude/mean cm	2*	0.70%
	No waiting area privacy	1*	0.40%

*Cell size less than 5

Medical Care Gaps

Survey respondents were asked if there ever was a time when they were not receiving HIV medical care since diagnosis/treatment. For those who answered yes, a follow-up question asked about the reasons for their gap in medical care. Respondents could list more than one

answer. Results are displayed in Tables 40 and 41. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The majority of respondents have always received HIV medical care since diagnosis (74.4%) but about 23% have experienced a gap in medical care. The top three reasons respondents listed for their gap were the cost of medical care/no insurance (5.7%), living outside the U.S./moved/in prison (3.6%), and not wanting HIV care or medications/issues with their doctor (3.2%).

Table 40: Ever Not Receive HIV Medical Care

Has there ever been a time when you were not receiving medical care for your HIV? (n=273)		
	Number	Percent
Yes	64	22.80%
No	209	74.40%

Table 41: Reasons for Gap in Medical Care

Please explain your reasons for the gap in medical care (n=53)		
	Number	Percent
Lived outside the U.S./moved/in prison	10	3.60%
Healthy status, didn't need doc or HIV medical care	5	1.80%
Mental health issues/depression	3*	1.10%
Didn't want HIV medical care/meds/had issues with doc/had TB/no health care provider follow-up	9	3.20%
Cost of health care/no insurance	16	5.70%
Drug/substance abuse	5	1.80%
Lived in rural area/homeless	2*	0.70%
Denial after diagnosis	3*	1.10%
Incomplete ADAP recertification	1*	0.40%
No treatment available at time/didn't have treatment	6	2.10%

*Cell size less than 5

Medical Treatment and Medical Care Service Ratings

Respondents were asked to rate HIV medical treatment and medical care services according to their perceived level of need, importance, and satisfaction. Results are displayed in

Tables 42, 43, and 44. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The scale rating used for level of service need from highest to lowest was "need, sometimes need, do not need, and not applicable." The top services needed were HIV/AIDS medications (91.5%), lab tests (82.9%), and doctor visits (80.10%). Help taking HIV/AIDS medications and dealing with side effects (34.2%) was the only medical care service that didn't receive a high level of need. However, the majority of respondents still responded that the service was needed.

Table 42: Medical Treatment and Medical Care Need Ratings

What is your level of need for these services?			
Scale		Number	Percent
Doctor visits for HIV/AIDS (n=278)	Need	225	80.10%
	Sometimes Need	37	13.20%
	Do Not Need	9	3.20%
	Not Applicable	7	2.50%
Lab tests (CD4 count, viral load test, etc.) (n=278)	Need	233	82.90%
	Sometimes Need	32	11.40%
	Do Not Need	7	2.50%
	Not Applicable	6	2.10%
HIV/AIDS medications (pharmacy, ADAP, etc.) (n=279)	Need	257	91.50%
	Sometimes Need	5	1.80%
	Do Not Need	9	3.20%
	Not Applicable	8	2.80%
Help taking HIV/AIDS medications and dealing with side effects (n=273)	Need	96	34.20%
	Sometimes Need	59	21.00%
	Do Not Need	80	28.50%
	Not Applicable	38	13.50%

The scale rating used for level of service importance from highest to lowest was "very important, important, neutral, not important, not very important, and not applicable." The top important medical services were HIV/AIDS medications (91.5%), lab tests (86.1%), and doctor visits (86.1%). Lab tests and doctor visits were seen as equally important by respondents living

with HIV. Help taking HIV/AIDS medications and dealing with side effects (40.2%) was the only medical care service that didn't receive a high level of importance. However, the majority of respondents still responded that the service was very important. These ratings were very similar to those for level of need.

Table 43: Medical Treatment and Medical Care Importance Ratings

How important are these services to you?			
	Scale	Number	Percent
Doctor visits for HIV/AIDS (n=281)	Very Important	242	86.10%
	Important	28	10.00%
	Neutral	7	2.50%
	Not Important	1*	0.40%
	Not Very Important	1*	0.40%
	Not Applicable	2*	0.70%
Lab tests (CD4 count, viral load, etc.) (n=280)	Very Important	242	86.10%
	Important	34	12.10%
	Not Important	1*	0.40%
	Not Very Important	1*	0.40%
	Not Applicable	2*	0.70%
HIV/AIDS medications (pharmacy, ADAP, etc.) (n=278)	Very Important	257	91.50%
	Important	15	5.30%
	Not Very Important	2*	0.70%
	Not Applicable	4*	1.40%
Help taking HIV/AIDS medications and dealing with side effects (n=277)	Very Important	113	40.20%
	Important	54	19.20%
	Neutral	33	11.70%
	Not Important	14	5.00%
	Not Very Important	19	6.80%
	Not Applicable	44	15.70%

*Cell size less than 5

The scale rating used for level of service satisfaction from highest to lowest was "very satisfied, satisfied, neutral, dissatisfied, very dissatisfied, and not applicable." The top satisfactory services were similar again: HIV/AIDS medications (77.6%), lab tests (76.9%), and

doctor visits (76.9%). Help taking HIV/AIDS medications and dealing with side effects (30.6%) was the only medical care service that didn't receive a high level of satisfaction. However, the majority of respondents still responded that the service was very satisfactory. Although all medical treatment and medical care services were rated as very satisfactory, the satisfaction ratings were not as high as those for level of need and importance. Help taking HIV/AIDS medications and dealing with medications was the service that had the highest percentage of dissatisfactory (3.9%) and very dissatisfactory ratings (3.2%).

Table 44: Medical Treatment and Medical Care Satisfaction Ratings

What is your level of satisfaction with these services?			
	Scale	Number	Percent
Doctor visits for HIV/AIDS (n=278)	Very Satisfied	216	76.90%
	Satisfied	46	16.40%
	Neutral	8	2.80%
	Dissatisfied	5	1.80%
	Very Dissatisfied	1*	0.40%
	Not Applicable	2*	0.70%
Lab tests (CD4 count, viral load test, etc.) (n=278)	Very Satisfied	214	76.20%
	Satisfied	48	17.10%
	Neutral	11	3.90%
	Dissatisfied	2*	0.70%
	Very Dissatisfied	1*	0.40%
	Not Applicable	2*	0.70%
HIV/AIDS medications (pharmacy, ADAP, etc.) (n=277)	Very Satisfied	218	77.60%
	Satisfied	36	12.80%
	Neutral	13	4.60%
	Dissatisfied	2*	0.70%
	Very Dissatisfied	1*	0.40%
	Not Applicable	7	2.50%
Help taking HIV/AIDS medications and dealing with side effects (n=276)	Very Satisfied	86	30.60%
	Satisfied	55	19.60%
	Neutral	37	13.20%
	Dissatisfied	11	3.90%

	Very Dissatisfied	9	3.20%
	Not Applicable	78	27.80%

*Cell size less than 5

Barriers to Medical Care of PLWHA in Utah

The survey also asked why HIV-positive individuals have difficulty accessing medical care in Utah. Respondents were asked to select their top five barriers to receiving medical treatment. In 2012, the Ryan White Part B Program conducted a literature review of the most common barriers to HIV medical care. The 20 most common barriers identified in the literature were included in the survey. Respondents could list more than one answer. Results are displayed in Table 45 with barriers listed in descending order. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The top five barriers to medical care services were: 1) not having enough insurance coverage (32%); 2) the cost of services to me (31.3%); 3) my concern that others may see me when I get medical care and learn about my HIV (18.5%); 4) my state of mind or mental ability to deal with the services and treatments (17.1%); and 5) not knowing what treatment is available to me/do not know if services exist (16%).

Table 45: Medical Care Top Barriers

What are the top 5 things that keep you from getting medical help/treatment? (n=157)		
	Number	Percent
Not having enough insurance coverage.	90	32%
The cost of services to me.	88	31.3%
My concern is that others may see me when I get medical care and learn about my HIV.	52	18.5%
My state of mind or mental ability to deal with the services and treatments.	48	17.1%
Not knowing what treatment is available to me/do not know if services exist.	45	16%
The location of the organization providing services.	43	15.3%
Not having transportation.	40	14.2%
My physical health.	30	10.7%

The amount of paperwork I have to fill out to get the service.	27	9.6%
Lack of service integration (i.e. no one stop location with several health services/ resources)	26	9.3%
My thinking that I am not being affected by the infection.	20	7.1%
The amount of time I have to wait to get an appointment with someone.	20	7.1%
The organizations providing services make me feel like a number.	19	6.8%
Poor organization among the groups providing services.	17	6%
The level of knowledge of the person providing the service.	13	4.6%
The level of discrimination/judgment/ insensitivity that I feel from the people providing services.	13	4.6%
Other reason	13	4.6%
My concern of being reported to the police.	9	3.2%
I do not have a pharmacy to go to.	9	3.2%
The ability of the person providing services to speak in a language that I understand.	8	2.8%
Other reason specified Coordinating time to go	2*	0.7%
Substance abuse	1*	0.4%
Hospice	1*	0.4%
Incarcerated	1*	0.4%
No support group	1*	0.4%

*Cell size less than 5

Support Service Needs of PLWHA in Utah

Several survey questions addressed the third research question related to support service needs of PLWHA in Utah. Therefore, this section is divided into four subsections: Case Management, Others that Connect to Services, Support Service Ratings, and Services in English.

Case Management

Survey respondents were asked whether they have a case manager who helps them receive HIV-related services. For those who answered no, a follow-up question asked the reasons why they didn't have a case manager. Respondents could list more than one reason. The results by subcategory are displayed in Tables 46 and 47. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. When comparing subgroups, about 94% of heterosexuals had a case manager while 80% of

nonurban Utah residents had a case manager. Among respondents who were unsure whether they had a case manager, minorities had the highest percentage (7.59%) and IDU had the lowest percentage (0%). The top two reasons respondents listed for not having a case manager were that they didn't need one (1.4%) and no reason (.7%).

Table 46: Have a Case Manager

Do you have a case manager that helps you get HIV-related services? (n=281)			
	Yes (%)	No (%)	I'm not sure (%)
Entire Sample (n=281)	87.90%	6.80%	5.30%
Women (n=42)	88.09%	7.14%	4.76%
Men (n=237)	88.6%	6.32%	5.06%
Whites (n=215)	89.3%	6.04%	4.65%
Minorities (n=79)	86.07%	6.32%	7.59%
IDU (n=33)	90.9%	9.09%	0%
MSM (n=172)	86.04%	6.97%	6.97%
Heterosexuals (n=16)	93.44%	4.91%	1.63%
Urban (n=245)	88.57%	6.12%	5.3%
Non-urban (n=15)	80%	13.33%	6.66%

Table 47: Reasons Not Having a Case Manager

Reasons for not having a case manager: (n=9)		
	Number	Percent
Don't need one	4*	1.40%
Embarrassed	1*	0.40%
Incarcerated	1*	0.40%
Don't like UAF	1*	0.40%
No reason	2*	0.70%

*Cell size less than 5

Survey respondents with a case manager were asked how long it had been since they last had contact with their case manager. The results by subcategory are displayed in Table 48. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. A little more than half of the respondents last had contact

with a case manager within the past month (53.7%) with almost another 30% at six months (totaling 83.7%). When comparing subgroups, 69.1% of minorities had contact with their case manager within the past month and 1.4% had their last contact over a year ago. About 38% of nonurban residents had contact with their case manager within the past six months and 7.69% had their last contact over a year ago. The MSM group had the lowest percentage of contact within the past month (52.86%) while women had the lowest percentage of contact within the past six months (26.31%). About 3% of IDU had their last case manager contact over six months ago.

Table 48: Last Contact with Case Manager

How long has it been since you last had contact with your case manager? (n=257)				
	Within the past month (%)	Within the past 6 months (%)	Within the past year (%)	More than a year (%)
Entire Sample (n=257)	53.70%	29.90%	4.30%	3.60%
Women (n=38)	65.78%	26.31%	2.63%	5.26%
Men (n=218)	57.33%	33.94%	5.04%	3.66%
Whites (n=200)	54.50%	36%	5%	4.50%
Minorities (n=81)	69.01%	26.76%	2.81%	1.40%
IDU (n=30)	66.66%	30%	0%	3.33%
MSM (n=157)	52.86%	37.57%	5.73%	3.82%
Heterosexuals (n=57)	59.64%	31.57%	3.50%	5.26%
Urban (n=225)	58.22%	33.33%	5.33%	3.11%
Non-urban (n=13)	53.84%	38.46%	0%	7.69%

Survey respondents with a case manager were given the opportunity in an open-ended question to express what they thought would improve case management services. Respondents could list more than one answer. Results are displayed in Table 49. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The most common responses are listed in descending order by their percentage.

The top three ways respondents listed to improve case management were: 1) easier, more frequent contact/communication/more available/keep appointments/friendlier (10.3%); 2) provide services outside of Salt Lake City (rural areas, prison) and more case managers/too much turnover (8.9%); and 3) educate/inform about available services/renewal (7.8%).

Table 49: Improve Case Management

What do you think would improve case management services? (n=179)		
	Number	Percent
Easier, more frequent contact/communication/more available/keep appts/friendlier	29	10.30%
Provide services outside of SLC (rural areas, prison) and more case managers/ too much turnover	25	8.90%
Education/inform about available services/renewal	22	7.80%
Dental care	6	2.10%
Provide notification-program changes/service updates/ADAP approval/renewal/new cms	6	2.10%
More mental services and support groups (including straight group)	4*	1.40%
Insurance issues/help with drug company programs/get refills on time	4*	1.40%
Transportation assistance/more bus passes/tokens	3*	1.10%
Financial assistance	3*	1.10%
Housing assistance	1*	0.40%

*Cell size less than 5

Others that Connect to Services

Survey respondents with or without a current case manager were asked if there was someone else other than a case manager that connects them to HIV-related services. For those who answered yes, a follow-up question asked for more information about that person. Respondents could list more than one person. Results are displayed in Tables 50 and 51. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 74% of respondents did not have someone other than a case manager to connect them to HIV-related services. Women were the group with the highest percentage (45.23%) receiving help from someone else while nonurban residents were the lowest (13.33%). The top two responses were HIV/AIDS agencies (11%) such as Royal

Court of the Golden Spike Empire (RCGSE), Utah AIDS Foundation (UAF), People with AIDS Coalition of Utah (PWACU), Pneumocystis pneumonia (PCP) and Nevis AIDS Coordinating Unit (NACU) and their doctor/pharmacist (10.7%).

Table 50: Someone Else that Connects to Services

Is there someone else (other than a case manager) who connects you to HIV-related services? (n=279)		
	Yes (%)	No (%)
Entire Sample (n=279)	25.30%	74.00%
Women (n=42)	45.23%	54.76%
Men (n=235)	22.12%	77.87%
Whites (n=214)	25.7%	74.29%
Minorities (n=88)	21.79%	78.2%
IDU (n=32)	31.25%	68.75%
MSM (n=171)	23.97%	76.02%
Heterosexuals (n=60)	30%	70%
Urban (n=244)	24.59%	75.4%
Non-urban (n=15)	13.33%	86.66%

Table 51: Who Else Connects to Services

Other than a case manager, who else connects you to HIV-related services? (n=66)		
	Number	Percent
Spouse/family/friends	4*	1.40%
Doctor/pharmacist	30	10.70%
HIV/AIDS agencies-RCGSE, UAF, PWACU, PCP, NACU	31	11.00%
Support group	1*	0.40%
Therapist/psychologist/counselor	3*	1.10%

*Cell size less than 5

Support Service Ratings

Respondents were asked to rate support services according to their perceived level of need, importance, and satisfaction. The results are displayed in Tables 52, 53, and 54. All

percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. The scale rating used for level of service need from highest to lowest was “need, sometimes need, do not need, and not applicable.” The top services needed were dental care (72.2%), help paying for health insurance (63.7%), and case management (57.7%). HIV-positive individuals are at greater risk for oral health problems because of a weakened immune system that cannot counter oral infections (NIDCR, 2012). Common oral problems include oral warts, fever blisters, hairy leukoplakia, oral candidiasis, aphthous ulcers, and dry mouth (NIDCR, 2012). Women’s health (10.3%) and inpatient/outpatient substance abuse treatment (9.6%) were the least needed support services according to respondents as it most often did not apply to their situation.

Table 52: Support Services Need Ratings

What is your level of need for these services?			
		Number	Percent
Women's health (OBGYN, pregnancy testing, prenatal care, etc.) (n=270)	Need	29	10.3%
	Sometimes Need	10	3.6%
	Do Not Need	8	2.8%
	Not Applicable	223	79.4%
Inpatient/outpatient substance abuse treatment (n=271)	Need	27	9.6%
	Sometimes Need	19	6.8%
	Do Not Need	48	17.1%
	Not Applicable	177	63.0%
Case management (n=272)	Need	162	57.7%
	Sometimes Need	79	28.1%
	Do Not Need	15	5.3%
	Not Applicable	16	5.7%
HIV/AIDS support group (n=274)	Need	60	21.4%
	Sometimes Need	53	18.9%
	Do Not Need	105	37.4%
	Not Applicable	56	19.9%
Psychiatrist visits/mental health counseling (n=271)	Need	91	32.4%
	Sometimes Need	59	21.0%

	Do Not Need	66	23.5%
	Not Applicable	55	19.6%
Food bank (n=271)	Need	105	37.4%
	Sometimes Need	43	15.3%
	Do Not Need	66	23.5%
	Not Applicable	57	20.3%
Transportation (bus, Trax, taxi, etc.) (n=272)	Need	86	30.6%
	Sometimes Need	33	11.7%
	Do Not Need	80	28.5%
	Not Applicable	73	26.0%
Help paying for health insurance (COBRA, HIP, co-pays, etc.) (n=272)	Need	179	63.7%
	Sometimes Need	25	8.9%
	Do Not Need	27	9.6%
	Not Applicable	41	14.6%
Information about treating (n=273)	Need	102	36.3%
	Sometimes Need	67	23.8%
	Do Not Need	70	24.9%
	Not Applicable	34	12.1%
Information about how HIV is spread (n=273)	Need	64	22.8%
	Sometimes Need	56	19.9%
	Do Not Need	108	38.4%
	Not Applicable	45	16.0%
Help with housing (n=272)	Need	108	38.4%
	Sometimes Need	41	14.6%
	Do Not Need	66	23.5%
	Not Applicable	57	20.3%
Dental care (n=272)	Need	203	72.2%
	Sometimes Need	31	11.0%
	Do Not Need	22	7.8%
	Not Applicable	16	5.7%

The scale rating used for level of service importance from highest to lowest was “very important, important, neutral, not important, not very important, and not applicable.” Both service need and service importance questions were asked because a service can be important to a person with HIV but not needed and vice versa. For example, an HIV-positive individual might

think support groups are important but not personally need the service. The top important support services were dental care (66.9%), help paying for health insurance (64.1%), case management (53%), and information about treatment (52%). Women's health (11.4%) and inpatient/outpatient substance abuse treatment (11.4%) were equally the least needed support services according to respondents but once again it was most often not applicable to their situation. These ratings were very similar to those for level of need.

Table 53: Support Services Importance Ratings

How important are these services to you?			
		Number	Percent
Women's health (OBGYN, pregnancy testing, prenatal care, etc.) (n=268)	Very Important	32	11.4%
	Important	7	2.5%
	Neutral	4*	1.4%
	Not Important	1*	.4%
	Not Very Important	6	2.1%
	Not Applicable	218	77.6%
Inpatient/outpatient substance abuse treatment (n=273)	Very Important	32	11.4%
	Important	18	6.4%
	Neutral	14	5.0%
	Not Important	9	3.2%
	Not Very Important	18	6.4%
	Not Applicable	182	64.8%
Case management (n=275)	Very Important	149	53.0%
	Important	72	25.6%
	Neutral	29	10.3%
	Not Important	5	1.8%
	Not Very Important	9	3.2%
	Not Applicable	11	3.9%
HIV/AIDS support group (n=276)	Very Important	58	20.6%
	Important	29	10.3%
	Neutral	53	18.9%
	Not Important	30	10.7%
	Not Very Important	47	16.7%
	Not Applicable	59	21.0%
Psychiatrist visits/mental health counseling (n=272)	Very Important	81	28.8%
	Important	44	15.7%

	Neutral	46	16.4%
	Not Important	23	8.2%
	Not Very Important	25	8.95
	Not Applicable	53	18.9%
Food bank (n=274)	Very Important	92	32.75
	Important	38	13.5%
	Neutral	28	10.05
	Not Important	17	6.05
	Not Very Important	23	8.2%
	Not Applicable	76	27.05%
Transportation (bus, Trax, taxi, etc.) (n=275)	Very Important	78	27.85%
	Important	31	11.0%
	Neutral	25	8.9%
	Not Important	15	5.3%
	Not Very Important	25	8.9%
	Not Applicable	101	35.9%
Help paying for health insurance (COBRA, HIP, co-pays, etc.) (n=274)	Very Important	180	64.1%
	Important	22	7.8%
	Neutral	8	2.8%
	Not Important	3*	1.1%
	Not Very Important	9	3.2%
	Not Applicable	52	18.5%
Information about treating (n=279)	Very Important	146	52.0%
	Important	52	18.5%
	Neutral	27	9.6%
	Not Important	7	2.5%
	Not Very Important	16	5.7%
	Not Applicable	31	11.0%
Information about how HIV is spread (n=277)	Very Important	108	38.4%
	Important	45	16.0%
	Neutral	43	15.3%
	Not Important	15	5.3%
	Not Very Important	29	10.3%
	Not Applicable	37	13.2%
Help with housing (n=274)	Very Important	118	42.0%
	Important	31	11.0%
	Neutral	22	7.8%
	Not Important	7	2.5%
	Not Very Important	21	7.5%
	Not Applicable	75	26.7%

Dental care (n=276)	Very Important	188	66.9%
	Important	42	14.9%
	Neutral	9	3.2%
	Not Important	2*	.7%
	Not Very Important	10	3.6%
	Not Applicable	25	8.9%

*Cell size less than 5

The scale rating used for level of service satisfaction from highest to lowest was "very satisfied, satisfied, neutral, dissatisfied, very dissatisfied, and not applicable." The top satisfactory services were: Case management (49.8%), help paying for health insurance (40.2%), and information about treatment (33.1%). Most of the satisfactory and very satisfactory ratings for support services were below 30%. Although the vast majority of ratings for each support service were very satisfactory, the ratings were not as high as those for level of need and importance. Again, women's health (11.4%) and inpatient/outpatient substance abuse treatment (11.4%) were the least satisfactory support services according to respondents. Dental care had the highest percentages of dissatisfactory (15.3%) and very dissatisfactory ratings (15.3).

Table 54: Support Services Satisfaction Ratings

What is your level of satisfaction with these services?			
		Number	Percent
Women's health (OBGYN, pregnancy testing, prenatal care, etc.) (n=269)	Very Satisfied	30	10.7%
	Satisfied	3*	1.1%
	Neutral	4*	1.4%
	Dissatisfied	1*	.4%
	Very Dissatisfied	1*	.4%
	Not Applicable	230	81.9%
Inpatient/outpatient substance abuse treatment (n=272)	Very Satisfied	18	6.4%
	Satisfied	11	3.9%
	Neutral	18	6.4%
	Dissatisfied	7	2.5%
	Very Dissatisfied	2*	.7%
	Not Applicable	216	76.9%
Case management (n=274)	Very Satisfied	140	49.8%

	Satisfied	48	17.1%
	Neutral	42	14.9%
	Dissatisfied	14	5.0%
	Very Dissatisfied	15	5.3%
	Not Applicable	15	5.3%
HIV/AIDS support group (n=266)	Very Satisfied	42	14.9%
	Satisfied	19	6.8%
	Neutral	42	14.9%
	Dissatisfied	11	3.9%
	Very Dissatisfied	16	5.7%
	Not Applicable	136	48.4%
Psychiatrist visits/mental health counseling (n=270)	Very Satisfied	58	20.6%
	Satisfied	36	12.8%
	Neutral	37	13.2%
	Dissatisfied	11	3.9%
	Very Dissatisfied	14	5.0%
	Not Applicable	114	40.6%
Food bank (n=272)	Very Satisfied	74	26.3%
	Satisfied	36	12.8%
	Neutral	26	9.3%
	Dissatisfied	11	3.9%
	Very Dissatisfied	14	5.0%
	Not Applicable	111	39.5%
Transportation (bus, Trax, taxi, etc.) (n=272)	Very Satisfied	38	13.5%
	Satisfied	18	6.4%
	Neutral	43	15.3%
	Dissatisfied	16	5.7%
	Very Dissatisfied	16	5.7%
	Not Applicable	141	50.2%
Help paying for health insurance (COBRA, HIP, co-pays, etc. (n=270)	Very Satisfied	113	40.2%
	Satisfied	34	12.1%
	Neutral	34	12.1%
	Dissatisfied	13	4.6%
	Very Dissatisfied	14	5.0%
	Not Applicable	62	22.1%
Information about treating (n=275)	Very Satisfied	93	33.1%
	Satisfied	59	21.0%

	Neutral	40	14.2%
	Dissatisfied	10	3.6%
	Very Dissatisfied	5	1.8%
	Not Applicable	68	24.2%
Information about how HIV is spread (n=276)	Very Satisfied	83	29.5%
	Satisfied	54	19.2%
	Neutral	48	17.1%
	Dissatisfied	5	1.8%
	Very Dissatisfied	5	1.8%
	Not Applicable	81	28.8%
Help with housing (n=273)	Very Satisfied	65	23.1%
	Satisfied	24	8.5%
	Neutral	37	13.2%
	Dissatisfied	14	5.0%
	Very Dissatisfied	20	7.1%
	Not Applicable	113	40.2%
Dental care (n=274)	Very Satisfied	70	24.9%
	Satisfied	32	11.4%
	Neutral	35	12.5%
	Dissatisfied	43	15.3%
	Very Dissatisfied	43	15.3%
	Not Applicable	51	18.1%

*Cell size less than 5

Services in English

Survey respondents were asked whether they were comfortable receiving HIV services in English and results are displayed in Table 55. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. While 13.9% of the sample was Hispanic, the majority of respondents stated they felt comfortable receiving services in English (93.2%). Of these, only 2.5% (all Hispanic) were somewhat not comfortable or not comfortable receiving services in English.

Table 55: Comfort Receiving Services in English

How comfortable are you receiving HIV services in English? (n=277)		
	Number	Percent
Comfortable	262	93.20%
Somewhat comfortable	8	2.80%
Somewhat not comfortable	2*	0.70%
Not comfortable	5	1.80%

*Cell size less than 5

HIV Preventive Behaviors of PLWHA in Utah:

Various survey questions were asked to answer the last research question about HIV preventive behaviors of PLWHA in Utah. Therefore, this section is divided into six subsections: Injection Drug Use, Sex Under the Influence, Sexual Partners, Unprotected Sex, Asking & Disclosing HIV Status, and Trading Sex.

Injection Drug Use

Survey respondents were asked if they had injected drugs or substances not prescribed to them in the last 12 months. For those who answered yes, a follow-up question was asked to determine the last time they injected drugs or substances. Another follow-up open-ended response question asked what types of drugs were injected. Respondents could list more than one injecting drug. The results by subcategory are displayed in Tables 56 and 57. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 88% of respondents answered that they had not injected drugs/substances in the last year, leaving almost 12% who had injected drugs/substances. Women had the highest percentage of injection drug use in the last year (14.28%). To answer the follow-up question of the last time injecting drugs/substances, heterosexuals were highest at one week (75%), MSM were highest at one month (26.31%), and minorities were highest for three months (33.33%), nine months (33.33%), and 12 months (16.66%). This suggests that subgroups

with the shortest interval of time since injecting drugs/substances could inject more frequently. The most frequently used drug reported in the open-ended response was methamphetamine (7.1%) followed by heroin (2.1%).

Table 56: IDU & Last Time of Use

Have you injected drugs/substances not prescribed to you in the last 12 months? (n=281)								
			If yes, when was the last time? (n=28)					
	Yes (%)	No (%)	1 week (%)	1 month (%)	3 months (%)	6 months (%)	9 months (%)	12 months (%)
Entire Sample	11.7%	88.3%	4.3%	1.8%	2.1%	0%	1.4%	.4%
Women	14.28%	85.71%	80%	0%	20%	0%	0%	0%
Men	11.39%	88.60%	34.78%	21.73%	21.73%	0%	17.39%	4.34%
Whites	12.55%	87.44%	52.17%	17.39%	21.73%	0%	8.69%	0%
Minorities	8.86%	91.13%	0%	16.66%	33.33%	0%	33.33%	16.66%
IDU	100%	0%	42.85%	17.85%	21.42%	0%	14.28%	3.57%
MSM	12.20%	87.79%	31.57%	26.31%	26.31%	0%	15.78%	0%
Heterosexuals	8.19%	91.80%	75%	0%	25%	0%	0%	0%
Urban	10.61%	89.38%	36.36%	22.72%	18.18%	0%	18.18%	4.54%
Nonurban	13.33%	86.66%	50%	0%	50%	0%	0%	0%

Table 57: IDU Drugs

Which drugs/substances did you in inject in the last 12 months? (n=26)		
	Number	Percent
Meth	20	7.1%
Heroin	6	2.1%
Suboxin	1*	.4%

*Cell size less than 5

Survey respondents were asked if they had shared (sterilized or dirty) needles/syringes/works (works translates to paraphernalia used for injecting drug substances) while injecting drugs in the last 12 months. For those who answered yes, a follow-up question asked when the last time was that they shared drugs or substances. The results by subcategory are displayed in Table 58. All percentages represent the percentage of the entire sample.

Percentages might not add up to 100% due to the exclusion of nonresponses. Nearly 96% of respondents answered that they had not shared needles, syringes, etc. while injecting drugs in the last year, leaving about 4% who had shared needles or syringes, etc. Nonurban residents had the highest percentage of sharing "works" in the last year (13.33%). To answer the follow-up question of when their last time was sharing needles/syringes, MSM had the highest percentage for one week ago (14.28%) and one month ago (28.57%), minorities had the highest percentage at three months ago (100%), women had the highest percentage at six months ago (33.33%), and heterosexuals had the highest percentage at 12 months ago (100%).

Table 58: Sharing Needles & Last Time of Use

Have you shared needles, syringes, etc. while injecting drugs in the last 12 months? (n=281)								
			If yes, when was the last time? (n=11)					
	Yes (%)	No (%)	1 week (%)	1 month (%)	3 months (%)	6 months (%)	9 months (%)	12 months (%)
Entire Sample	4.3%	95.7%	.4%	.7%	1.4%	.4%	1.1%	0%
Women	7.14%	92.85%	0%	0%	33.33%	33.33%	33.33%	0%
Men	3.79%	96.20%	12.5%	25%	37.5%	0%	25%	0%
Whites	5.58%	94.41%	9.09%	18.18%	36.36%	9.09%	27.27%	0%
Minorities	1.26%	98.73%	0%	0%	100%	0%	0%	0%
IDU	100%	0%	.4%	.7%	1.4%	.4%	1.1%	0%
MSM	4.06%	95.93%	14.28%	28.57%	28.57%	0%	28.57%	0%
Heterosexuals	1.63%	98.36%	0%	0%	0%	0%	100%	0%
Urban	3.67%	96.32%	12.5%	25%	25%	12.5%	25%	0%
Non-urban	13.33%	86.66%	50%	0%	50%	0%	0%	0%

Sex Under the Influence

Survey respondents who have had sex in the last year were asked if they had sex while under the influence of alcohol or drugs in the past 12 months. For those who answered yes, a follow-up question asked which drugs they used. Respondents could list more than one drug. The results displayed by subcategory are found in Tables 59 and 60. All percentages represent the

percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Nearly 40% of respondents answered they had never had sex under the influence of alcohol and nearly 39% reported they had never had sex under the influence of drugs. About 15% of respondents reported they had sex under the influence of alcohol most of the time or sometimes. In addition, 16% responded they had sex under the influence of drugs most of the time or sometimes. MSM reported the highest percentages of having sex under the influence of alcohol most of the time (6.66%). Women reported the highest percentages for never having sex under the influence of alcohol (83.33%) and drugs (84.21%). The most frequently used drug for sex from the open-ended response was methamphetamine (8.5%) followed by marijuana (5%).

Table 59: Sex under the Influence

How often have you had sex under the influence of alcohol or drugs in the past 12 months?						
	Alcohol (n=155)			**Drugs** (n=156)		
	Most of the time (%)	Sometimes (%)	Never (%)	Most of the time (%)	Sometimes (%)	Never (%)
Entire Sample	3.20%	12.10%	39.50%	6.00%	10.00%	38.40%
Women	0%	16.66%	83.33%	10.52%	5.26%	84.21%
Men	6.61%	22.79%	69.85%	11.02%	19.85%	66.91%
Whites	6.55%	20.49%	72.13%	13.82%	17.88%	66.66%
Minorities	5.12%	25.64%	69.23%	2.56%	17.94%	76.92%
IDU	4.34%	17.39%	78.26%	52.17%	39.13%	8.69%
MSM	6.66%	22.85%	69.52%	12.38%	20%	64.76%
Heterosexuals	0%	24%	76%	0%	7.40%	92.59%
Urban	6.47%	22.30%	70.50%	11.51%	17.98%	69.06%
Non-urban	0%	25%	75%	11.11%	22.22%	55.55%

Table 60: Sex under the Influence Drugs

When you had sex under the influence of drugs, which drugs did you use? (n=42)		
	Numbers	Percent
Meth	24	8.50%
Marijuana	14	5.00%
Alcohol	5	1.80%
Cocaine	4*	1.40%
Heroine	2*	0.70%
Poppers	2*	0.70%
GHB	1*	0.40%
Ketamine	1*	0.40%
LSD	1*	0.40%

*Cell size less than 5

Sexual Partners

Survey respondents who have had sex in the last year were asked various questions about sexual partners beginning with whether they had sex (vaginal or anal) in the past 12 months. Survey respondents were also asked if they only have sex with HIV-positive individuals. The purpose of asking this question in the needs assessment was to determine whether PLWHA in Utah are utilizing the sero-sorting method (sex with only HIV-positive individuals) as a method for HIV prevention. In addition, survey respondents were asked if they have sex with only one primary partner. For those who answered they have sex with more than one partner, a follow-up question asked where they find their sexual partners. Results are displayed in Tables 61, 62, 63, and 64. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Slightly more than half of the respondents answered they had sex in the last year (55.5%). Thirty-two percent of respondents had sex with both HIV positive and negative individuals, 16% only had sex with HIV-positive individuals, and 7.5% did not know if they only had sex with HIV-positive individuals. Furthermore, almost 34% responded they had sex with only one primary partner while 21.4% said they had sex with

more than one partner. For those who had sex with more than one partner, the three most common ways to find sexual partners were online/internet (11.4%), friends (3.9%), and clubs/bars (2.8%).

Table 61: Sex in Last Year

Have you had sex within the past 12 months? (n=281)		
	Number	Percent
Yes	156	55.5%
No	125	44.5%

Table 62: Sex Only with HIV Positive Individuals

Do you only have sex with HIV positive individuals? (n=156)		
	Number	Percent
Yes	45	16.0%
No	90	32.0%
I don't know	21	7.5%

Table 63: Sex with One Primary Partner

Do you have sex with only one primary partner? (n=155)		
	Number	Percent
Yes	95	33.8%
No, I have sex with more than one partner	60	21.4%

Table 64: Where Sexual Partners are Found

If you have sex with more than one partner, where do you find your sexual partners? (n=49)		
	Number	Percent
Online/internet	32	11.4%
Friends	11	3.9%
Clubs/bars	8	2.8%
Everywhere	2*	.7%
Phone app	1*	.4%
Public	1*	.4%

*Cell size less than 5

Survey respondents who have had sex in the last year were asked more questions about whether they had sex (vaginal or anal) based on their partner type. If survey respondents did not have sex with a male in the last 12 months then they skipped the rest of the questions about sex with males. This pattern continued for survey respondents who did not have sex with a female or transgender person. Results are displayed in Table 65. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 50% reported they had sex with a male, 30.6% reported they had sex with an HIV-positive male, 48% reported they had not had sex with a female, 35.9% reported they had not had sex with an HIV-positive female, 53.4% reported they had not had sex with a transgender person, and 37.7% reported they had not had sex with an HIV-positive transgender person.

Table 65: Sex with Partner Types

In the past 12 months, have you had sex with a…..?			
		Number	Percent
Male (n=155)	Yes	141	50.20%
	No	14	5%
HIV-positive male (n=152)	Yes	86	30.60%
	No	54	19.20%
	Don't know/Maybe	12	4.30%
Female (n=154)	Yes	18	6.40%
	No	135	48.00%
	Don't know/Maybe	1*	0.40%
HIV-positive female (n=106)	Yes	4*	1.40%
	No	101	35.90%
	Don't know/Maybe	1*	0.40%
Transgender person (n=152)	Yes	1*	0.40%
	No	150	53.40%
	Don't know/Maybe	1*	0.40%
HIV-positive transgender person (n=108)	Yes	1*	0.40%

	No	106	37.70%
	Don't know/Maybe	1*	0.40%

*Cell size less than 5

Unprotected Sex

The survey respondents who had sex in the last 12 months were asked whether they had unprotected (without a condom) sex (vaginal or anal) based on their partner type. Results are displayed in Table 66. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Thirty-two percent reported they had unprotected sex with a male, 9.3% reported they had unprotected sex with a male IDU, 33.8% reported they did not have unprotected sex with a female, 37% reported they did not have sex with a female IDU, 38.8% reported they did not have sex with a transgender person, and 38.1% reported they did not have sex with a transgender IDU.

Table 66: Unprotected Sex with Partner Types

In the past 12 months, have you had unprotected sex with a…..?			
		Number	Percent
Male (n=153)	Yes	90	32%
	No	63	22.40%
Male injecting drug user (IDU) (n=153)	Yes	26	9.30%
	No	102	36.30%
	Don't know/Maybe	25	8.90%
Female (n=106)	Yes	9	3.20%
	No	95	33.80%
	Don't know/Maybe	2*	0.70%
Female injecting drug user (IDU) (n=106)	Yes	1*	0.40%
	No	104	37.00%
	Don't know/Maybe	1*	0.40%
Transgender person (n=112)	Yes	2*	0.70%
	No	109	38.80%
	Don't know/Maybe	1*	0.40%
Transgender injecting drug user (IDU) (n=109)	Yes	1*	0.40%
	No	107	38.10%
	Don't know/Maybe	1*	0.40%

*Cell size less than 5

Female survey respondents were asked whether they had sex (vaginal or anal) with a man who has sex with men (MSM). Next, all survey respondents were asked if they use protection when they have oral sex. Results are displayed in Table 67. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. Eleven percent of female respondents reported they did not have sex with a MSM. The majority of the respondents answered "does not apply to me" (52.7%) since the question was directed at female respondents and most survey respondents were male. With regard to oral sex, 53% of all respondents reported they do not use protection when they have oral sex while approximately 15% reported they do use protection or only sometimes use protection.

Table 67: Female Sex with MSM & Oral Sex Protection

Female Sex with MSM and Oral Sex			
		Number	Percent
If you are female, have you had sex with a MSM? (n=183)	Yes	3*	1.10%
	Sometimes	1*	0.40%
	No	31	11.00%
	Does not apply to me	148	52.70%
When you have oral sex, do you use protection? (n=265)	Yes	27	9.60%
	Sometimes	16	5.70%
	No	149	53.00%
	Does not apply to me	73	26.00%

*Cell size less than 5

Asking & Disclosing HIV Status

Survey respondents were asked if they ask the HIV status of their sex partners. The results by subcategory are displayed in Table 68. All percentages represent the percentage of the

entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 42% of respondents answered they did ask the HIV status of their sex partner while about 19% did not, and about 26% answered it does not apply to them (likely because they do not have sex). Women were the group with the lowest percentage (30.76%) asking for the HIV status of their sex partners while MSM were the highest (47.56%). IDU were the group with the highest percentages asking sometimes (21.87%) and not at all (31.25%).

Table 68: Asking Sex Partner HIV Status

Do you ask the HIV status of your sex partners? (n=266)				
	Yes (%)	Sometimes (%)	No (%)	Does not apply to me (%)
Entire Sample (n=266)	41.60%	8.50%	18.90%	25.60%
Women (n=39)	30.76%	0 %	28.20 %	41.02%
Men (n=225)	46.66%	10.22%	18.22 %	24.88%
Whites (n=206)	47.08%	10.19%	16.50 %	26.21%
Minorities (n=73)	39.72%	4.10%	28.76 %	27.39%
IDU (n=32)	34.37%	21.87 %	31.25 %	12.5%
MSM (n=164)	47.56%	13.41%	17.68%	21.34%
Heterosexuals (n=54)	35.18%	0%	20.37%	44.44%
Urban (n=233)	45.49%	9.87%	18.88%	25.75%
Non-urban (n=13)	38.46%	0 %	15.38%	46.15%

Survey respondents were asked if they disclose their HIV status to their sex partners. For those who answered no or sometimes, a follow-up question asked if they ever notified their sex partner of their HIV status anytime afterward. For those who answered no, another follow-up question requested reasons why they did not notify their sex partner. Respondents could list more than one reason. Results by subcategory are displayed in Tables 69, 70, and 71. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 64% of respondents answered they did disclose their HIV

status to their sex partners while 6% did not, 5% disclosed sometimes, and about 21% answered it does not apply to them (likely because they do not have sex). Women and nonurban residents were the groups with the equally lowest percentage (50%) disclosing HIV status to their sex partners while MSM was the highest (74.23%). IDU was the group with the highest percentage disclosing sometimes (9.37%) and minorities were the group with the highest percentage not disclosing at all (18.42%). About 6.8% of respondents answered they revealed their HIV status to their sex partners sometime after having sex while 7.1% did not, 2.8% disclosed afterward sometimes, and about 40% answered it does not apply to them (likely because they do not have sex). Women were the group with the lowest percentage (3.12%) disclosing HIV status to their sex partners sometimes afterward while IDU was the highest (13.33%). IDU was the group with the highest percentage disclosing sometimes (26.66%) and not at all (13.33%). The top two reasons for not disclosing HIV status were: 1) undetectable/on meds/used protection/stopped intercourse prior to ejaculation (2.1%), and 2) scared/rejection/embarrassed (1.4%).

Table 69: Disclosing HIV Status to Sex Partner

Do you disclose your HIV status to your sex partners? (n=268)				
	Yes (%)	Sometimes (%)	No (%)	Does not apply to me (%)
Entire Sample (n=268)	64.10%	4.60%	6.00%	20.60%
Women (n=40)	50%	5%	7.5%	37.5%
Men (n=226)	70.35%	4.42%	6.19 %	19.02%
Whites (n=205)	73.17%	3.41%	2.92 %	20.48%
Minorities (n=76)	52.63%	6.57%	18.42%	22.36%
IDU (n=32)	75%	9.37%	3.12%	12.5%
MSM (n=163)	74.23%	4.90%	5.52 %	15.33%
Heterosexuals (n=58)	53.44%	1.72%	8.62%	36.20%
Urban (n=234)	68.80%	5.12%	5.55%	20.51%
Non-urban (n=14)	50%	0 %	7.14 %	42.85%

Table 70: Notify Sex Partner of HIV Status Afterward

If you do not reveal your HIV status before having sex, do you ever tell or notify your sex partners anytime afterward? (n=160)				
	Yes (%)	Sometimes (%)	No (%)	Does not apply to me (%)
Entire Sample (n=160)	6.80%	2.80%	7.10%	40.20%
Women (n=32)	3.12%	3.12 %	12.5%	81.25%
Men (n=127)	14.17%	5.51 %	12.59%	67.71%
Whites (n=115)	13.04%	6.08 %	7.82 %	73.04%
Minorities (n=52)	10%	2 %	30%	62%
IDU (n=15)	13.33 %	26.66%	13.33%	46.66%
MSM (n=84)	13.09%	8.33%	11.90%	66.66%
Heterosexuals (n=46)	8.69%	0%	8.69%	82.60%
Urban (n=137)	11.67%	5.83%	10.94%	71.53%
Non-urban (n=10)	10%	0%	0%	90%

Table 71: Reasons Did Not Notify Sex Partner of HIV Status

If you have not told your sex partners about your HIV status after you had sex with him/her, what are the reasons? (n=15)		
	Number	Percent
Undetectable/on meds/used protection/stopped intercourse prior to ejaculation	6	2.1%
Scared/rejection/embarrassed	4*	1.4%
Sex was anonymous	1*	.4%
They didn't ask	1*	.4%
Been in prison	1*	.4%
HIV+ info on online profile	1*	.4%
In a monogamous relationship	1*	.4%
Don't know	1*	.4%

*Cell size less than 5

Trading Sex

Survey respondents were asked if they traded sex for money, drugs or another reason in the past 12 months. For those who answered yes, a follow-up question asked when the last time was they traded sex. For those who traded sex for a reason other than money or drugs, an additional follow-up question asked about those other reasons. Respondents could list more than

one response. Results by subcategory are displayed in the following Tables 72, 73, and 74. All percentages represent the percentage of the entire sample. Percentages might not add up to 100% due to the exclusion of nonresponses. About 94% of respondents answered they did not trade sex for money, about 93% answered they did not trade for drugs, and about 92% answered they did not trade for some other reason. All nonurban residents responded they had never traded sex for money, drugs or another reason in the last 12 months. IDU had the highest percentage for trading sex for money (15.15%) and drugs (21.87%) while men had the highest percentage for trading sex for some other reason (2.2%). As for the follow-up question asking when the last time was they traded sex for money, 100% of women and heterosexuals did so within the last week. Those who traded sex for drugs were mostly whites, MSM, and urban residents mostly within the last three months. Those who traded sex for another reason were mostly whites, minorities, and MSM between three and 12 months ago. The only other reasons listed that sex was traded for were housing (.7%) and food (.7%).

Table 72: Trading Sex for Money, Drugs or Other Reason

Within the past 12 months have you traded sex for money, drugs or another reason?						
	Money (n=274)		**Drugs** (n=273)		**Other** (n=265)	
	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)
Entire Sample	3.20%	94.30%	3.90%	93.20%	1.80%	92.50%
Women	2.56%	97.43%	2.56%	97.43%	0%	100%
Men	3.43%	96.56%	4.31%	95.68%	2.20%	.88%
Whites	2.36%	97.63%	4.26%	95.73%	1.93 %	97.10%
Minorities	6.57%	93.42%	2.66%	97.33%	1.36 %	98.63%
IDU	15.15%	84.84%	21.87%	78.12%	10%	90%
MSM	1.77%	98.22%	3.55%	96.44%	1.21%	98.78%
Heterosexuals	1.66%	98.33%	1.66%	98.33%	0 %	100%
Urban	3.75%	96.25%	4.18%	95.81%	2.13 %	97%
Non-urban	0%	100%	0%	100%	0 %	100%

Table 73: Last Time Traded for Sex

When was the last time you traded sex for money, drugs or another reason?															
	Money (n=8)					**Drugs** (n=8)					**Other** (n=4)				
	1 week (%)	1 month (%)	3 months (%)	9 months (%)	12 months (%)	1 week (%)	1 month (%)	3 months (%)	9 months (%)	12 months (%)	1 week (%)	1 month (%)	3 months (%)	9 months (%)	12 months (%)
Entire Sample	0.40%	0%	0.40%	1.10%	1.10%	1.10%	0.70%	0.70%	0%	0.40%	0%	0%	0.40%	0.40%	0.70%
Women	100%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Men	0%	0%	14.28%	42.85%	42.85%	28.57%	28.57%	28.57%	0%	14.28%	0%	0%	25%	25%	50%
Whites	0%	0%	0%	50%	50%	33.33%	33.33%	33.33%	0%	0%	0%	0%	33.33%	0%	66.66%
Minorities	20%	0%	20%	40%	20%	50%	0%	0%	0%	50%	0%	0%	0%	100%	0%
IDU	25%	0%	0%	25%	50%	40%	20%	20%	0%	20%	0%	0%	0%	50%	50%
MSM	0%	0%	0%	33.33%	66.66%	16.66%	33.33%	33.33%	0%	16.66%	0%	0%	50%	0%	50%
Heterosexuals	100%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Urban	12.5%	0%	12.5%	37.5%	37.5%	37.5%	25%	25%	0%	12.5%	0%	0%	25%	25%	50%
Non-urban	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%

Table 74: Trading Sex Other Reasons

What other reasons did you trade sex for? (n=4)		
	Number	Percent
Food	2*	.7%
Housing	2*	.7%

*Cell size less than 5

Discussion

Medical Treatment and Medical Care Needs

Shortfalls in the spectrum of engagement in HIV medical care including late diagnosis, poor linkage and retention in medical care, as well as insufficient use and adherence to ART, are obstacles to obtaining successful treatment outcomes (Gardner et al., 2011). Furthermore, proper engagement of HIV infected individuals is a strategy to decrease ongoing HIV transmission and stem the HIV epidemic (Gardner et al., 2011). According to the needs assessment results, improved and faster linkage to medical care is an important need to be addressed in Utah for PLWHA since about 15% of respondents did not receive an HIV medical care visit until six months to a year after diagnosis which is considered a late diagnosis. According to the literature, HIV-positive individuals with longer delays in obtaining medical care have a greater likelihood of developing AIDS and account for the largest proportion of detectable viral loads (Gardner et al., 2011). In addition, it is important to consider why there might be a difference in obtaining a place for medical care between MSM and heterosexuals in Utah. Stigma and discrimination can affect whether MSM seek and are able to obtain high-quality medical and health services (CDC, 2013a). Retention in medical care also lies along the engagement in HIV medical care continuum for PLWHA in Utah. About 23% of needs assessment survey respondents reported having a period of time when they were not receiving HIV medical care since diagnosis. A substantial portion of HIV-infected patients have poor retention in medical care which predicts poorer survival with HIV (Giordano et al., 2007). Incomplete engagement of HIV-positive individuals is an area to be addressed nationally and in Utah. An International Association of Physicians in AIDS Care (IAPAC) panel indicated that to improve entry into and retention in HIV medical care, the following were recommended: 1) Systematic monitoring of successful entry into HIV

care for all individuals diagnosed with HIV, 2) Systematic monitoring of retention in HIV care for all patients, 3) Brief, strengths-based case management for individuals with a new HIV diagnosis, and 4) Intensive outreach for individuals not engaged in medical care within six months of a new HIV diagnosis (Thompson, 2012).

Along the engagement in HIV medical care spectrum, another concern for PLWHA in Utah is inadequate adherence to HIV medications. Of all respondents, about 28% skip or stop taking medications at least once a year. All IDU respondents reported skipping/stopping medications with most skipping every week or every month. It is important to consider why IDU were the least likely to take medications in Utah. Research indicates that IDU often do not receive ART because of providers' beliefs that IDUs will not adhere to treatment, will not respond to it or may develop resistant viral strains if treated (NIDA, 2012). Another at-risk group requiring greater attention with medication adherence is minorities in Utah who were most likely to skip medications every day. Evidence-based recommendations from the International Association of Physicians in AIDS Care (IAPAC) panel indicate that to improve medication adherence the following should be implemented: 1) among regimens of similar efficacy and tolerability, once-daily regimens for treatment-naïve patients beginning ART, 2) switching treatment-experienced patients receiving complex or poorly tolerated regimes to once-daily regimens, given regimens with equivalent efficacy, 3) among regimens of equal efficacy and safety, fixed-dose combinations to decrease pill burden, 4) reminder devices and use of communication technologies with an interactive component, and 5) education and counseling using specific adherence-related tools (Thompson et al., 2012). Research has also shown that the Life-Steps single-session intervention utilizing cognitive-behavioral, motivational interviewing

and problem-solving techniques demonstrated improvement in medication adherence (Safren et al., 2000).

Another need within medical care and treatment is improved health care provider treatment to HIV-infected individuals in Utah. Of the 10% who felt they were treated poorly by a health care provider, most believed it was due to their income or sexual orientation. Research shows that many physicians respond professionally to those with HIV or AIDS but that attitudinal barriers may be hindering some physicians from providing treatment (Gerbert, Maguire, Bleecker, Coates & McPhee, 1991). However, physicians who had treated 10 or more HIV-infected patients had less negativity toward HIV-positive individuals (Gerbert, 1991). The literature has also shown that HIV-infected individuals who perceive themselves to have a good relationship with their health care provider reported better adherence to HIV treatment (Demmer, 2003). Similarly, research demonstrates that the manner in which HIV-infected women felt treated by their health care provider impacted their willingness to accept or continue treatment for HIV infection (Sowell, Seals, Moneyham, Guillory, Demi & Cohen, 1996). Thus, it is of utmost importance for Utah health care providers to establish respectful relationships with their HIV patients to increase treatment adherence and ultimately suppress HIV transmission. It is recommended that HIV patients carefully choose an HIV health care provider based on the following elements to establish a comfortable relationship: 1) select a physician with training and experience in treating HIV, 2) select a physician who has similar ideas about treating HIV, 3) take an active role in planning and making health care decisions, and 4) be transparent about HIV information including medical records, opinion about medications, lifestyle choices, and your support group (AIDS InfoNet, 2014). Research has shown that enhancing providers' skills in effective communication and relationship building may improve patient retention in HIV care.

Four elements to improve HIV patient-provider interactions include: 1) providers treating their HIV patients with dignity and respect, 2) providers listening carefully to patients, 3) providers providing education in ways the patient can understand, and 4) providers knowing the patient as a person (Flickinger, Saha, Moore & Beach, 2013).

Barriers to Medical Care Needs

The main barriers to medical care for PLWHA in Utah that were identified in the needs assessment were not having enough insurance coverage and the cost of services. This need for financial assistance arose in various other parts of the needs assessment. For example, among survey respondents who had not received a CD4 count, viral load test, or ART within the past 12 months, no insurance was listed as a top reason for all three tests in the current needs assessment. Additionally, needs assessment survey respondents who have experienced a gap in medical care indicated it was most often due to the cost of medical care or not having insurance. Finally, the second largest need among support services mentioned on the needs assessment was help paying for health insurance. The barrier of insufficient personal financial resources is faced by other HIV-infected individuals living outside Utah in the U.S. as well (Heckman, 1998). Many HIV-positive individuals in Utah face financial barriers to medical care which frequently lead to unmet medical and support service needs that may result in poorer outcomes for HIV-positive individuals. One way to address this identified barrier and improve financial security among HIV patients is to create employment opportunities through skill enhancement (Mascarenhas, 2014). This will not only address economic empowerment but also increase self-confidence of PLWHA and their families (Mascarenhas, 2014). In addition, providing rent, mortgage and utility assistance through programs similar to Tulsa CARES can ease financial burdens for basic

housing needs which allow PLWHA to focus on their health care needs (Tulsa, 2011). Tulsa CARES also provides financial literacy classes to educate about financial stability (Tulsa, 2011).

A second significant barrier to HIV medical care identified from the needs assessment was “my state of mind or mental ability to deal with the services and treatments.” The need for mental health services is great among those living with HIV in Utah and nationally (Burnam et al., 2001). Research has shown that among depressed HIV-positive men, those who were employed and those with health insurance were more likely to receive mental health services. Inequalities in access to medical care for HIV-positive individuals are evident nationally (Katz, Douglas, Bolan & Marx, 2010). Increased treatment and access to mental health services for those with HIV in Utah is needed. According to the literature, symptoms of depression and poor mental health quality of life were found to significantly reduce use of ART among HIV-infected women. Those who received mental health treatment were more likely to adhere to ART for HIV (Cook et al., 2002). Greater engagement in medical care is also linked to greater use of support services such as mental health services (Conviser & Pounds, 2003). Therefore, efforts to enhance access to psychological treatment to those affected with HIV in Utah will not only eliminate a barrier to HIV medical care and increase use of HIV therapies but may create improved patient engagement in HIV medical care. An integrated approach to addressing mental health in the context of HIV care is based on growing evidence of its efficiency, effectiveness, and cost-savings (Patel et al., 2013). Adequate assessment and customization is essential for planning the integration of mental health care (Patel et al., 2013). It is recommended that Utah integrate mental health services into HIV primary care similar to the Whole Life project, a collaboration of psychiatry and medical departments (Dodds et al., 2004). The Whole Life project has also become a sustainable effort as a result of the changes brought about in organizational structures,

service delivery, and provider conceptualization of health for people infected with HIV (Dodds et al., 2004).

Support Service Needs

Case management is the current standard for the initial linkage to HIV medical care (Craw et al., 2008). However, three case management needs arose from the needs assessment results. First, increased case management is necessary among nonurban Utah residents who had the highest percentage of respondents without a case manager. Nonurban residents also had the highest percentage having their last contact with a case manager more than a year ago. A top common response to improve case management was providing case management outside of the Salt Lake area such as in rural areas and prisons. HIV-positive individuals living in rural areas in other parts of the U.S. also frequently experience unmet support need often due to lack of infrastructure to support the delivery of comprehensive HIV services (Reif, Golin, & Smith, 2007). It is recommended that Utah case management in rural settings take the form of technology-based interventions such as telecommunication and video-conferencing practice models to allow HIV clients easier access, communication, and recordkeeping with providers (Allen, 1998).

The second case management need arising from the needs assessment results was increased case management among minorities and MSM. HIV-positive minorities in Utah were the most unsure about whether they had a case manager. MSM had the least contact with a case manager in the last month. Research has demonstrated that the intervention of case management among minorities can decrease HIV risk behaviors such as injection drug use (Robles et al., 2004). Since minorities and MSM with HIV are disproportionately affected by HIV and AIDS, culturally competent case management in Utah is essential for improved outcomes (Stone, 2004).

Case managers can optimize the care they provide to minorities and MSM in Utah by using a cultural competence framework, enhancing communication, and diversifying clinical staff (Stone, 2004). Five components associated with a culturally competent case manager include: valuing diversity, making a cultural self-assessment, understanding the dynamics when cultures interact, incorporating cultural knowledge, and adapting practices to address diversity (Allen, 1998).

Furthermore, it is important to consider why women in Utah had the least contact with a case manager in the last six months and were most likely to get help from someone other than a case manager. Some studies have shown that a woman's identity as a caregiver is a powerful factor in how she accesses care and treatment (Allen, 2000). This role can explain why women seek or leave treatment (family reasons) (Allen, 2000). Research findings in the literature suggest that case management is associated with improvements in multiple outcomes for HIV-infected women and that a client-centered approach to providing services was effective in utilization of services (Magnus, 2011).

The last case management need from all HIV-positive respondents was education about HIV and available services. Two of the top three ways suggested to improve case management by survey respondents were more frequent contact/communication with their case manager and increased information about available HIV services. In addition, not knowing what treatment or services are available was listed as one of the top five barriers to medical care for those with HIV. HRSA has recognized case management as a priority intervention to improve engagement and retention in HIV medical care as well as address several barriers to receiving HIV medical care (Tobias, Cunningham, Cunningham, & Pounds, 2007). Case management as an intervention has shown to increase six month linkage to HIV medical care when compared with passive

referral by almost 18% (Gardner et al., 2005). It is recommended that Utah case managers review and follow the state HIV Medical Case Management Standards of Care (UDOH, 2012). Furthermore, it is recommended that case managers follow case management supporting values including: 1) offer referral and support services in an effort to link clients to medical care, 2) incorporate an education component, and 3) be flexible with a continuum of services for different levels of need (UDOH, 2012). Addressing the three case management concerns described will lead to improved linkage, engagement, and retention of HIV individuals in medical care.

The greatest support service needed and most important support service need from the needs assessment was dental care but it also was the most dissatisfactory support service. According to the existing literature, despite the high rate of oral disease among HIV-infected individuals, many do not use dental care regularly (Coulter et al., 2000). Dental care use was the most uncommon among African Americans, those whose exposure to HIV was caused by blood transfusions, those with less education, those who were unemployed, and those without a regular source of dental care (Coulter et al., 2000). Other research among PLWHA who reported unmet oral health needs since testing positive revealed three barriers to oral care which were cost, access to dental care, and fear of dental care (Jeanty et al., 2012). Innovative strategies are needed to increase access to and retention in dental care for PLWHA in Utah. The Utah Ryan White Part B Program can investigate programs like the Community-Based Dental Partnership Program (CBDPP) to increase access to oral health care services for HIV-positive individuals while providing education and clinical training for dental care providers (HRSA, 2012). Since several needs of PLWHA in Utah require financial investment, it is recommended that HIV agencies and programs prioritize support service needs.

HIV Preventive Behavior Needs

The first predominant HIV preventive behavior need from the needs assessment results was reduced injection drug use among PLWHA in Utah, especially among regular injecting drug users, women, and heterosexuals. From the research, the HIV Harm Reduction Program (HHRP+) has demonstrated decreased use of illicit opiates among HIV seropositive persons as well as increased adherence to ART (Margolin, Avants, Warburton, Hawkins, & Shi, 2003). Furthermore, they had lower addiction severity scores and were less likely to have engaged in high risk behavior by the end of the program (Margolin et al., 2003). Programs like HHRP+ are needed in Utah to reduce harm and promote healthy behaviors among HIV-positive individuals.

The second HIV preventive behavior need from the needs assessment results was decreased sexually risky patterns including unprotected sex (vaginal, anal or oral), sex with more than one partner including those who are not HIV-positive, and having sex under the influence of alcohol or drugs, especially among MSM. Much research in the literature has found that homosexual men under the influence of drugs or alcohol are more likely to participate in sexually risky behaviors like unprotected sex (Bimbi, Nanin, Parsons, Vicioso, Missildine, & Frost, 2006). Research data also shows that sex under the influence of drugs leading to unprotected sex is common and increasing among gay men nationally (Ekstrand, Stall, Paul, Osmond, & Coates, 1999). Motivational interviewing has been shown to enhance self-efficacy to practice safer sex for PLWHA (Chariyeva, Golin, Earp, & Suchindran, 2012). In fact, the more motivational interviewing counseling time and sessions PLWHA receive, the greater the improvements in self-efficacy to practice safer sex (Chariyeva et al., 2012). A meta-analytic review in the literature revealed that prevention interventions targeting PLWHA are effective in reducing unprotected sex and acquisition of sexually transmitted diseases (Crepaz et al., 2006). It

is recommended that interventions include: behavioral theory delivered by health care providers or counselors, focus on HIV transmission risk behaviors delivered in an intensive manner to individuals. Information should also be delivered in routine service or medical care settings, and provide skills-building to be most successful (Crepaz et al., 2006). These effective strategies and interventions like motivational interviewing can be incorporated into Utah community HIV prevention efforts to reduce sexual risk taking among PLWHA in Utah.

Another HIV preventive behavior need from the needs assessment results was increased disclosure of HIV status to sex partners among PLWHA in Utah, especially among women, nonurban residents, and minorities. Disclosure of HIV status among adults has been associated with decreased sexual risk behaviors (Hightow-Weidman et al., 2012). In the research literature, PLWHA who mislead a sex partner about HIV status since diagnosis reported recent HIV transmission risk behaviors such as unprotected sex with an HIV-negative or unknown partner (Benotsch et al., 2012). These individuals also had lower HIV knowledge (Benotsch et al., 2012). Nondisclosure of HIV status may also interfere with an HIV-positive person's ability to engage in regular HIV care (Wohl et al., 2011). It is important to consider why minorities in Utah do not disclose their HIV status. A top reason for not disclosing HIV status from the needs assessment was fear/rejection/embarrassment. Research indicates that a higher prevalence of stress has been reported in minority communities because of stigma, prejudice and discrimination (Wohl et al., 2011). Research confirms that stigma is associated with nondisclosure to sex partners (Wolitski, Pals, Kidder, Courtenay-Quirk, & Holtgrave, 2008). The Disclosure Processes Model theory suggests that the disclosure process consist of antecedent goals, the disclosure event itself, mediating processes and outcomes, and a feedback loop (Chaudoir, Fisher, & Simoni, 2011). Interventions to reduce HIV-related stigma among the Utah public and interventions targeted at

increasing knowledge and accurate disclosure through the Disclosure Processes Model theory are needed to reduce the transmission of HIV.

Limitations

The survey used in the needs assessment was not an established survey instrument tested for validity and reliability. Additionally, since the survey was only available in English and Spanish, the survey by its nature likely excluded non-Hispanic immigrant populations and refugees who do not read or understand English or Spanish well. Although the pilot test using cognitive interviews with both high and low literacy populations demonstrated that the $10 reward offered for completing the survey was a fair incentive among 80% of the participants, it is possible that some highly literate clients were not motivated by the reward given the length of the survey and time necessary to complete it. It is also possible that less literate and mentally ill clients (who often need more help with HIV medical care and support services and who are often low-income clients) could have been unmotivated to complete the survey despite the incentive because the survey was too long. The Ryan White Part B Program plans to conduct in-depth interviews and/or focus groups with HIV-positive individuals in FY 2014 to fulfill the evaluation requirements outlined by HRSA. This evaluation project will focus on individuals for whom completing a written survey may prove difficult (e.g., low-literate, refugees, disabled, mentally ill, etc.) so as to include their perspectives in an alternative manner.

Second, there were research limitations in the methodology. Quota sampling methodology was not achieved because of early termination of data collection and instead a convenience sample was utilized which is neither desirable nor strategic. Therefore, the data presented is not representative of the HIV population which was originally anticipated. The smaller sample size in the study may have led to inaccurate frequencies. However, four out of the

six planned quota strata were met and the remaining two quota were nearly met. Furthermore, no sampling randomization was conducted meaning the data cannot be generalized to the overall HIV-positive population of Utah. Another limitation from terminating data collection early was that there was not enough time to include surveys from the HIV specialty doctors who distributed surveys, who serve HIV individuals with private insurance and have higher incomes. These responses from more affluent HIV individuals could have provided a differing perspective of needs and assisted to make the needs assessment more representative of higher incomes.

Since sampling was conducted through HIV-related organizations that serve low-income populations, the acquired sample is possibly biased toward HIV-positive individuals who are already engaged in HIV treatment, medical care and support services as well as low socio-economic populations. Sampling was mostly biased toward past or current clients of the Ryan White Part B Program. However, of the 2,782 PLWHA in Utah, 695 are currently being served by the Ryan White Part B Program. Therefore, approximately 25% of the PLWHA in Utah are Ryan White clients. In addition, bias also could have been introduced into the study through the self-selected survey participants.

Third, there were weaknesses in survey distribution. The first several hundred surveys that were mailed and distributed were not numbered beforehand. Therefore, the origin of which distributing organization the first several returned surveys were coming from was assumed to be from the Ryan White Part B Program client database. This likely led to an overestimation of surveys from this program and underestimation of surveys received from the other participating organizations. However, this did not affect survey results and data.

Conclusions

New HIV infections and inadequate engagement, linkage, and retention of HIV-positive individuals in HIV medical care continue to be problems in Utah. The research presented identified various unmet needs and barriers to HIV services that if addressed can decrease HIV transmission and improve engagement, linkage, and retention of PLWHA. In the future, public health practitioners at the UDOH and other HIV agencies should conduct needs assessments for PLWHA with quota sampling methodology or more rigorous methodology to continue to make program adjustments based on new unmet needs.

Timetable for Project Completion

Miriam Cariello conducted all the steps outlined in the timetable (see Table 75) with supervision from Marcee Mortensen, the Ryan White Part B Program ADAP Administrator. Assistance was provided by providers of HIV-related services, Ryan White staff, and interns to distribute the survey, mail gift cards, and conduct data entry.

75: Timetable of Project Completion

Graduate Project Phases	May 2013	June 2013	July 2013	August 2013	Sept. 2013	Oct. 2013	Nov. 2013	Dec. 2013	Jan. 2014	Feb. 2014	March 2014	April 2014	May 2014	June 2014	July 2014
Survey Development	X	X	X	X											
Pilot test of Survey Instrument				X											
Survey Printing							X								
Survey Distributing Organization Recruitment							X	X	X	X	X	X			
Data Collection								X	X	X	X	X	X		
Data Entry									X	X	X	X	X		
Preliminary Report of Findings											X				
Data Cleaning													X		
Data Analysis														X	
Final Needs Assessment Report															X

References

Aberg, J.A., Gallant, J.E., Anderson, J., Oleske, J.M., Libman, H., Currier, J.S., Stone, V.E., and Kaplan, J.E. (2004). Primary Care Guidelines for the Management of Persons Infected with Human Immunodeficiency Virus: Recommendations of the HIV Medicine Association of the Infectious Diseases Society of America. *Clin Infect Dis*, 39(5):609-629.

The AIDS InfoNet (2014). Choosing an HIV Care Provider. The New Mexico AIDS Education and Training Center & the International Association of Providers of AIDS Care (IAPAC). Retrieved from http://www.aidsinfonet.org/fact_sheets/view/202?lang=eng

Allen, K. (1998). *Treatment Improvement Protocol (TIP) Series, No. 27: Chapter 5-Case Management for Clients with Special Needs.* Rockville: Maryland. Center for Substance Abuse Treatment.

Allen, K. (2000). *Treatment Improvement Protocol (TIP) Series, No. 37: Chapter 7-Counseling Clients with HIV and Substance Abuse Disorders.* Rockville: Maryland. Substance Abuse and Mental Health Services Administration (US)/Center for Substance Abuse Treatment.

Beatty, P.C. & Willis, G.B. (2007). Research Synthesis: The Practice of Cognitive Interviewing. *Public Opin Q.* 71(2): 287-311. Retrieved from http://poq.oxfordjournals.org/content/71/2/287.full

Benotsch, E., Rodriguez, V., Hood, K., Lance, S., Green, M., Martin, A. & Thrun, M. (2012). Misleading Sexual Partners About HIV Status Among Persons Living with HIV/AIDS. *Journal of Community Health*; 37(5): 1049-1057.

Bimbi, D.S., Nanin, J.E., Parsons, J.T., Vicioso, K.J., Missildine, W. & Frost, D.M. (2006). Assessing Gay and Bisexual Men's Outcome Expectancies for Sexual Risk Under the Influence of Alcohol and Drugs. *Substance Use & Misuse*; 41(5):643-652.

Bradford J.B. (2007). The promise of outreach for engaging and retaining out-of-care persons in HIV medical care. *AIDS Patient Care STDS*, 21(1):85-91.

Branson, B.M., Handsfield, H.H., Lampe, M.A., Janssen, R.S., Taylor, A.W., Lyss, S.B., Clark, J.E. (2006). Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. *Morbidity and Mortality Weekly Report,* Bureau of Communicable Disease Control (BCDC). (2013). HIV/AIDS Treatment and Care Program. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm

Brownson, R.C., Fielding, J.E. & Maylahn, C.M. (2009). Evidence-Based Public Health: A Fundamental Concept for Public Health Practice. *Annu. Rev. Public Health*; 30:175-201.

Burnam, M.A., Bing, E.G., Morton, S.C., Sherbourne, C., Flieshman, J.A., London, A.S., Vitiello, B., Stein, M., Bozzette, S.A., Shapiro, M.F. (2001). Use of Mental Health and Substance Abuse Treatment Services Among Adults with HIV in the United States. *Arch Gen Psychiatry*; 58(8): 729-736.

Center for Disease Control and Prevention (CDC). (2013a). HIV Among Gay and Bisexual Men. *CDC.* Retrieved from http://www.cdc.gov/hiv/pdf/risk_gender_238900B_HIV_Gay_Bisexual_MSM_FS_final.pdf

Center for Disease Control and Prevention (CDC). (2013b). HIV Basics. *CDC.* Retrieved from http://www.cdc.gov/hiv/risk/age/index.html

Chariyeva, Z., Golin, C., Earp, J.A. & Suchindran, C. (2012). Does motivational interviewing counseling time influence HIV-positive persons' self-efficacy to practice safer sex? *Patient Education and Counseling*; 87(1): 101-107.

Chaudoir, S.R., Fisher, J.D. & Simoni, J.M. (2011). Understanding HIV disclosure: A review and application of the Disclosure Processes Model. *Social Sciences & Medicine*; 72(10): 1618-1629.

Cheever, L.W., (2007). Engaging HIV-Infected Patients in Care: Their Lives Depend on It. *Clin Infect Dis, 44 (11):1500-1502.*

Chin, J. & Mann, J.M. (1988). The global patterns and prevalence of AIDS and HIV infection. *AIDS*; 2(1): 247-52.

Choi, K.H., Kumekawa, E., Dang, Q., Kegeles, S.M., Hays, R.B., Stall, R. (1999). Risk and protective factors affecting sexual behavior among young Asian and Pacific Islander men who have sex with men: Implications for HIV prevention. *Journal of Sex Education & Therapy*, 24(1-2), 47-55.

Conviser R. & Pounds M.B. (2002). The role of ancillary services in client-centered systems of care. *AIDS Care*, 14(1):119-31.

Cook, J.A., Cohen, M.H., Burke, J., Grey, D., Anastos, K., Kirstein, L., Palacio, H., Richardson, J., Wilson, T. & Young, M. (2002). Effects of Depressive Symptoms and Mental Health Quality of Life on Use of Highly Active Antiretroviral Therapy among HIV-Seropositive Women. Journal of Acquired Immune Deficiency Syndromes; 30(4): 101-109.

Coulter, I.D., Marcus, M., Freed, J.R., Der-Martirosian, C., Cunningham, W.E., Andersen, R.M., Maas, W.R., Garcia, I., Schneider, D.A., Genovese, B., Shapiro, M.F. & Bozzette, S.A. (2000). Use of Dental Care by HIV-infected Medical Patients. *Journal of Dental Research*; 79(6):1356-1361.

Craw, J.A., Gardner, L.I., Marks, G., Rapp, R.C., Bosshart, J., Duffus, W.A., … Schmit, K. (2008). Brief strengths-based case management promotes entry into HIV medical care: results of the antiretroviral treatment access study-II. *J Acquir Immune Defic Syndr*; 47: 597-606.

Crepaz, N., Lyles, C.M., Wolitski, R.J., Passin, W.F., Rama, S.M., Herbst, J.H., Purcell, D.W., Malow, R.M. & Stall, R. (2006). Do prevention interventions reduce HIV risk behaviors among people living with HIV? A meta-analytic review of controlled trials. *Official Journal of the International AIDS Society*; 20(2): 143-157.

Crystal, A., C., Bernhardt, S.A., Lowe, M. Mietchen, M., and Johnston, J. (2012). Comparison of HIV/AIDS Rates Between U.S.-Born Blacks and African Born Blacks in Utah, 2000 – 2009. *The Open AIDS Journal*, 6 (13): 156-162.

Das M., Chu P.L., Santos G.M., et al (2010). Decreases in community viral load are accompanied by reductions in new HIV infections in San Francisco. *PLoS One*; 5:11068.

Demmer, C. (2003). Relationship with health care provider and adherence to HIV medications; *Psychological Reports*, 93(2):494-6.

Diaz, R. M. (2010). Two Communities-Community Involvement & Activism as a Protective Factor for HIV. *Cesar E. Chavez Institute*. Retrieved from http://cci.sfsu.edu/taxonomy/

Dodds, S., Nuehring, E.M., Blaney, N.T., Blakley, T., Lizzotte, J.M., Lopez, M., Potter, J.E. & O'Sullivan, M.J. (2004). Integrating mental health services into primary HIV care for women: the Whole Life project. *Public Health Rep*; 119(1): 48-59.

Donnell D., Baeten J.M., Kiarie J., Thomas, K.K., Stevens, W., Cohen, C.R.,…Celum, C. (2010). Heterosexual HIV-1 transmission after initiation of antiretroviral therapy: a prospective cohort analysis. *Lancet*. 375:2092-

Dowshen, N., Forke, C.M., Johnson, A.K., Kuhns, L.M., Rubin, D. & Garofalo, R. (2011). Religiosity as a protective factor against HIV risk among young transgender women. *The Journal of Adolescent Health*, 48(4):410-414.

Ekstrand, M.L., Stall, R.D., Paul, J.P., Osmond, D.H. & Coates, T.J. (1999). Gay men report high rates of unprotected anal sex with partners of unknown or discordant HIV status. *Epidemiology and Social: Original Papers*; 13(12): 1525-1533.

Flickinger, T.E., Saha, S., Moore, R.D. & Beach, M.C. (2013). Higher Quality Communication and Relationship Are Associated With Improved Patient Engagement in HIV Care. J AcquirImmune Defic Syndr (JAIDS); 63(3): 362-366.

Gardner, E.M., McLees, M.P., Steiner, J.F., del Rio, C., and Burman, W.J. (2011). The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection. *Clin Infect Dis*, 52 (6):793-800.

Gardner, L.I., Metsch, L.R., Anderson-Mahoney P., Loughlin, A.M., del Rio, C., Strathdee, S.,… Holmberg, S.D. (2005). Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS*;19:423-31.

Gerbert, B, Maguire, B.T., Bleecker, T, Coates, T.J. & McPhee, S.J. (1991). Primary Care Physicians and AIDS Attitudinal and Structural Barriers to Care. *JAMA*; 266(20):2837-2842.

Giordano, T.P., Gifford, A.L., White, A.C., Alamazor, M.E.S., Rabeneck, L., Hartman, C., Backus, L.I., Mole, L.A. & Morgan, R.O. (2007). Retention in Care: A Challenge to Survival with HIV Infection. *Clin Infect Dis*.; 44(11): 1493-1499.

Grassly, N.C. Garnett, G.P., Schwartländer, B., Gregson, S. & Anderson, R.M. (2001). The effectiveness of HIV prevention and the epidemiological context. *Bull World Health Organ*, 79(12): 1121-1132.

Health Resources and Services Administration (HRSA). (2009). Part B- AIDS Drug Assistance Program. *HRSA.* Retrieved from http://hab.hrsa.gov/abouthab/partbdrug.html

Health Resources and Services Administration (HRSA). (2012). Dental Programs: Part F. *HRSA.* Retrieved from http://hab.hrsa.gov/abouthab/partfdental.html#3

Heckman, T.G., Somlai, A.M., Peters, J., Walker, J., Otto-Salaj, L., Galdabini, C.A. & Kelly, J.A. (1998). Barriers to care among persons living with HIV/AIDS in urban and rural areas. *AIDS Care*; 10(3):365-375.

The Henry J. Kaiser Family Foundation (2014). The Global HIV/AIDS Epidemic. *Kaiser Family Foundation.* Retrieved from http://kff.org/global-health-policy/fact-sheet/the-global-hivaids-epidemic/

Hightow-Weidman, L.B., Phillips, G., Outlaw, A.Y., Wohl, A.R., Fields, S., Hidalgo, J. & Legrand, S. (2012). Patters of HIV Disclosure and Condom Use Among HIV-Infected Young Racial/Ethnic Minority Men Who Have Sex with Men. *AIDS and Behavior*; 17(1):360-368.

Jeanty, Y., Cardenas, G., Fox, J.E., Pereyra, M., Diaz, C., Bednarsh, H., Redznik, D.A., Abel, S.N., Bachman, S.S. & Metsch L.R. (2012). Correlates of unmet dental care need among HIV-positive people since being diagnosed with HIV. *Public Health Rep*; 127(2):17-24.

Katz, Mitchell H., Cunningham, William E., Mor, Vincent, Andersen, Ronald M., Kellogg, Tim, Zierler, Sally, Crystal, Stephen C., Stein, Michael D., Cylar, Keith, Bozzette, Samuel A. & Shapiro, Martin F. (2000). Prevalence and Predictors of Unmet Need for Supportive Services Among HIV-Infected Persons: Impact of Case Management. *Medical Care*, 38(1):58-69.

Katz, M.H., Douglas, J.M., Bolan, G.A. & Marx, R.M. (2010). Depression and use of mental health services among HIV-infected men. *AIDS Care*; 8(4): 433-442.

Magnus, M., Schmidt, N., Kirkhart, K., Schieffelin, C., Fuchs, N., Brown, B. & Kissinger, P.J. (2011). AIDS Patient Care and STDs; 15(3): 137-145.

Margolin, A., Avants, S.K., Warburton, L.A., Hawkins, K.A & Shi, J. (2003). A randomized clinical trial of a manual-guided risk reduction intervention for HIV-positive injection drug users. *Health Psychology*; 22(2): 223-228.

Mascarenhas, A. (2014). Move to help people with HIV become financially independent. *Journal of Courage: The Indian Express.* Retrieved from http://indianexpress.com/article/cities/pune/move-to-help-people-with-hiv-become-financially-independent/

Morris, M., Kurth, A.E., Hamilton, D.T., Moody, J. & Wakefield, S. (2009). Concurrent Partnerships and HIV Prevalence Disparities by Race: Linking Science and Public Health Practice. *Am J. Public Health*; 99(6):1023-1031.

NASTAD & the Kaiser Family Foundation. (2009). The National HIV Prevention Inventory: The State of HIV Prevention across the U.S. NASTAD & The Kaiser Family Foundation. *NASTAD.* Retrieved from http://www.nastad.org/Docs/102406_National%20HIV%20Prevention%20Inventory%20-%20July%202009%20-%20FINAL.pdf

National Institute of Dental and Craniofacial Research (NIDCR). (2012). HIV/AIDS and Oral Health. *National Institutes of Health (NIH)*. Retrieved from http://www.nidcr.nih.gov/OralHealth/Topics/HIV/default.htm

National Institute on Drug Abuse. (2008). HIV/AIDS Risk & Protective Behaviors among American Young Adults. *National Institutes of Health.* Retrieved from http://www.monitoringthefuture.org/pubs/monographs/hiv-aids_2010.pdf

National Institute on Drug Abuse (2012). Providers Defer HIV Treatment for Injection Drug Users (IDU). *National Institutes of Health.* Retrieved from http://www.drugabuse.gov/related-topics/trends-statistics/infographics/providers-defer-hiv-treatment-injection-drug-users-idus

Patel, V., Belkin, G.S., Chockalingam, A., Cooper, J., Saxena, S. & Unutzer, J. (2013). Grand Challenges: Integrating Mental Health Services into Priority Health Care Platforms. *PLOS Med*; 10(5):e1001448.

Reif, S., Goli, C.E. & Smith, S.R. (2007). Barriers to accessing HIV/AIDS care in North Carolina: Rural and urban differences. *AIDS Care*; 17(5): 558-565.

Robles, R.R., Reyes, J.C., Colon, H.M., Sahai, H., Marrero, C.A., Matos, T.D., Calderon, J.M. Shepard, E.W. (2004). Effects of combined counseling and case management to reduce HIV risk behaviors among Hispanic drug injectors in Puerto Rico: A randomized controlled study. *Journal of Substance Abuse Treatment*; 27(2): 145-152.

Safren, S.A., Otto, M.W., Worth, J.L., Salomon, E., Johnson, W., Mayer, K. & Boswell, S. (2000). Two strategies to increase adherence to HIV antiretroviral medication: Life-Steps and medication monitoring. *Behavior Research and Therapy*; 39:1151-1162.

Sowell, R.L., Seals, B., Moneyham, L., Guillory, J., Demi, A. & Cohen, L. (1996). Barriers to health-seeking behaviors for women infected with HIV. *Nursing Connections*; 9(3): 5-17.

Stone, V.E. (2004). Optimizing the Care of Minority Patients with HIV/AIDS. *Clin Infect Dis*.; 38(3):400-404.

Thompson, M.A., Mugavero, M.J., Amico, K.R., et al. (2012). Guidelines for Improving Entry Into and Retention in Care and Antiretroviral Adherence for Persons with HIV: Evidence-Based Recommendations from an International Association of Physicians in AIDS Care Panel.

Tobias C., Cunningham W.E., Cunningham C.O., Pounds M.B. (2007). Making the connection: the importance of engagement and retention in HIV medical care. *AIDS Patient Care STDS*, 21(1):S3-8.

Tulsa CARES. (2011). Housing is Healthcare. *Tulsa CARES*. Retrieved from http://www.tulsacares.org/hivaids/housing/

Utah Department of Health (UDOH). (2012). Ryan White Part B Comprehensive HIV/AIDS Care and Services Plan for the Ryan White Part B Funded Services in Utah. *UDOH.* Retrieved from http://health.utah.gov/epi/treatment/resources/comp_service_plan.pdf

Utah Department of Health (UDOH). (2011a). 2011 HIV/AIDS Highlights in Utah. *UDOH*. Retrieved from http://health.utah.gov/epi/diseases/hivaids/surveillance/hiv_2011.pdf

Utah Department of Health (UDOH). (2011b). Utah HIV/AIDS Treatment and Care and HIV Prevention Needs Assessment Report. *UDOH Bureau of Epidemiology.*

Utah Department of Health (UDOH). (2012). State of Utah HIV Medical Case Management Standards of Care. UDOH. Retrieved from http://health.utah.gov/epi/treatment/resources/case_manage_standard.pdf

Utah Department of Health (UDOH). (2013). Utah Department of Health. *UDOH.* Retrieved from http://health.utah.gov/

Willis, G. B. (1999). Cognitive Interviewing *A "How To" Guide*. *Research Triangle Institute.* Retrieved from http://www.hkr.se/PageFiles/35002/GordonWillis.pdf

Wohl, A.R., Galavan, F.H., Myers, H.F., Garland, W., George, S., Witt, M., Cadden, J., Operskalski, E., Jordan, W., Carpio, F., & Lee, M.L. (2011). Do Social Support, Stress, Disclosure and Stigma Influence Retention in HIV Care For Latino and African American Men Who Have Sex With Men and Women? *AIDS and Behavior*; 15(6): 1098-1110.

Wolitski, R.J., Pals, S.L., Kidder, D.P., Courtenay-Quirk, C., & Holtgrave, D.R. (2008). The Effects of HIV Stigma on Health, Disclosure of HIV Status, and Risk Behavior of Homeless and Unstably Housed Persons Living with HIV. AIDS Behav; 13:1222-1232.

World Health Organization (WHO). (2004). Chapter 4: Determinants (Risk and protective factors) Indicators. *WHO.* Retrieved from http://www.who.int/hiv/pub/me/en/

Appendices

2013 Utah Needs Assessment Survey

UTAH DEPARTMENT OF
HEALTH

The purpose of this survey is to gather information on the status and needs of people living with HIV or AIDS in Utah. Your answers will not be shared with anyone. Please answer each question to the best of your knowledge. Your responses will help us plan for and advocate for HIV-related services in Utah.

This survey does not ask for your name, address, or other personal information that can identify you. You do not have to answer any question you do not want to. Any information you give will be kept confidential. By beginning the survey, you acknowledge that you have read this information and consent to participate, with the knowledge that you can end the survey at any time without penalty. There are no risks to participation in this study. If you would prefer to have someone read the survey to you, ask a survey administrator. If you have any questions about the survey, please contact the Utah Ryan White Part B Program at 801-538-6191 or RWP@utah.gov.

Questions 1-15 ask about HIV, medical care, and case management. For each question, check the answer(s) that best reflects your opinion. Your answers will not be shared with anyone and will not affect your ability to get services. Please read the entire question, including the words in italics.

1. Do you have HIV or AIDS?
- ☐ Yes
- ☐ No, or I don't know (***Stop here.*** *Return survey to survey administrator.*)

2. What is your age in years? __ __
If you are younger than 18 years please ***stop here*** *and return survey to survey administrator.*

3. When you learned you were HIV positive, how soon did you seek medical care (doctor visit, lab tests, treatment, etc.)?
- ☐ Within 2 weeks
- ☐ Within 1 month
- ☐ Within 3 months
- ☐ Within 6 months
- ☐ Within a year
- ☐ I have not had medical care

4. Has your doctor told you that you have AIDS (the most advanced stage of HIV)?
- ☐ Yes – What year? (*Please specify*) __ __ __ __
- ☐ No

5. Do you have one place you go for HIV medical care?
- ☐ Yes
- ☐ No

6. Are you taking HIV medications now?
- ☐ Yes
- ☐ No (*Skip to question 8*)

7. How often do you miss doses or stop taking HIV meds (whether on purpose or not)?
- ☐ Every day
- ☐ Every week
- ☐ Every month
- ☐ Every other month
- ☐ Once a year

8. In which ways do you pay for your HIV medical care (including HIV medications)?
(*Mark yes or no for each item*)

• *Medicaid*	☐ Yes	☐ No
• *Medicare*	☐ Yes	☐ No
• Private/Employer health insurance	☐ Yes	☐ No
• State High Risk Insurance Program (*HIPUtah*)	☐ Yes	☐ No
• Ryan White Program (including the AIDS Drug Assistance Program [*ADAP*])	☐ Yes	☐ No

☐ Other (*Please specify*) _____

9. In the past 12 months, have you had any of the following?

- ***CD4* test** (white blood cells that fight infection)
  - ☐ Yes. If yes, what number was your last *CD4* count?_____
  - ☐ No *(Please explain the reason)*
    _____
    _____

- **Viral load test** (measures number of viruses)
  - ☐ Yes. If Yes, what was your last viral load? *(Please write detectable or undetectable)*
    _____
  - ☐ No *(Please explain the reason)*
    _____
    _____

- **Antiretroviral therapy (ART)** (medications to fight HIV)
  - ☐ Yes— If Yes, which medications?
    _____
    _____
  - ☐ No *(Please explain the reason)*
    _____
    _____

10. Do you have a case manager who helps you get HIV-related services?

- ☐ Yes
- ☐ No – (*Please explain the reason then skip to question 13*)

  _____
- ☐ I'm not sure

11. How long has it been since you last had contact with your case manager?

- ☐ Within the past month
- ☐ Within the past 6 months
- ☐ Within the past year
- ☐ More than a year

If more than 6 months, please explain:

_____
_____
_____

12. What do you think would improve case management services? (*Please specify*)

_____
_____
_____

13. Is there someone else (other than a case manager) who connects you to HIV-related services?

- ☐ Yes – Who? *(Please specify)*_____
- ☐ No

14. Did you ever feel treated poorly at your HIV doctor's office?

- ☐ Yes
- ☐ No (*Skip to question 15*)

If Yes, please check any of the reasons you feel may have caused you to be treated poorly: (*Mark yes or no for each item*)

• My race/ethnicity	☐ Yes	☐ No
• My age	☐ Yes	☐ No
• My gender/sex	☐ Yes	☐ No
• My sexual orientation	☐ Yes	☐ No
• My drug use	☐ Yes	☐ No
• My immigration status	☐ Yes	☐ No
• My difficulty speaking English	☐ Yes	☐ No
• My HIV status	☐ Yes	☐ No
• My income/money I make	☐ Yes	☐ No
• Where I live	☐ Yes	☐ No

☐ Other (*Please specify*)

_____
_____
_____

15. Has there ever been a time when you were not receiving medical care for your HIV (since diagnosis/treatment)?

- ☐ Yes
- ☐ No

If yes, please explain the reason(s) for your gap in medical care:

_____
_____
_____

Questions 16-22 ask about HIV risk behavior(s). The following questions help us with HIV prevention efforts. Your answers will not be shared with anyone and will not affect your ability to get services. Please read the entire question, including the words in italics.

16. Have you injected drugs/substances <u>not prescribed to you</u> in the last 12 months?

- ☐ Yes – When was the last time? *(Circle one)*
  1 week, 1 month, 3 months, 6 months, 9 months, 12 months
  Which drugs? (*Please specify*) _____
- ☐ No

17. Have you shared (sterilized or dirty) needles, syringes, etc. (works) while injecting drugs in the last 12 months?

- ☐ Yes – When was the last time? *(Circle one)*
  1 week, 1 month, 3 months, 6 months, 9 months, 12 months
- ☐ No

18. Have you had sex (vaginal or anal) within the past 12 months?

- ☐ Yes
- ☐ No *(Skip to question 36)*

19. How often have you had sex under the influence of alcohol in the last 12 months?

- ☐ Most of the time
- ☐ Sometimes
- ☐ Never

20. How often have you had sex under the influence of drugs in the last 12 months?

- ☐ Most of the time – Which drugs? (*Please specify*) _____
- ☐ Sometimes – Which drugs? (*Please specify*) _____
- ☐ Never

21. Do you have sex with only one primary partner?

- ☐ Yes
- ☐ No, I have sex with more than one partner —**Where do you find your sexual partners?** *(Please specify)*
  _____

22. Do you <u>only</u> have sex with HIV positive individual(s)?

- ☐ Yes
- ☐ No
- ☐ I don't know

Questions 23-41 ask about sexual behavior. Check the answer box to the following questions as they relate to sex partner(s) within the past 12 months. Please read the entire question, including the words in italics.

Within the past 12 months have you had:	Yes	No	Maybe/ Don't know
23. sex (vaginal or anal) with a male? *(If no, skip to question 27)*	☐	☐	☐
24. unprotected (without a condom) sex (vaginal or anal) with a male?	☐	☐	☐
25. sex (vaginal or anal) with a male injecting drug user (IDU) ?	☐	☐	☐
26. sex (vaginal or anal) with a HIV-positive male?	☐	☐	☐
27. vaginal or anal sex with a female? *(If no, skip to question 31)*	☐	☐	☐
28. unprotected (without a condom) vaginal or anal sex with a female?	☐	☐	☐
29. vaginal or anal sex with a female injecting drug user (IDU)?	☐	☐	☐
30. vaginal or anal sex with a HIV-positive female?	☐	☐	☐
31. vaginal or anal sex with a transgender person? *(If no, skip to question 35)*	☐	☐	☐
32. unprotected (without a condom) vaginal or anal sex with a transgender person?	☐	☐	☐
33. vaginal or anal sex with a transgender injecting drug user (IDU)?	☐	☐	☐
34. vaginal or anal sex with a HIV-positive transgender person?	☐	☐	☐

Within the past 12 months:	Yes	Some-times	No	Does not apply to me
35. If you are female, have you had vaginal or anal sex with a man who have sex with men (MSM)?	☐	☐	☐	☐
36. When you have oral sex, do you use protection?	☐	☐	☐	☐
37. Do you ask the HIV status of your sex partner(s)?	☐	☐	☐	☐
38. Do you disclose your HIV status to your sex partner(s)? *(If yes, skip to question 41)*	☐	☐	☐	☐
39. If you do not reveal your HIV status before having sex, do you ever tell or notify your sex partner(s) anytime afterward?	☐	☐	☐	☐

40. If you have not told your sex partner(s) about your HIV status after you had sex with him/ her, please list the reason(s):

_____

_____

_____

41. In the past 12 months have you traded sex for …

Money ☐ No ☐ Yes – If yes, when was the last time? (*Circle one*)
1 week, 1 month, 3 months, 6 months, 9 months or 12 months

Drugs ☐ No ☐ Yes – If yes, when was the last time? (*Circle one*)
1 week, 1 month, 3 months, 6 months, 9 months or 12 months

Other ☐ No ☐ Yes – If Yes, please specify_____
When was the last time? (*Circle one*)
1 week, 1 month, 3 months, 6 months, 9 months or 12 months

Questions 42-46 ask about barriers to HIV-related services. From the list below, rank the top five (5) barriers that keep you from obtaining HIV medical help or treatment. Write the alphabetical letters of your 5 greatest barriers in the spaces at the bottom of this page.

Knowledge/Education

A. Not knowing what treatment is available to me/do not know if services exist.

B. My thinking that I am not being affected by the infection.

C. The level of knowledge of the person providing the service.

Confidentiality Concerns

D. My concern is that others may see me when I get care and learn about my HIV.

E. My concern of being reported to the police.

Cost/Financial Issues

F. The cost of services to me.

G. Not having enough insurance coverage.

Cultural Competency/Quality of Care

H. The level of discrimination/judgment/insensitivity that I feel from the people providing services.

I. The ability of the person providing services to speak in a language that I understand.

J. The organizations providing the services make me feel like a number.

Actual Services

K. The amount of time I have to wait to get an appointment with someone.

L. The amount of paperwork I have to fill out to get the service.

M. Poor organization among the groups providing services.

N. Lack of service integration (i.e. no one stop location with several health services/resources)

Personal Navigation/Access

O. My state of mind or mental ability to deal with the services and treatments.

P. My physical health.

Q. Not having transportation.

R. I do not have a pharmacy to go to.

S. The location of the organization providing services.

T. ***Other Reason*** (*Please specify*) _____

Rank top 5 barriers here:

42. _____ *(#1 thing making it difficult to get HIV care)*

43. _____ *(#2 greatest barrier)*

44. _____ *(#3 thing)*

45. _____ *(#4 thing)*

46. _____ *(#5 thing)*

☐ I do not have any barriers to receiving HIV care

Questions 47-62 ask about the level of importance of HIV services in the last 12 months. Please circle how important the following services are to you on a scale from 1-5. Circle "Not Applicable" if you do not need or participate in the service listed.

	How important are these *services* to YOU in the last 12 months?						
		Very Important	Important	Neutral	Not Important	Not Very Important	Not Applicable
47.	Doctor visits for HIV/AIDS	5	4	3	2	1	0
48.	Lab tests (*CD4* count, viral load test, etc.)	5	4		2	1	0
49.	HIV/AIDS medications (pharmacy, ADAP, etc.)	5	4	3	2	1	0
50.	Women's health (OBGYN, prenatal care, testing, etc.)	5	4	3	2	1	0
51.	In-patient/out-patient substance abuse treatment	5	4	3	2	1	0
52.	Case management	5	4	3	2	1	0
53.	HIV/AIDS support group	5	4	3	2	1	0
54.	Psychiatrist visits/mental health counseling/ therapy	5	4	3	2	1	0
55.	Food bank	5	4	3	2	1	0
56.	Help with transportation (bus, Trax, taxi, etc.)	5	4	3	2	1	0
57.	Help paying for health insurance (*COBRA, HIP*, co-pays, etc.)	5	4	3	2	1	0
58.	Information about treating HIV/AIDS	5	4	3	2	1	0
59.	Information about how HIV is spread	5	4	3	2	1	0
60.	Help taking HIV/AIDS medications and/or dealing with side effects	5	4	3	2	1	0
61.	Help with housing	5	4	3	2	1	0
62.	Dental care	5	4	3	2	1	0

Questions 63-78 ask about your level of need for HIV services. Please circle the answer that shows if you have needed any of the following HIV-related services in the last 12 months. Circle "Not Applicable" if you do not need or participate in the service listed.

What is YOUR level of need for these services in the last 12 months? (whether you've been receiving the service or not)

		Need	Sometimes Need	Do Not Need	Not Applicable
63.	Doctor visits for HIV/AIDS	3	2	1	0
64.	Lab tests (*CD4* count, viral load test, etc.)	3	2	1	0
65.	HIV/AIDS medications (pharmacy, ADAP, etc.)	3	2	1	0
66.	Women's health (OBGYN, pregnancy prenatal care, testing, etc.)	3	2	1	0
67.	In-patient/out-patient substance abuse treatment	3	2	1	0
68.	Case management	3	2	1	0
69.	HIV/AIDS support group	3	2	1	0
70.	Psychiatrist visits/mental health counseling/therapy	3	2	1	0
71.	Food bank	3	2	1	0
72.	Help with Transportation (bus, Trax, taxi, etc.)	3	2	1	0
73.	Help paying for health insurance (COBRA, HIP, co-pays, etc.)	3	2	1	0
74.	Information about treating HIV/AIDS	3	2	1	0
75.	Information about how HIV is spread	3	2	1	0
76.	Help taking HIV/AIDS medications and/or dealing with side effects	3	2	1	0
77.	Help with housing	3	2	1	0
78.	Dental care	3	2	1	0

Questions 79-94 ask about your level of satisfaction as a client of HIV services in the last 12 months. Please circle how satisfied you are with the following HIV-related services. Circle "Not Applicable" if you do not need or participate in the service listed.

What is YOUR level of satisfaction with these services in the last 12 months?

		Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied	Not Applicable
79.	Doctor visits for HIV/AIDS	5	4	3	2	1	0
80.	Lab tests (*CD4* count, viral load test, etc.)	5	4	3	2	1	0
81.	HIV/AIDS medications (pharmacy, ADAP, etc.)	5	4	3	2	1	0
82.	Women's health (OBGYN, prenatal care, testing,, etc.)	5	4	3	2	1	0
83.	In-patient/out-patient substance abuse treatment	5	4	3	2	1	0
84.	Case management	5	4	3	2	1	0
85.	HIV/AIDS support group	5	4	3	2	1	0
86.	Psychiatrist visits/mental health counseling/therapy	5	4	3	2	1	0
87.	Food bank	5	4	3	2	1	0
88.	Help with transportation (bus, Trax, taxi, etc.)	5	4	3	2	1	0
89.	Help paying for health insurance (COBRA, HIP, co-pays, etc.)	5	4	3	2	1	0
90.	Information about treating HIV/AIDS	5	4	3	2	1	0
91.	Information about how HIV is spread	5	4	3	2	1	0
92.	Help taking HIV/AIDS medications and/or dealing with side effects	5	4	3	2	1	0
93.	Help with housing	5	4	3	2	1	0
94.	Dental care	5	4	3	2	1	0

Questions 95-122 ask demographic questions. Please read the entire question, including the words in italics.

95. Which best describes you? *(check all that apply)*
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Pacific Islander
- ☐ Black—Where were you born?
  - ☐ United States
  - ☐ Africa
  - ☐ Other country
- ☐ Hispanic or Latino
- ☐ White/Caucasian
- ☐ Other (*Please specify*)_____

96. What was your birth gender?
- ☐ Female
- ☐ Male

97. Which best describes you now?
- ☐ Female
- ☐ Male
- ☐ Transgender- male to female
- ☐ Transgender- female to male
- ☐ Transgender- unspecified

98. Which best describes you?
- ☐ Heterosexual/Straight *(Skip to question 99)*
- ☐ Homosexual-Lesbian
- ☐ Homosexual-Gay
- ☐ Bisexual
- ☐ Transgender

99. Do you feel part of a unified lesbian, gay, bisexual, transgender (LGBT) community?
- ☐ Yes
- ☐ No
- ☐ Sometimes

100. Do you have a partner, spouse or significant other?
- ☐ Yes
- ☐ No

101. Are you pregnant now?
- ☐ Not applicable for me
- ☐ Yes
- ☐ No

102. What is the highest grade or year of school you have completed?
- ☐ Never attended school (only kindergarten)
- ☐ Grades 1-8 (Elementary)
- ☐ Grades 9-12 but did not graduate
- ☐ Grade 12 or *GED* (High school graduate)
- ☐ College 1-3 yrs. (Some college/technical school)
- ☐ College 4 yrs. (College graduate)
- ☐ Post-graduate education

103. Which of the following categories best describes your annual household income from all sources before taxes?
- ☐ $1 to $11,490
- ☐ $11,491 to $17,235
- ☐ $17,236 to $22,980
- ☐ $22,980 to $28,725
- ☐ $28,726 to $34,470
- ☐ $34,471 to $40,215
- ☐ $40,216 to $45,960
- ☐ $45,961 and above

104. Whether you file taxes or not, how many dependents do you claim (including self)?_____

105.What is your current zip code?__ __ __ __ __

106. How long have you lived in Utah (in total)?
__ __ months OR __ __ years

107. Which best describes you? (*Mark yes or no for each item*)

• I work full time (40 hours/week)	☐Yes	☐ No
• I work part time (<40 hours/week)	☐Yes	☐ No
• I am self-employed	☐Yes	☐ No
• I am out of work for 1+ years	☐Yes	☐ No
• I am out of work for <1 year	☐Yes	☐ No
• I am unable to work/on disability	☐Yes	☐ No
• I am a homemaker	☐Yes	☐ No
• I am a student	☐Yes	☐ No
• I am retired	☐Yes	☐ No

108. Are you a refugee?
- ☐ Yes– What country of origin?_____
- ☐ No

109. Are you currently in prison or jail?
- ☐ Yes—If yes, for how long?
  __ __ years/months *(circle one)*
- ☐ No

110. In the past 12 months have you:
(*Mark yes or no for each item*)

• owned a home/apt?	☐Yes	☐ No
• rented a home/apt?	☐Yes	☐ No
• lived in a hotel or motel?	☐Yes	☐ No
• lived with family or friends?	☐Yes	☐ No
• lived in a drug treatment center?	☐Yes	☐ No
• been homeless or lived in a shelter?	☐Yes	☐ No
• lived in a halfway house?	☐Yes	☐ No
• been in prison or jail?	☐Yes	☐ No

111. If you were in prison/ jail in the past 12 months, were you sexually active while there?
- ☐ Not applicable, I was not in prison or jail
- ☐ Yes
- ☐ No

112. What language(s) do you speak? (*Mark yes or no for each item*)

English	☐Yes	☐ No
Spanish	☐Yes	☐ No

- ☐ Other (*Please specify*)_____

113. How comfortable are you receiving HIV services in English?
- ☐ Comfortable
- ☐ Somewhat comfortable
- ☐ Somewhat not comfortable
- ☐ Not comfortable

114. How long ago did you learn you were HIV-positive?
- ☐ Less than 12 months
- ☐ 1-4 years
- ☐ 5-9 years
- ☐ 10 years or more
- ☐ I do not remember

115. Were you diagnosed with HIV in Utah?
- ☐ Yes
- ☐ No—In what state? _____

116. How did you get HIV? (*Mark yes, no or maybe for each item*)
- ☐ I do not know *(Skip to question 117)*

• Having sex with a man	☐Yes	☐No	☐Maybe
• Having sex with a woman	☐Yes	☐No	☐Maybe
• Needles or tattoo	☐Yes	☐No	☐Maybe
• Transfusion/blood products	☐Yes	☐No	☐Maybe
• Perinatal – Mother to infant during birth	☐Yes	☐No	☐Maybe

117. Have you ever tested positive for any of the following diseases? (*Mark yes or no for each item*)

• Hepatitis C	☐Yes	☐No	☐Don't know
• Hepatitis B	☐Yes	☐No	☐Don't know
• Chlamydia	☐Yes	☐No	☐Don't know
• Gonorrhea	☐Yes	☐No	☐Don't know
• Syphilis	☐Yes	☐No	☐Don't know
• HPV/genital warts	☐Yes	☐No	☐Don't know
• Herpes	☐Yes	☐No	☐Don't know

118. Have you been tested for tuberculosis (TB)?
- ☐ Yes
- ☐ No *(Skip to question 121)*
- ☐ I do not know *(Skip to question 121)*

119. When was the last time were you tested for tuberculosis?

- ☐ Within the last year
- ☐ 1-4 years ago
- ☐ 5-10 years ago
- ☐ 10 + years ago

120. If you tested positive for TB were you treated for active TB (contagious disease)?

- ☐ My test results were not positive
- ☐ Yes
- ☐ No

121. What is the single most important change you would suggest to improve services for individuals or families living with HIV?

_____
_____
_____
_____

122. Please write anything else that you would like to say about your HIV care.

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

- ☐ I am not currently receiving HIV care

To receive your $10 Smith's gift card,
please mail in the survey and the gift card slip in the postage-paid envelope to:

NA Survey
Utah Department of Health (UDOH)
Bureau of Epidemiology
Box 142104
Salt Lake City, UT 84114-2104

THANK YOU from the
Utah *Ryan White* Part B Program

If you are not currently connected with a case manager and would like to be, please call 801-538-6191.

Also, if you have any questions, comments, or concerns about the items in this survey please contact us at 801-538-6191 or by email at RWP@utah.gov.

The study results will be published on the UDOH website in 2014.

Table 76: Data Cleaning Survey Response Changes

Survey Question	Original Survey Responses	Categories Responses were Changed Into
What is your age in years?	Responses like 35, 22, 40, 57, etc. were given	1= 18-29 2= 30-39 3= 40-49 4= 50-59 5= 60-69 6= 70-79 7= 80-89
Has your doctor told you that you have AIDS (the most advanced stage of HIV)? - If so, what year were you diagnosed?	Responses like 1999, 2012, 2004, etc. were given	1= 2010-2014 2= 2005-2009 3= 2000-2004 4= 1995-1999 5= 1998-1994 6= 1993-1989 7= 1988-1984
Please explain the reason why you haven't had a CD4 test in the last 12 months.	Only responses given were no insurance and couldn't afford doctor visits	1= No insurance 2= Couldn't afford doctor visits
What was your last CD4 count?	Responses like 250, 565, 490, etc. were given	1= <200 2= 200-349 3= 350-499 4=500+ 5=Don't know/don't remember
Please explain the reason why you haven't had a viral load test in the last 12 months.	Only responses given were no insurance, don't like taking medications, and I'm undetectable	1= No insurance 2= Don't like taking meds 3= I'm undetectable
What was your last viral load?	Responses like detectable 1,500, undetectable, I don't know, etc. were given	1=Detectable 2=Undetectable 3=Don't know/don't remember
Please explain the reason why you haven't received ART medications in the last year.	Responses like medication is poison, I'm not taking medications, I don't have insurance, etc. were given	1= No insurance 2= Don't like taking meds 3= Counts good/undetectable 4= Not taking meds/not prescribed 5= I don't know 6= In hospice
Which ART medications have you used in the last year?	Responses like Isentress, Stiruva, Complera, etc. were given	1= Atripla 2= Stribild 3= Isentress 4= Truvada 5= Reyatax 6= Norvir 7= Epivir 8= Tivicay 9= Epzicom 10= Stiruva 11= Prezista 12= Intelence 13= Kaletra 14= Complera 15= Viramune 16= Selzentry 17= Sustiva 18= Trizivir 19= Prevestatin 20= Combivir 21= Ziagen 22= Lamivudine 23= Viread 24= Atazanavir 25= Entriva 26= Ritonavir 27= Tenofovir 28= Abacavir 29= Acyclovir 30= Baraclude 31= Emtricitabin 32= Aptile 33= Don't know/remember
Please explain the reason you don't have a case manager who helps you get HIV-related services?	Responses like I can do it on my own, I'm in prison, embarrassed, etc. were given	1= Don't need a cm 2= Embarrassed 3= Incarcerated 4= Don't like UAF 5= No reason

What do you think would improve case management services?	Responses like there's too much case managers turnover so we need more, need bus tokens, make it easier to contact them through phone and email, etc. were given	1= Transportation assistance/more bus passes/tokens 2= Financial assistance 3= Education//inform about available services /renewal 4=Outside of SLC/in rural areas/in prison, overloaded with cases/hire more case managers/too much turnover 5= Dental care 6= Housing assistance 7= Notification of program changes/service updates/ ADAP approval/renewal/new cms 8= More mental services and support groups (including straight group) 9= Easier to contact/communicate with/more available/more frequent contact/keep appts/friendlier 10= Insurance issues/help with drug company programs/get refills on time
Is there someone else (other an a case manager) who connects you to HIV-related services?-If yes, who?	Responses like my husband, doctor, therapist, etc. were given	1= Spouse/family/friends 4= Support group 2= Doctor/pharmacist 5= Therapist/psychologist 3= HIV/AIDS agencies-RCGSE, UAF, PWACU, PCP, NACU
Did you ever feel treated poorly at your health care providers office? -Other (please specify)	Responses like I was in prison, my mental and emotional state, etc. were given	1= Rude/uncompassionate doctor 2= My mental/emotional health/status 3= Being a prisoner 4= Couldn't keep appt for being late 5= Rude/mean cm 6= No waiting area privacy
Has there ever been a time when you were not receiving medical care for your HIV (since diagnosis/treatment)? -If yes, please explain your reasons for the gap in medical care.	Responses like I didn't have insurance, I was living internationally, drugs, etc. were given	1= Lived outside of U.S./moved/in prison 2= healthy status/didn't need doc/HIV care 3= Mental health issues/depression 4= Didn't want HIV care/meds/had issues with doc/had TB/no health care provider follow-up 5= Cost of care/no insurance 6= Drug/substance abuse 7= Lived in rural area/homeless 8= Denial after diagnosis 9= Incomplete ADAP recertification 10= No treatment available/didn't seek treatment
Have you injected drugs/substances not prescribed to you in the last 12 months? -If yes, which drugs? (Please specify)	Only responses given were meth, heroin, and suboxin.	1= Meth 2= Heroin 3= Suboxin
How often have you had sex under the influence of drugs in the last 12 months? -If most of the time or sometimes, which drugs? (specify)	Responses like pot, cocaine, marijuana, etc. were given	1= Meth 4= Marijuana 7= GHB 2= Heroin 5= Alcohol 8= Ketamine 3= Cocaine 6= LSD 9= Poppers
If you have sex with more than one partner, where do you find your sexual partners?	Responses like Adam4Adam website, phone app, bar, etc. were given	1= Online/internet 4= Everywhere 2= Friends 5= Phone app 3= Clubs/bars 6= Public
If you have not told your sex partner(s) about your HIV status after you had sex	Responses like sex was anonymous, they didn't ask, scared of rejection,	1= Scared/rejection/embarrassed 2= HIV+ info on online profile

with him/her, please list the reason(s):	etc. were given	3= They didn't as 4= Been in prison 5= Undetectable/on meds/used protection/ pulled out before shooting 6= In a monogamous relationship 7= Don't know 8= Sex was anonymous
n the past 12 months have you traded sex for…other? -If yes, please specify	Only responses given were for food and housing	1= Food 2= Housing
What are the top 5 things that keep you from getting medical help/treatment? -Other Reason (Please specify)	Responses like drugs, I'm in hospice, and I have no support, etc. were given	1= Substance abuse 4= Incarcerated 2= Coordinating time to go 5= No support group 3= Hospice
Which race best describes you? -Other race (Please specify)	Only responses given were Middle Eastern and Haitian	1= Middle Eastern 2= Haitian
What is your current zip code?	Responses like 84604, 84118, 84020, etc. were given	1= Salt Lake County 8= Box Elder County 2= Utah County 9= Kane County 3= Washington County 10= Cache County 4= Davis County 11= Grand County 5= Weber County 12= Summit County 6= Sevier County 13= Duchesne County 7= Tooele County 14= County outside of Utah . (CA and NV) Zip codes were also translated into2010 US census "Zip Code Tabulation Areas" and matched with their 2010 US census "Urbanized Areas." 1= Urbanized area 2= Non-urban area (including urban clusters) 3= Inconclusive/don't know
How long have you lived in Utah (in total)? (write # months or # years)	Responses like 3 years 6 months and 10 years, etc. were given	1=0-10 years 4=31-40 years 7=61-70 years 2=11-20 years 5= 41-50 years 8=71-80 years 3=21-30 years 6=51-60 years
Are you a refugee?-If Yes, what country of origin?	Only response given was Conga	1= Conga
Are you currently in prison or jail?-If yes, for how long? (years/months)	Responses like 12 years, 2 years 1 month, etc. were given	1= 0-12 months 4= 11-20 years 2=1-5 years 5= 21-30 years 3= 6-10 years
What language(s) do you speak? -Other (Please specify)	French, German, Italian, Portuguese, Thai, Japanese, Chinese, Burmese, Creole, Afrikaans, Lingala, Kiwanda, Swahili	1= European language (French, German, Italian, Portuguese) 2= Asian language (Thai, Japanese, Chinese, Burmese) 3= Creole 4= African language (Afrikaans, Lingala, Kiwanda, Swahili)
What is the single most important change you would suggest to improve services for individuals or families living with HIV?	Responses like case managers should let us know all the services available, make meds cheaper, and	1= Case management/ Communication/Love/Client focused 2= Education/Info/Resources made known

	create a heterosexual support group, etc. were given	3= Medical help (meds, better doc, dental, vision, hearing) 4= Financial assistance/ Insurance/Legal/Recertification 5= Service location 6= I'm fine/no change 7= Transportation/Housing/ Food assistance 8= Access 9= Mental health/counseling/support group/substance abuse
Please write anything else that you would like to say about your HIV care.	Responses like I love Clinic 1A and my doctor, bus passes, and have services in southern Utah were given	1= Case management/ Communication/Love/Client focused 2= Education/Info/Resources made known 3= Medical help (meds, better doc, dental, vision, hearing) 4= Financial assistance/ Insurance/Legal/Recertification 5= Service location 6= I'm fine/no change 7= Transportation/Housing/ Food assistance 8= Access 9= Mental health/counseling/support group/substance abuse 10= Gratitude/happy with services